

INTERNAL REGULATIONS and PROCEDURES
OF
THE
EUROPEAN FEDERATION OF CROHN'S AND ULCERATIVE COLITIS
ASSOCIATIONS
(EFCCA)

Adopted on 26/5/2017

INTRODUCTION

The following rules are introduced for the better management of the European Federation of Crohn's and Ulcerative Colitis Associations (EFCCA) and are to be read in conjunction with, but subject to its Constitution.

This document and its contents – approved by the General Assembly the 26/05/2017 under the provision of art. 6.1 of EFCCA Constitution - definitively supersedes the previous “bye-laws”, as amended and previously approved in substitutes and cancel the previously Strasbourg on 7 September 1993, Marbella on 7 October 1994, London on 16 –18 October 1997 and Berlin on 12 June 2003 and also re-approved in total at the 12 June meeting in Berlin.

This document is composed of five parts:

- (i) Regulations and procedures;
- (ii) Annex I: Relationships with pharmaceutical and other commercial organizations – the annex supersedes the previously approved guidelines on the relationship with pharma industries and other commercial stakeholders.
- (iii) Annex II: Internet – the annex supersedes the previously approved ruling about transparency and website.
- (iv) Annex III: Fee scheme – the annex contains the premises and the approved amounts of the annual membership fees.
- (v) Annex IV: EYG Rules and Regulations

REGULATIONS AND PROCEDURES

SECTION 1 – MEMBERSHIP

Art. 1.1 Application for becoming Full Member

New members are accepted by resolution of the General Assembly and under the conditions set in article 5.1. of the EFCCA Constitution. The request to join EFCCA as full member should be addressed to the EFCCA Board no less than 6 (six) months before the General Assembly annual meeting.

The request shall contain the following documents:

- A written statement showing that the applying organization has corporate, non-for-profit personality, according to the laws and practices of its State of origin;
- A copy of the Constitution or Statute, and of the Internal regulations (if any) duly translated in English;
- A short description (in English) of the activities organized and of the goals of the organization;
- A statement that the applying organization represents the majority of IBD patients within a specific linguistic group in a specific country.

The EFCCA Board, upon receipt of the application, may appoint a Board member or any EFCCA delegate to revise the documents and provide the Board with observations.

After the analysis of the observation above mentioned, the Board may decide to:

- Request for further information;
- Suspend the application for lack of the requisites and notify the reason to the applicant;
- Formulate a formal proposal of the memberships' approval to be submitted to the General Assembly at the next available annual meeting and invite the applying organization to participate in the subsequent GA as “observer incoming member”.

The Board may also and, in any case, at its full discretion:

- Invite the applying organization to apply as associate member when not in possession of all the necessary requisites for joining as full member;
- Invite the applying organization to participate in the subsequent General Assembly as “observer”.

At the General Assembly annual meeting, the existing members – after having heard the opinion of the EFCCA Board – could admit by resolution the incoming organization respecting the conditions, and specifically, the majority set in art. 5.1. of EFCCA Constitution.

Art. 1.2 Application for becoming Associate Member

New associate members are accepted by resolution of the General Assembly and under the conditions set in article 5.1. of the EFCCA Constitution. The request to join EFCCA as associate member should be addressed to the EFCCA Board no less than 6 (six) months before the General Assembly.

The request shall contain the following documents:

- A written statement showing that the applying organization has corporate, non-for-profit personality, according to the laws and practices of their State of origin;
- A statement showing that the applying organization, independently of its geography location, considers Europa as area of interest to improve IBD patient's right.
- A copy of the Constitution/Statute and of the Internal regulations (if any) duly translated in English;
- A short description (in English) of the activities organized and of the goals of the organization.

The EFCCA Board, once received the application, may appoint a Board member or any EFCCA delegate to revise the documents and provide the Board with observations.

After the analysis of the observation above mentioned, the Board may decide to:

- Request for further information;
- Suspend the application for reasons that have to be notified to the applicant;
- Formulate a formal proposal for the associate memberships' approval to be submitted to the General Assembly at the next available annual meeting and invite the applying organization to participate in the subsequent General Assembly as "observer incoming associate member" and invite the applying association to participate in the subsequent General Assembly as "observer".

