

# EFCCA Commitment to transparency

How EFCCA ensures  
independence, integrity,  
and accountability in  
everything we do.

European Federation of  
ulcerative Colitis and Crohn's  
Associations



united we stand

transparency@efcca.org

# EFCCA Commitment to transparency

Transparency has always been of paramount importance to EFCCA, as a European federation of 25 national IBD associations. The trust and confidence of the 2.2 million people with IBD in Europe is one of our most treasured assets, and EFCCA will protect this, throughout all its activities.

Transparency is a term that we used to refer to principles of independence, integrity, accountability, and good practice. The current EFCCA Strategy Plan places transparency in high regard, which is why we have developed the 'Aqua' programme — just as people need clean, clear water; clean, clear practice must be at the heart of EFCCA.

Under the Aqua programme, EFCCA puts great energy and effort into transparent practice, and we're pleased to announce many policy statements in this document which we've already implemented.



Furthermore, we would like to invite you to email [transparency@efcca.org](mailto:transparency@efcca.org) to request information on finances, projects or relationships. We're pleased to respond to requests from anyone, on any subject, at any time.

This is our commitment to transparency, which we're proud to put our names to.

**Marco Greco Ph. D.**  
EFCCA Chairman

# Financial transparency

**Transparency** has always been important to EFCCA. We hope that the EFCCA financial transparency policy maintains and develops EFCCA as a truly transparent organization, so that all European people with IBD can be confident about our activities and relationships.

As the EFCCA Treasurer, I am pleased to implement the “EFCCA Financial Transparency Policy”.

**Policy statement 1.1:** Any individual or organization may request specified financial information from EFCCA, and EFCCA will prepare and provide it to them.

There are two provisions:

- EFCCA will protect personal information (information that identifies a living human being) in accordance with European Data Protection Law (we will provide anonymized information if appropriate).
- EFCCA will provide any financial data that it already holds, where the request does not require excessive time or resources to assemble that data.

**Policy statement 1.2:** EFCCA will pro-actively share financial information by:

- Creating regular reports for the Ex-Com containing summary financial data.
- Creating a full Annual Report of all financial activities, presented and approved by the General Assembly, and available externally.
- Ensuring that accounts are independently audited each year, in accordance with European law.
- Responding to “transparency information requests” from anyone who makes them.

We hold all our funds on behalf of all European people with IBD, so it is essential to be open and clear about our activities and financial planning. I welcome the opportunity to share this information, whilst of course protecting personal information.

**This is our commitment to transparency**

**Ben Wilson**  
*Treasurer*

# 1.0 Financial transparency



## Current financial strategy

- To protect national associations by not raising subscriptions during the economic crisis.
- Where possible, to ensure that projects have more than one sponsor.
- Where possible, to seek for non-pharmaceutical commercial sponsorship (for example, from communications or media companies).
- Not to publicly fundraise or take subscriptions from individuals, since this is the domain of the national IBD Associations.

## Four-stage long-term strategy

1. Increase corporate sponsorship to fund paid staff.
2. Employ paid staff with income-generating responsibilities.
3. With this paid staff, tender successfully and win EU grants and non-pharma funding.
4. **Long-term goal: Replace pharma funding with EU grants and non-pharma sponsorship**

## Current funding proportions

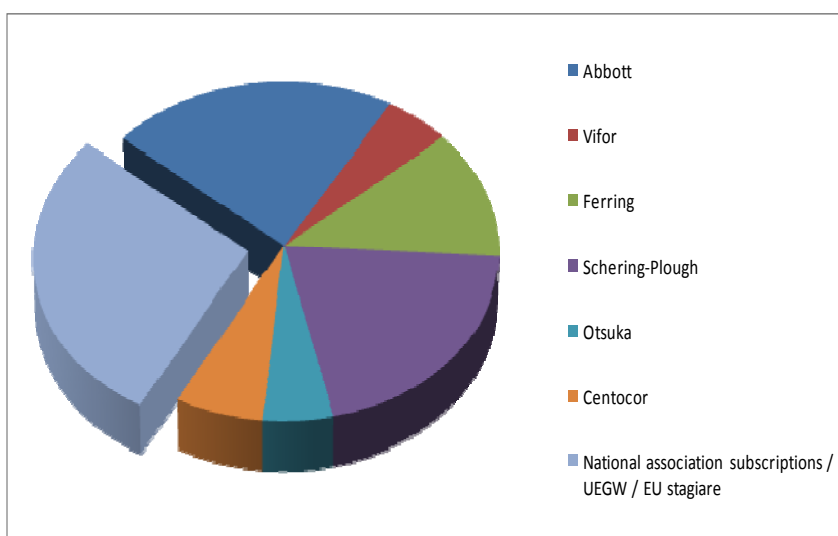
From the 2009 annual report, EFCCA is funded at approximately 30% from subscriptions from national IBD associations, and 70% from commercial sponsorship.

