

Introduction

FEDERG is the non-profit federation of European associations of patients affected by rare and/or genetic kidney diseases. To further its aims, FEDERG seeks funding and support from a variety of sources in addition to voluntary income from its supporters (donations and fundraising activities).

The purpose of this policy is to ensure that in seeking and securing such funding and support, FEDERG has a clearly understood, ethical way of collaborative working. It is designed to address sponsorship, cause related marketing, donations and gifts in kind. “Sponsorship” means payment by a private sector organisation – or individual – in return for public association with an activity, project, event or asset. This could be in cash or in kind.

Guiding Principles

- FEDERG will treat requests from external organisations fairly, openly and equally.
- FEDERG conducts due-diligence checks in advance partnering with other organisations and individuals. FEDERG is careful when collaborating with other organisations and individuals that it maintains its independence status and does not allow external partnerships to bring the name of FEDERG into disrepute.
- Upon their commencement, partnerships are kept under regular review. When there is any possibility of reputational risk to FEDERG, FEDERG will withdraw from any such activity or initiative.
- FEDERG aims to ensure that the activities of proposed funders are consistent with FEDERG’s values, goals and actions of promoting and/or enabling good health. Each collaboration will be assessed on a case-by-case basis with due consideration given to any possible risks
- FEDERG will be transparent in its relationships with other organisations and individuals; it should always be documented explicitly what each party is bringing and gaining from a formal relationship.
- FEDERG will be transparent about who it is partnering with and the nature of the relationship. A list of commercial partners and corporate sponsors will be maintained on FEDERG website (www.federg.org).
- FEDERG will acknowledge and thank commercial partners and sponsors of individual projects or activities proportionately so as to avoid undisclosed advertising. FEDERG will consider carefully any request to display corporate logos and avoid giving them undue prominence.
- No person acting on behalf of FEDERG is permitted to accept honoraria from any company or individual, only reimbursement of effective expenses can be accepted.
- FEDERG will not share or sell the details of its supporters or networks, nor promote or endorse products or services from supporters, partners or third parties.

Avoidance Criteria

Partnerships with companies involved in any of the following will be avoided:

- Activities that are demonstrably harmful to health and wellbeing or in other ways demonstrably harmful to the public good, in the judgment of FEDERG board;
- Production, promotion or provision of unproven therapies or products demonstrably harmful to anyone affected by rare and/or genetic kidney disease;
- Tobacco manufacture and sale.

Cause Related Marketing, Affinity Marketing, and Product Endorsements

- By entering into a commercial partnership, FEDERG does not endorse or approve products or companies, and a statement to this effect will be included alongside any branding or promotion associated with products.
- FEDERG will not promote any products unless published research has shown direct benefit to its beneficiaries.
- No commercial partners or sponsors (including subsidiaries) will have direct access to FEDERG databases.

Obligations of Supporters and Partners

- A formal collaboration is considered a business arrangement; therefore, all aspects must be clear and explicit to all parties involved. All agreements are exchanged in writing and supporters or partners are required to endorse and abide by FEDERG Ethical Policy.
- Approval must be sought from FEDERG for any copy produced which refers to a FEDERG initiative supported/sponsored by a supporter or partner organisation or individual.
- FEDERG name and logo are its property and may not be used by a commercial partner or sponsor without its explicit permission.
- Staff, volunteers, and directors on both sides should be aware of the potential for bias generated through collaborations, where this might impinge on professional judgment and impartiality.
- Both parties commit to confidentiality at all times.

Conflicts of Interest

When establishing a new collaboration, both parties must aim to ensure that there are no conflicts of interest that cannot be safely managed. FEDERG will ensure that any possible conflicts of interest are managed and a suitable mitigation strategy put in place.

Process

All proposals to accept funding and support from external organisations and potential partners must be approved by the board, together with an account of the due diligence performed on the potential funder.

Due diligence will include the nature, activities and reputation of the funder; the nature of the sponsorship or proposed relationship; proposed activities, size of the proposed funding



Ethical Collaboration Policy

or support; any risks to FEDERG and may include consulting with other charities or organisations that have dealt with the company.

FEDERG will expect funders or commercial partners to comply with their respective industry codes of practice governing funding or supportive relationships with charities.

Contact for Sponsorship and Commercial Participation Issues

Tess Harris, President

Email: info@federg.org | Tel: +44 (0) 20 7387 0543