
Eurordis' Position on NGOs' Transparency

Eurordis believes that transparency cannot be restricted to the narrow issue of transparency on funding - a necessary but not sufficient condition of transparency.

Any policy on transparency should provide clear answers to the following questions:

- Who does the NGO represent? What is its representativeness?
- How is the NGO funded and which public or private interests does it represent?
- Does the NGO have a track record of credible work?
- Does the NGO really contribute to the debate? Does it have clear written public statements on its positions?

Eurordis believes that the transparency of an NGO lies primarily in:

- Its mission and values;
- The legitimacy of its membership base;
- Its governance practices;
- Its internal and public policy practices.

Consequently, the transparency of an NGO also lies in:

- The transparency of its financial information;
- Internal and external financial control by independent audits;
- The transparency of its financial relationships with funding sources, both public and private;
- The transparency of its financial relationships with commercial companies;
- The prevention of potential conflicts of interest, both public and private.

In all of its activities Eurordis respects and promotes the fundamental value of transparency, by following the principles of:

- Legitimacy;
- Credibility;
- Responsibility;
- Independence;
- Accountability.

Following the recent initiative by Commissioner Kallas on Transparency, Eurordis wishes to contribute to the debate going on at EU level on legitimacy and transparency of non governmental organisations (NGOs).

Eurordis welcomes the current focus on transparency of lobbyists seeking to influence European Institutions; lobbyists include health advocates such as NGOs and patient organisations.

Eurordis calls for a better distinction between:

- lobbying activities by stakeholders with a financial interest;
- advocacy activities by groups of individuals or associations voicing citizens' needs and views on critical issues such as health, research, consumer rights, the environment, human rights, etc.

Eurordis has always been fully aware of the importance of transparency towards its constituents, third parties and the public at large. Eurordis has therefore adopted a long-term perspective on these issues, and has progressively upgraded its own standards, pro-actively developing its own set of principles, policies and practices.

Eurordis believes that NGOs should contribute to the current debate by putting forward a set of good practices.

1. Political legitimacy through membership and governance

Membership

Eurordis is a patient-driven organisation and, as such, firmly believes that its first source of legitimacy and the main guarantee of its independence stem from its membership base.

Eurordis has several categories of members: the Full Members are the only ones allowed to vote at the General Assembly and to present candidates to the Board [By-Laws: "Each full member designates one person to represent it at the General Assembly. Associate and allied members do not hold a vote. Only those full members who are up-to-date with their membership fee payments can vote]. Full Members are all - and exclusively - rare diseases patient organisations.

To become a member of Eurordis, organisations must provide their by-laws, activity and financial reports, and composition of their Board, as well as fill an application form. The documents provided are then evaluated against a set of criteria to assess:

- the real nature of the association as a patient-driven association;
- its financial independence;
- and the reality of its activities.

Every new member must be sponsored by another member and the Board has the final say. Members express their commitment to Eurordis' work and achievements through:

- provision of an annual update;
- regular information about their activities;
- and payment of an annual membership fee.

Eurordis' Full Members take part in the strategic and political decisions of Eurordis. Over 60 volunteers regularly take part in Eurordis' Task Forces, Project Steering Committees and other working groups, while over 400 patient organisations have participated in Eurordis' activities in 2003-2004.

The list of Eurordis' members is made public and regularly updated. Therefore, when a representative of Eurordis takes the floor, there is no confusion so as to who is represented.

Lack of clarity about who is represented by certain pressure groups in Brussels is often confusing and misleading. Eurordis believes the level of advocacy and the quality of many political debates would improve if all involved parties defined themselves more clearly when approaching EU officials, contributing to open consultations or participating in conferences and meetings at EU level. Some well-known lobbyists in Brussels are regularly invited to take the floor during important events because of their commitment to several organisations, but it can be unclear whom they are advocating for on any particular occasion.

Eurordis believes that this situation is detrimental to the elaboration of EU laws and policies; it can also create a negative impact for the European public policy and image among EU citizens.

Governance

Eurordis' mandate from its members is to make visible the experience of rare disease patients and speak on their behalf to EU Institutions and other bodies. Because Eurordis is a patient-driven alliance, it has adopted a set of policies and good practices to reflect this position at three levels: Eurordis strategy & activities, Eurordis public policy statements, and Board governance practices.