At the General Assembly annual meeting, the existing members – after having heard the opinion of the EFCCA Board – could admit by resolution the incoming associate organization respecting the conditions, and specifically, the majority set in art. 5.1. of EFCCA Constitution.

Art. 1.3 Application for switching from Associate Member to Full Member

Any associate member can demand to become full member, if the conditions set in art. 5 of the EFCCA Constitution are fulfilled. The request to apply for the full membership in EFCCA should be addressed to the EFCCA Board no less than 6 (six) months before the General Assembly.

The request shall contain a written statement of "patronage" of at least one full member, duly signed by the chairman of the "patron" association.

The EFCCA Board, once received the application, may appoint a Board member or any EFCCA delegate to revise the documents and provide the Board with observations.

After the analysis of the observation above mentioned, the Board may decide to:

- Request for further information;
- Formulate a formal proposal for the full memberships' approval to be submitted to the General Assembly at the next available annual meeting and invite the applying organization to participate in the subsequent General Assembly as “observer incoming full member”.

At the subsequent General Assembly annual meeting, the EFCCA Board shall present the demand for the full membership.

Any member can propose to postpone the demand to become a full member for a maximum period of three years. The approval of this proposal requires a qualified majority of three quarters of the actual full members present or represented.

If the General Assembly has not voted for a postponement of the demand, the existing members will vote about the incoming member application according to the majority set in art. 5.1. of EFCCA Constitution.

Art. 1.4 Annual membership fee

An annual membership fee is due by all member organizations. Member organizations that have not paid their annual dues (including all arrears) do not have the right to attend or vote at the General Assembly. The EFCCA Secretary will state – at the beginning to the annual meeting – to the General Assembly if any member association has not right to vote at the current Assembly.

The amount of the membership fee is calculated following the membership fee scheme proposed by the Board. Once approved by the General Assembly, the “fee scheme” becomes part of this internal regulation (Annex III).

The EFCCA Board maintains the power to present amendments of the fee scheme if and when it deems necessary.

The amendments or a new fee scheme – if approved with resolution by the General Assembly, will substitute the current fee scheme.

Art. 1.5 Member resignation

Voluntary resignation may apply in any situation in which a member does not want to continue to be member of EFCCA.

Members may request to resign their membership with a written communication addressed to the EFCCA Board. The EFCCA Board will report at the subsequent General Assembly Annual meeting about the voluntary resignation.

The member resignation becomes effective after being acknowledged by the General Assembly. The acknowledgement of the General Assembly is not a vote but only reflects the will of the

member association and authorizes the EFCCA Board to proceed with the necessary procedure to make effective the resignation, namely the modification of the Constitution.

Board member(s) coming from the resigning organization could keep their duty inside the Board until the end of his/her office term or resign.

Any former member who has resigned and who seeks readmission to membership must do so by filing an application for readmission including a statement detailing the reasons the member resigned and the reasons the member is seeking readmission.

Art. 1.6 Expulsion or suspension of a member

A member organization can be expelled or suspended for not fulfilling their membership obligations, namely if a member does not fulfill anymore the conditions set in article 5.1. of the EFCCA Constitution or it fails to pay its membership fee for more than two consecutive years.

A proposal to expel or suspend a member organization may be initiated by at least three full Member Organizations and presented to the EFCCA Board. The request should at least contain: the reasons of the request and if the request concerns an expulsion or a suspension. In the latest case, namely a suspension, the request should contain the condition(s) or the measure(s) the suspended member organization has to fulfill to be reinstated as a full or associate member.

The proposal for expulsion shall be sent to the Member Organization concerned, and it shall have at least three months to prepare a written response, together with the right to attend and speak at the General Assembly meeting at which the expulsion or suspension proposal will be considered.