The diagram below shows the precise proportions from each commercial sponsor, and from national associations.

An **options appraisal conducted in August 2010** found that adjustments in the percentage of funding to 60:40% would result in either:

- Suspension of almost all EFCCA activities, or
- National association subscriptions more than doubling.

For more details on the options appraisal, please email [treasurer@efcca.org](mailto:treasurer@efcca.org).



## EFCCA's governing codes

EFCCA considers principles from the following sources in all activities:

- the International Federation of Pharmaceutical Manufacturers and Associations' (IFPMA) Code of Pharmaceutical Marketing Practices.
- The European Federation of Pharmaceutical Industries and Associations' (EFPIA) Code on the Promotion of Prescription-Only Medicines to, and Interactions with, Healthcare Professionals.
- Directive 2001/83/EC on the Community Code relating to medicinal products for human use, as amended by Directive 2004/27/EC.
- The World Health Organisation's Ethical criteria for medicinal drug promotion.
- Ethical rules of l'Association Generale de l'Industrie du Medicament (AGIM).

## The EFPIA code

EFCCA's primary code of practice has been adopted from:

European Federation of Pharmaceutical Industries and Associations (2006) *EFPIA code of practice on relationships between the pharmaceutical industry and patient organisations*. Available at: [www.efpia.eu/Content/Default.asp?PageID=559&DocID=3484](http://www.efpia.eu/Content/Default.asp?PageID=559&DocID=3484)

EFCCA seeks to build upon the following principles that EFPIA, together with pan- European patient organisations, last updated in September 2006:

- The independence of EFCCA, in terms of political judgement, policies and activities, shall be assured.
- All partnerships between EFCCA and the pharmaceutical industry shall be based on mutual respect, with the views and decisions of each partner having equal value.
- The pharmaceutical industry shall not request, nor shall EFCCA undertake, the promotion of a particular prescription-only medicine.
- The objectives and scope of any partnership shall be transparent. Financial and non-financial support provided by the pharmaceutical industry shall always be clearly acknowledged.
- EFCCA welcomes broad funding, from multiple sources.



# Transparency in relationships

EFCCA recognises that it has some common interests with pharmaceutical organizations, to represent or support the needs of patients. To ensure that relationships between EFCCA and the pharmaceutical industry are ethical and transparent, EFCCA has adopted the EFPIA Code of Practice, and has exceeded EFPIA's requirements with the following additional policies.

**Policy statement 2.1:** EFCCA will ensure that any contracts with third parties contain essential protective clauses, for example:

- EFCCA's independence is assured throughout all activities.
- EFCCA reserves the right to choose vendors and control project budgets.
- EFCCA reserves the right to define timescales, objectives, resources.
- EFCCA may terminate an agreement at any time.
- EFCCA will not approve or promote any commercial product or service, and entering into an agreement must not denote any such approval.
- The right of EFCCA any national association to opt-out of any activity is assured and fully respected.

**Policy statement 2.2:** Any individual or organization may request specified contractual information from EFCCA, and EFCCA will prepare and provide it to them.

There are two provisions:

- EFCCA will protect sensitive commercial information if necessary.
- EFCCA will provide any contractual data that it already holds, where the request does not require excessive time or resources to assemble that data.

**Policy statement 2.3:** EFCCA will pro-actively share information about its sponsors, partners, and other relationships by:

- Creating a full Annual Report of all activities, presented and approved by the General Assembly, and available externally, which lists all sponsors, partners, and allied organizations.
- Providing listings of all sponsors and partners on the EFCCA website, and on any other project-specific websites as appropriate.
- Responding to "transparency information requests" (See 2.2) from anyone who makes them.

**Policy statement 2.4:** EFCCA will fully comply with the EFPIA code, and other applicable national codes of practice as appropriate, which govern ethical and transparent relationships with commercial and pharmaceutical companies.

**This is our commitment to transparency**

**Marco Greco Ph.D.**  
*Chairman*

transparency@efcca.org





## Template sponsor's agreement

When creating a new agreement, EFCCA uses the following template as a basis and starting point.