- Strategy & Activities

This approach is reflected in the following documents:

- Mission Statement, recently revised through a thorough consultation process;
- By-Laws, revised in 2003 following changes in mission statement and membership structure;
- Five-Year Strategic Orientations;
- Annual Action Plan;
- Annual Activity Report, in which achievements against Action Plan are assessed.

These internal policy documents were presented, discussed and voted by Eurordis' members; they are made widely available through publication on Eurordis' website.

- Public Policy Statements

Eurordis' policy statements are written by its European Public Affairs Committee (EPAC). An ongoing process is used to create position papers and documents intended for dissemination. All Eurordis policy statements, position papers, comments on European policy, and responses to EU public consultations are made widely available to the general public on Eurordis' website.

- Board governance practices

This is reflected by:

1. The election process of Board Members: an annual “call for candidates” is sent to all members. Candidates must be approved by their patient organisations of origin. Each candidate must provide a profile, which is sent to all members before the vote. Board Members are elected by all Full Members based on a written vote (secret ballot).
2. The Board itself: Board members are representatives of patient organisations. Out of the 12 current members, 8 are patients or parents of children living with a rare disease. The 12 Board members represent 8 different EU countries.
3. The list of Board Members: this list is made public on Eurordis’ website.
4. At each Board meeting, an information and an action agenda are presented for opinion and decision. Minutes of Board meetings and the Table of Action & Decisions are approved at the following meeting. Decisions made in previous meetings are monitored by the Board via a Tracking Table of Decisions.
5. Each internal permanent committee has a written mandate and its composition is regularly revised by the Board of Officers. Such committees include the European Public Affairs Committee, the project steering committees of any EC funded project, and task forces such as the orphan drugs or paediatric ones.

Such a detailed description of Eurordis’ practices was provided to highlight the fact that we strongly believe in reliable governance practices as a guarantee for democratic policy development and control, and a safeguard against pressure from any individual, institution, group or stakeholder with a specific financial interest.

2. Financial independence through diversified, transparent and proportionate funding sources

- **Diversification**

In order to achieve its goals and reflect appropriately the concerns of rare disease patients, Eurordis must find funds to sustain its advocacy activities and remunerate its paid staff.

It is illusory to believe that an NGO can only work with good will and nice words while advocating for a good cause. Effective advocacy lies in intensive work, deep knowledge of issues, extensive collection of data, and constant interaction with all concerned parties. Despite the excellent work and tenacious commitment of non-paid staff, the following activities remain very costly and time-consuming:

- attend meetings;
- participate in conferences;
- search for and disseminate information;
- analyse policy documents;
- write position papers;
- keep track of EU legislation;
- put forward projects for funding;
- run programmes or services;
- and more generally, represent the interests of patients in all relevant fora.

It is important to note that time and resources of volunteers are always limited because they have a commitment to paid jobs. They are also “qualified” because they are associated with a rare disease, either as patient or as carer.

Eurordis believes that a guarantee of independence lies in the diversification of funding sources: if not appropriately handled, any kind of funding (public or private) may be risky and limit NGOs’ freedom of speech.

Since its creation in 1997, Eurordis’ core operations have been funded by members through fees and grants. A few years later, to develop projects and reach public health and research outcomes, Eurordis started benefiting from funding by the European Commission. More recently, Eurordis has accepted monies from mutual insurance funds, and various pharmaceutical and medical device companies.

- **Proportionality**

Eurordis has adopted the following rule: the total amount of funding by a commercial company cannot exceed the total amount of funding coming from Eurordis’ members.

The 2005 figures show that:

- Funding from private sources represents 18% of total funding (11% being the part covered by the pharmaceutical industry). Private sources include foundations, pharmaceutical companies, and health and other industry sector companies;
- Funding by the European Commission represents 32% of total funding;
- The rest (50%) is covered by Eurordis’ members (46% from membership fees and contribution by the French Muscular Dystrophy Association and Ligue Contre le Cancer - 4% from Inserm).