The Chairperson shall report about the expulsion or suspension and recommendation, and shall invite the defendant member organization, if present, to speak in his own behalf if it wishes. The members shall then vote by secret ballot on the proposed expulsion and/or suspension. A $\frac{2}{3}$ vote of those present and voting at the meeting, a quorum being present, shall be necessary for expulsion or suspension and it shall be effective immediately. If expulsion or suspension is not so voted, the proposal shall stand.

SECTION 2 – MEETINGS

Art. 2.1 General Assembly Annual Meeting

An annual meeting of all members – General Assembly shall be held in each calendar year at such time and place as may be determined by the General Assembly or by EFCCA Board depending on the suitability of the various members expressing an interest in holding the General Assembly Annual Meeting in their respective country and the available budget.

Art. 2.2 Representation

a. **Delegates from National Association (Number Of Delegates)**

Each member association may appoint up to a maximum of two representatives to participate in the EFCCA General Assembly and EFCCA activities.

As per historical tradition of the Federation, the representatives of the members, both full and associate, are called “Delegates”.

Each association has, in any case, one vote in the case the voting power is granted by EFCCA Constitution.

The name of the delegates shall be communicated to the EFCCA secretariat in due course and at least two months before the General Assembly.

Every substitution or change shall be duly notified to EFCCA secretariat. The lack of this notification makes EFCCA not liable for sending any kind of information or invitation to the delegates present in the database.

The EFCCA Board, following the advice of the Treasurer and depending on available budget, shall set the applicable expense reimbursement policy.

b. **By Proxy**

Any member – unable to send delegates to the General Assembly annual meeting – may request another member to represent him by proxy.

The proxy shall contain:

- The signature of the chairman of the member which releases the proxy;
- The indication of the member who receives the proxy;
- The indication of the name of the delegate(s) which in concrete will represent the member which releases the proxy.

Each member association may receive a maximum of one proxy and so is entitled to represent no more than only one other member association.

If the proxy is released to an associate member by a full member, the associate member will be entitled to vote only on behalf of the represented association, while will not be entitled to vote for itself.

The proxy form will be part of the meeting acts and recorded in EFCCA register.

c. **Appointment of a Moderator**

At the beginning of the General Assembly Annual Meeting, all the members appoint an Assembly Chairperson/Moderator in charge to lead the works set in the order of business.

This pro-tempore Chairperson/Moderator shall not be a member of the EFCCA Board.

The appointment of such pro-tempore Chairperson/Moderator is adopted by a simple majority of the actual full members present or validly represented.

Art. 2.3 General Assembly Acts

The General Assembly Acts contain a formal written record of discussions, resolutions and other relevant matters incurred in preparation of the meeting and during the meeting itself.

a. **Pre-Meeting**

The pre-meeting documentation (including e.g. order of business, budget, annual financial report, annual activity report, project proposals) shall be circulated not less than 2 (two) months before the beginning of the General Assembly Annual Meeting.

The above deadline may be modified and delayed for compelling reasons (e.g. delay in receiving the documentation from the auditor). In this last case the Board shall inform without delay the members.

b. **Minutes**

At the beginning the General Assembly Annual Meeting, the members shall appoint a minute taker.

The minute taker will take notes of the main events during the discussions, including (but not limited to) all proposals and amendments submitted in writing to the Chairperson of the meeting, order proposals, the decisions, and elections.

The minutes of the General Assembly are recorded in a register, signed by the Secretary or his / her substitute and by the Chairperson or his / her substitute. Such register is kept at the registered office of EFCCA, where it shall be at all times open for inspection by EFCCA's members.

c. **Minutes approval**

The register (e-archive) shall be available online. Member's organization shall log in the register to approve or contest the minutes in 60 days after the publication of the minutes. If no contestation occurs, the minutes shall be considered as approved. The contested parts shall be discussed and approved at the next General Assembly Annual Meeting.

Art. 2.4 Discussion procedure during the General Assembly

All items on the order of business shall be open to discussion before the voting procedure. Participants may indicate that they want to be added to the speaking list by raising their hand. The Chairperson/Moderator will determine the speaking time per each speaker before the first speaker begins. The Chairperson/Moderator will then open the floor for discussion. If necessary, the speaking time is adjusted.