### Transparency

1. The Sponsor must not seek to influence the text of EFCCA material they sponsor in a manner favourable to their own commercial interests. This does not preclude the Sponsor from correcting factual inaccuracies.
2. Where EFCCA receives financial support and/or significant indirect/non-financial support from the Sponsor, both parties will publish details of the relationship publicly, for example on websites and in annual reports. This may include a short description of the nature of the support. This information should be kept up-to-date.
3. Both parties must ensure that their relationship is always clearly acknowledged and apparent from the outset.
4. The Sponsor may not require that it be the sole funder of EFCCA, or any of EFCCA's major programmes.
5. EFCCA will not request or undertake the promotion of any pharmaceutical product or service in connection with this agreement, and will not take any action, including (without limitation) the payment of any money to a Government official, that would improperly influence any person or firm to do business with the pharmaceutical party.
6. Both parties must comply with all laws and regulations in the countries where it is undertaking the activities contemplated by this agreement.
7. The parties confirm that the patient organization maintains full control over the content of its work and retains its independence. The patient organization shall not present any favouritism toward the pharmaceutical sponsor, a specific treatment, or a specific product in its public relations efforts.
8. The Parties acknowledge and agree that EU and national legislation and codes of practice, prohibiting the advertising of prescription-only medicines to the general public, apply to all activities described in this Agreement.
9. EFCCA shall be solely responsible for carrying out the Tasks, such as the initiation and management of the Tasks. The sponsor must not seek to influence any of the Tasks or other work performed by EFCCA hereunder in a manner favourable to the sponsor's own commercial interest. However, this does not preclude The sponsor from correcting factual inaccuracies.
10. The public use of EFCCA's logo and/or proprietary material by The sponsor requires written permission from EFCCA. In seeking such permission, the specific purpose and the way the logo and/or proprietary material will be used must be clearly stated. Permission must be sought from the EFCCA Chairman before any material or activity may be credited, for example, as "*approved by EFCCA*", or "*Produced in collaboration with EFCCA*".
11. The Parties agree that EFCCA shall have no further obligations other than those explicitly mentioned in this Agreement and EFCCA shall under no circumstance be obliged to indemnify, defend, and hold harmless The sponsor from any and all liabilities, losses, damages, costs and expenses, it may suffer in connection with any claim, action or lawsuit brought by a third party relating from this Agreement.
12. If any term or provision of this Agreement shall be deemed to be invalid or unenforceable to any extent or in any application, then the remainder of this Agreement shall not be affected thereby and shall continue in full force and effect.
13. EFCCA shall at all times be independent of The sponsor. EFCCA is not an employee, servant or agent of The sponsor and no partnership, joint venture or agency will be created or will be deemed to be created by this Agreement or by any action of the parties under this Agreement and EFCCA shall not represent himself/herself to have or be in any such relationship with The sponsor.

### Events and hospitality

1. All events sponsored or organised by or on behalf of the Sponsor must be held in an appropriate venue that is conducive to the main purpose of the event, avoiding those that are 'renowned' for their entertainment facilities or are 'extravagant'.
2. All forms of hospitality provided by the Sponsor to EFCCA and its representatives or members shall be reasonable in level and secondary to the main purpose of the event, whether the event is organised by EFCCA or the Sponsor.

### Where advertisements are undertaken:

1. EFCCA will not promote or recommend a specific drug or treatment.
2. EFCCA only allows corporate advertisements:
3. Advertisements may feature a corporate name, but not any specific brand, product, service, or treatment name (in text).
4. Advertisements may feature a corporate logo, but must not show, or imply, any specific brand, product, service, or treatment; using logos, graphics or images.
5. EFCCA's own logo or name must not be used within the advertisement.

### Published information:

1. EFCCA reserves the right to remove any piece of information from its publications or websites at any time.
2. No organization is able to require that it is the sole provider of advertisements, or content. EFCCA may also publish content from other organizations, and the relative priority or position of this other content is at EFCCA's discretion.

29 September 2010

EFCCA  
Rue vieux marché aux grains 48  
B 1000  
Brussels  
Belgium



**United we Stand**

EFCCA recognizes the importance of transparency in all its activities.  
EFCCA supports this principle by:

- Creating regular reports for the Ex-Com containing important financial data.
- Creating a full annual report of all financial activities, presented at the General Assembly, and available externally.
- Ensuring that accounts are independently audited each year, in accordance with European law.
- Responding to “transparency information requests” from anyone who makes them.

**TRANSPARENCY INFO  
REQUEST**

**To make a “transparency information request”:**

We are pleased to make financial information available to you on request. Please complete this form, and return it to [transparency@efcca.org](mailto:transparency@efcca.org). We will provide a detailed response.