- **Transparency of information regarding Eurordis’ relationships with commercial companies**

Members and third parties need be aware of financial relationships Eurordis sustains with commercial companies. Eurordis therefore makes public and accessible the financial relationships it has with any commercial company. This information can be found on its website (www.eurordis.org); it includes funding sources, names of donors and monies received.

For instance, when a pharmaceutical company chooses to become a member of the Eurordis’ Round Table of Companies, it is required to read and sign a detailed Code of Conduct. The list of companies that are members of the Eurordis Round Table of Companies is accessible on Eurordis’ website.

- **Transparency of Eurordis’ financial information, democratic control and external audit**

Eurordis’ annual budget, financial statements for the previous year, Treasurer’s report as well as the report by the auditing firm Deloitte-Touch-Tomahtsu are presented at the Annual General Assembly and voted by members.

The previously mentioned documents are all available on Eurordis' website.

3. Transparency and policy to prevent potential conflicts of interest

Our policy states that the salaries of people representing Eurordis in various fora (such as Eurordis' representatives at the European Medicines Agency (EMA) and at the EC DG Public Health; or the European Public Affairs Officer) are paid directly by members and never by the industrial sector. Hence work related to the political activities of Eurordis and its "core business" is financially independent from financially interested parties; our freedom of speech remains intact; and Eurordis' voice only reflects rare disease patients' concerns.

The representatives of Eurordis participating in the scientific discussions at the EMA are experts in rare diseases and orphan drugs; they have to declare annually all contacts they have had with commercial companies that could potentially lead to a conflict of interest. These declarations are made publicly available at the EMA. EMA has a strong policy on conflict of interest, which is followed thoroughly by Eurordis' representatives.

Eurordis is of the view that its work in relation to general information on rare diseases and awareness-raising can be financed by the private sector. Eurordis believes that there is no conflict of interest in doing so. The private sector is often interested in information activities: it reflects a positive and philanthropic attitude to society and companies can benefit in terms of image and social responsibility.

The above-mentioned principles are reflected in all of Eurordis activities. They are particularly visible in relations with the following three entities:

- **EMA**

Within the Working Group of Patient Organisations, Eurordis has actively contributed to the elaboration of a document establishing guidelines and criteria to be followed by patient organisations in their relationship with the Agency.

Eurordis has actively advocated in favour of the adoption of strict and realistic rules, such as the declaration on funding sources by patient organisations. For instance, one of the rules states that the total amount and percentage received must appear along with the name of the source, whether it be public or private.

- **DG SANCO**

Eurordis has expressed full support to the European Commission for its initiative (in the new Health and Consumer Protection Programme) to include the possibility of allowing operational grants to provide core funding to certain European umbrella NGOs, including patient organisations.

Eurordis considers this proposal as a contribution to the independency of health-related NGOs and patient groups.

- **European Patient Forum (EPF)**

Eurordis is an active and founding member of the European Patient Forum and remains vigilant in regards to the operating and funding modalities of the Forum. Eurordis supports the establishment of a policy on transparency and independency within EPF, as well as a practice of funding diversification, notably through the above-mentioned opportunity for patient organisations to receive operational grants from DG SANCO.

Adopted by the Board of Officers, September 26th 2005,
After consultation of the European Public Affairs Committee.

On their behalf,

Yann Le Cam
Chief Executive Officer

About EURORDIS

The European Organisation for Rare Diseases (EURORDIS) represents more than 225 member associations in 24 different countries, covering more than 1000 rare diseases. It is the only organisation that represents the diversity of all rare diseases and countries and thus speaks on behalf of the 25 millions of patients affected by rare diseases throughout Europe.

EURORDIS is a non-governmental patient-driven organisation, dedicated to improving the quality of life of all people living with rare diseases in Europe. It is supported by its members and by the French Muscular Dystrophy Association (AFM), the European Commission and private donors. Further details concerning EURORDIS and rare diseases are available at: <http://www.eurordis.org>

Contact persons

- Jerome Parisse-Brassens, Information Manager (Paris)
jerome.parisse-brassens@eurordis.org + 33 1 56 53 52 61
- Flaminia Macchia Bangsgaard, European Public Affairs Officer (Brussels)
fmacchia@eurordis.org + 32 2 733 81 10