If the Chairperson/Moderator or anyone with the right to speak during the General Assembly has the opinion that all relevant arguments and contributions to the discussion have been made, he/she will propose to close the discussion. With a simple majority the General Assembly decides on the closing.

If the item discussed requires a vote, the Chairperson/Moderator calls for a vote.

If the item discussed requires an extensive discussion, with a simple majority the General Assembly shall decide on the reporting the item at the next Annual Meeting.

Art. 2.5 Voting and decision-making during the General Assembly

Ordinary management decisions shall be voted by the General Assembly with a simple majority and quorum with a public vote.

The vote shall be made by raising hand.

The Assembly Chairperson/Moderator asks for favorable vote, contrary votes and abstentions for the purpose of the correct reporting in the minutes.

Members of the Board shall not be allowed to vote in their capacity as representatives of their national associations. If a member organization is not able to send any delegate to the General Assembly Annual Meeting beside the delegate acting as director, the member organization could indicate a proxy organization (art. 2.2) entitled to represent the member organization during the voting.

Art. 2.6 Election of Board members

The Election of the Board members shall take place with a secret ballot. If the candidates are more than the necessary seats, the delegates will vote in a unique ballot indicating the preferences for the available positions. In the case of a tie between two candidates, another ballot may take place only between the two of them.

Two scrutinizers are appointed to count the votes: preference is given to representative of EFCCA Youth and delegates of the Associate members.

Art. 2.7 Election of the Chairperson

The election of the Chairperson takes place with a secret ballot. If there is only one candidate it may be elected by acclamation.

Art. 2.8 Special quorum decisions

In the case the EFCCA Constitution requires specific quorum for taking a decision, the Secretary is in charge to guarantee that the quorum is respected. In this case the voting procedure will be started with a counting of the number of votes present. While the voting procedure is in progress, nobody will be allowed to leave the plenary area.

Art. 2.9 Discharge of the Board

With the approval of the annual financial report and the budget, the General Assembly discharges the members of the Board from any liability in respect of the exercise of their management duties during the financial year concerned.

The discharge is without prejudice to the provisions of the law of Belgium relating to liability upon bankruptcy and does not extend to matters not disclosed to the Assembly.

Any organization could request to state its voting declaration (to be submitted in writing to Assembly Chairperson) in the minutes expressing the reason why is discharging or not the Board.

Art. 2.10 Motion of no confidence

If the discharge's vote does not reach the necessary majority, a motion of no confidence shall take

place.

All members of the EFCCA board shall step down of their respective positions and a new round of election shall be held for the nomination of a new Board.

SECTION 3 – BOARD: MEMBERS & MEETINGS

Art 3.1 Governance

The Board shall conduct the affairs and the management of EFCCA as it may deem proper and not inconsistent with the Belgian laws, the EFCCA Constitution, and these internal regulations.

The Board is responsible for policymaking, while employees (and to a certain extent, Board's members) are responsible for executing day-to-day management to implement board-made policy. However, the ultimate responsibility for the actions (and inactions) of the association, rests with the Board.

Art. 3.2 Method of selection of Board Members

All EFCCA delegates – both from full members and from associate members – are to be encouraged to proactively participate from time to time in the affairs of EFCCA by serving as Board members in order to promote an adequate member representation.

Board members shall hold office for a term of 2 (two) years and shall be eligible for successive term without limitation.

The Board may ask, occasionally and/or for specific subjects, other delegate(s) to attend their meetings in order to advise. The guest delegate has no right to vote.

The Board may ask, occasionally and/or for specific subjects, external person(s) to attend their meetings in order to advise. The guest has no right to vote.

Art. 3.3 Officers

The officers of EFCCA shall consist of: a Chairperson of EFCCA who shall also serve as Chairman of the Board, a Secretary, a Treasurer, and such other Officers as the Board may determine.

The Directors elect from among themselves the above officers.

Art. 3.4 Board Meetings

The Board shall by default meet at least twice in any year in addition to a meeting held at the time of the annual General Assembly. Special meetings may be called at any time by the Chairperson of the Board or upon the request of a majority of the Board members.