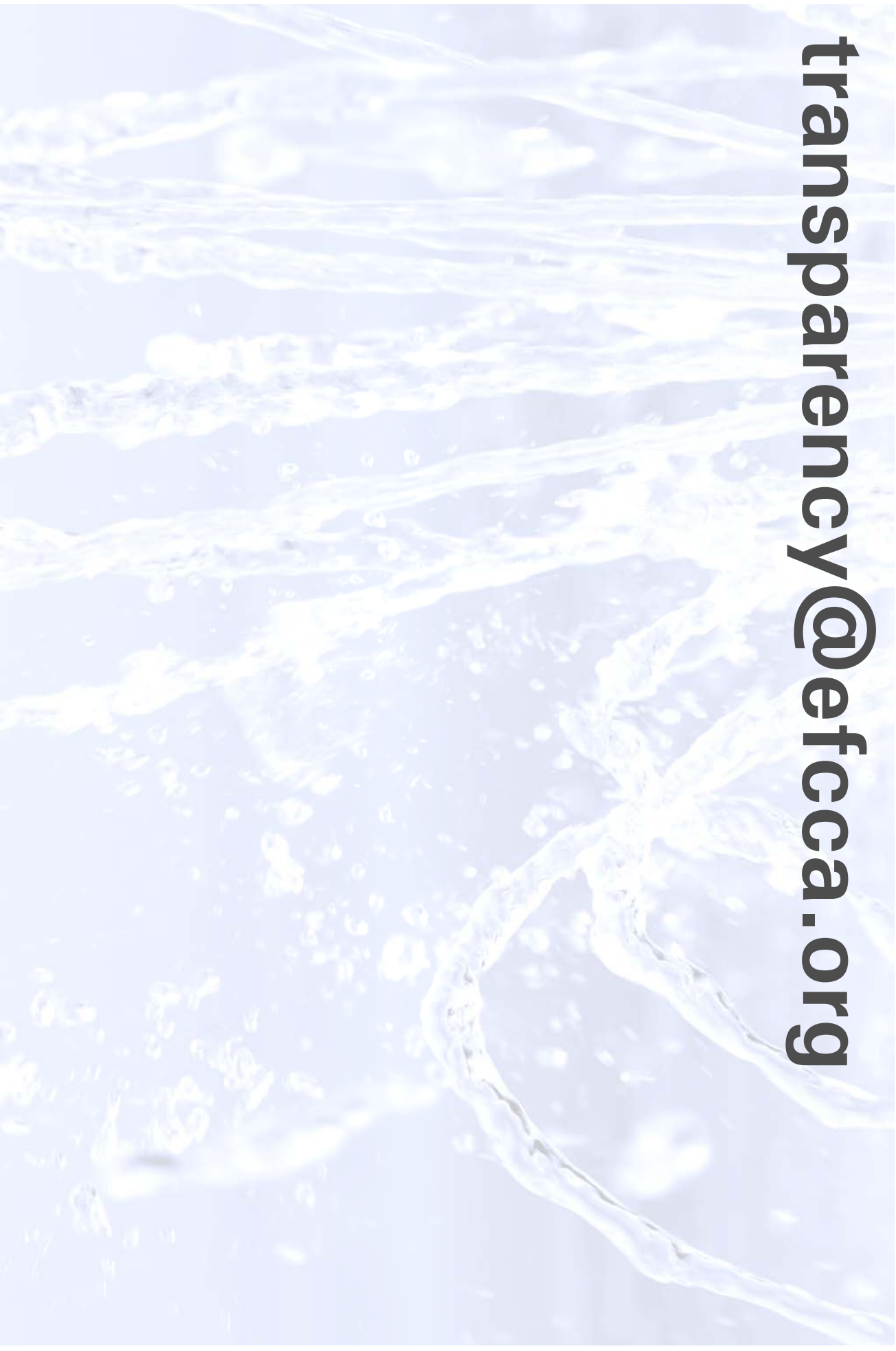
When responding to transparency info requests, we will protect and not disclose personal data.

<b>Name and contact details</b>  Including email, postal address, telephone, organization (if applicable)	
<b>Information requested</b>  Please be as specific as possible. For example: <ul style="list-style-type: none"><li>• Ask a specific question</li><li>• Refer to a specific account or activity</li></ul>	
<b>Date or period applicable</b>  For example: <ul style="list-style-type: none"><li>• Current, or previous financial year</li><li>• Specific month, or week</li><li>• Date of a specific transaction</li><li>• Specific start or end date</li></ul>	

- Please allow a maximum of 28 days for a full response to be returned to you.
- We may contact you for further information if we need it to complete your request.
- If the request involves significant administration work, EFCCA may make a small charge to cover these activities.



**[transparency@efccca.org](mailto:transparency@efccca.org)**



# EFCCA commitment to transparency

**independence, accountability, integrity**

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**united** we stand