The Chairperson leads the meeting and ensures that required quorum is met (at least three Board members). Board's members may participate in a meeting of the Board through use of a conference telephone or similar communications equipment, so long as all members participating in such meeting can hear one another. Decisions are made by a majority vote and the chairperson has no

veto power.

The meeting is open to the participation of the EFCCA staff, although with no voting right.

A report will be prepared of any such meeting and circulated to Member Associations as soon as reasonably possible after such meeting.

Art. 3.5 Executive Board

The Board of Directors may appoint an Executive Committee composed of not less than three (3) members of the Board of Directors, namely the Chairperson, the Secretary and the Treasurer.

The Executive Committee shall have the power to adopt temporary measures on all matters within the powers conferred to or duties imposed upon the Board of Directors subject to their ratification at the next scheduled Board meeting.

Art. 3.6 Responsibilities of the Chairperson

The Chairperson shall act as the primary spoken-person of EFCCA representing the mission and goals of EFCCA. He or she may be substituted when not available by the duly appointed vice-chairperson.

The Chairperson shall sign and execute contracts, bonds, mortgages, deeds, and other official documents or instruments in name of and engaging EFCCA.

The Chairperson shall conduct all meetings of the Board ensuring that all relevant matters are discussed and that effective decisions are made and carried out.

The Chairperson shall report to the Member Organizations at least once per year during the General Assembly Annual Meeting upon the state of affairs of EFCCA. This activities' report shall be included into the annual report.

Other relevant and urgent matters may be communicated during the year through the medium of newsletters or with the internal communication system and with the support of the staff.

The Vice-Chairperson shall act as Chairperson in all the matters whenever the Chairperson is unable to do so or when asked directly by the Chairperson when necessary through a proxy.

Art. 3.7 Responsibilities of the Secretary

The Secretary is responsible for supervising the undertaking all the organizational responsibilities referred to in the Constitution not allocated to another board member or to the staff, and in particular, for officially convening all meetings of the General Assembly.

The Secretary is responsible for supervising the archiving and/or registering of all minutes, records and decisions of EFCCA.

Art. 3.8 Responsibilities of the Treasurer

The Treasurer guarantees the full transparency in EFCCA finances according to the relevant and applicable legislation.

The Treasurer enrolls and supervises the necessary rules and procedures for reimbursement and payments.

At each GA meeting or at the request of the Board, the Treasurer reports the current state of the finance.

Art. 3.9 EFCCA Youth Group Representative

The EFCCA Youth Group Representative into the EFCCA Board is a full voting member of the Board by right. In addition to the ordinary tasks of each Board Member he shall take to the attention of the Board the specific point of view, the requests and the necessities of the EFCCA Youth Group. Together with the EYG leader, if a different person, he reports and responds directly to the Treasurer for the use of the budget allocated for the EYG activities.

Art. 3.10 Reimbursement

Board members shall not receive any salary for their services as Board members. The proper expenses of any Board Members, including attending any meetings, shall be reimbursed by EFCCA upon presentation of adequate expense justification documents stating the expenses incurred.

Art. 3.11 Project Groups, Experts and Advisors

The Board may appoint any Board Member together with/or any other suitable persons to constitute a Project Group to undertake any specific task on behalf of EFCCA.

Any Project Group appointed by the Board shall require to be subsequently approved by the Board at its next meeting and shall continue to exist until determined by the Board.

Any Project Group shall report on its activities and expenditures not less than twice in any year to the Board, through the Secretary and the Treasurer.

A Budget for each Project Group shall be prepared and approved by the Board before it shall incur any liabilities. The Board shall not authorize any expenditure for Project Groups where the total expenditure on all Project Groups would exceed the amount provided therefor in the Budget for the year approved by the General Assembly, unless special financing shall have been arranged by way of sponsorship or otherwise.

The proper expenses of the members of any such Project Group shall be reimbursed, subject to the established reimbursement policy.

The Board may also appoint experts or professionals for undertaking specific tasks.

Art. 3.12 Delegation of duties

In case of the absence of any officer of EFCCA, or for any other reason that the Board may deem sufficient, the Board may confer for the time being the powers or duties of any such officer upon another officer or upon any member of the Board, except that the duties of the Chairperson that may not be delegated to the Secretary and vice versa.

The duties of the Chairperson can be delegated for a period no longer than 6 months. If for any reason the elected Chairperson is not able to fulfill its duties for a period longer than 6 months, he/she has to resign as a Chairperson. The EFCCA board will appoint a temporary Chairperson who will be in charge until the first annual meeting where a new election could take place.

Art. 3.13 EFCCA YOUTH GROUP

The EFCCA Youth Group (infra EYG) is part of EFCCA and does not represent a separate legal entity.

The EFCCA General Assembly commits to allocate a specific annual budget for its activities. The activities and the related budget are managed by the EFCCA Youth Group in autonomy. An annual activities' report shall be presented at the EFCCA General Assembly Annual Meeting.

The rules and regulations of the EYG, such as rules for electing and choosing its members, or regulations on how to handle the annual EFCCA Youth Meeting or any other activities, are proposed by the EYG to the General Assembly which approves them as part of these Internal Regulations under Annex IV.

EFCCA, its members and its Board commit to guarantee the independence of the Youth Participant to appoint their representatives and the EYG leader(s).

SECTION 4 – FINANCIALS

Art. 4.1 Financial year

The financial year of EFCCA shall be from January 1 to December 31 of each year.

Art. 4.2 Depositories, Checks, etc.

The Funds of EFCCA shall be deposited in a bank account(s) located in Belgium and operated by the Treasurer and the EFCCA CEO. The Boards may set limits to transactions.

Art. 4.3 Audit

The accounts prepared by EFCCA staff – under the supervision of the Treasurer – to be presented at General Assembly Annual Meeting shall be duly audited in accordance with the applicable legislation. The external auditor of the account (s) shall be mandatory appointed by the Board excluding any person with a direct role within EFCCA. The auditor shall be remunerated.

SECTION 5 – MISCELLANEOUS

Art. 5.1 Annual Report

At the end of each year, the Board and the EFCCA CEO prepare an Annual Report to be circulated and approved by the GA. After the approval by the GA the Annual Report becomes public and shall be published at the EFCCA homepage and made available to any interested stakeholder through the transparency program (transparency@efcca.org).

Art. 5.2 Amendments to the Internal Regulations

These Internal Regulations may be amended by the General Assembly when deemed necessary. Amendments to these Internal Regulations shall require a favorable vote with a simple majority of the voting rights cast.

Art. 5.3 Communications

All communications to EFCCA should be address in writing to the official address of registration.

Each member association must indicate a contact point that is entitled to receive all the communications sent to the member association and in charge share the communication throughout the organization's internal structure.

Art. 5.4 Digital Archive

Digital archive (E-archive) is a collection of documents or records which have been deemed for permanent preservation because of their value as evidence or as a source for historical or other research of EFCCA. Records are created by the activities of the organization and people working for it (i.e. minutes, vote record, proposal, resolution, etc.).

The E-archive will be open to all the members association throughout their delegates and a registry of their access and comments will be kept when needed according to the current internal regulations, namely Art. 2.3.

Art. 5.5 EFCCA CEO

The CEO acts as head of the office staff and she/he is responsible to ensure an efficient and cost-effective management of the activities in order to implement the strategic objectives set out by the EFCCA Board as approved by the General Assembly.

The duties include: representing EFCCA to external parties, hiring and managing the staff, organizing the daily business of EFCCA, the Board and General Assembly meetings.

The Board could in writing delegate other duties to the CEO.

Art 5.6 Honorary titles

In recognition to exceptional contributions to EFCCA's mission and goals, the Board can award an honorary title "Ambassador of EFCCA" to selected individuals.

Ambassadors contribute to EFCCA through their experiences, knowledge and network but they do not have the power to legally represent or in any way engage EFCCA. Ambassadors may be invited to attend meetings, namely the General Assembly Annual Meeting, but shall not have the right to vote.