



European Dismelia Reference Information Centre

A Non-Profit Organisation registered in Sweden: No. 802444-3015

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Sweden**

Code of Good Practice

Preamble:

EDRIC and its member organisations are keen to work in a constructive manner together with all stakeholders to ensure that the credibility of its network is safeguarded.

For this reason, EDRIC has developed this Code of Good Practice to guide its relations with its members on the one hand, and with external collaborators and stakeholders on the other. We strongly encourage all member organisations to adhere to this Code when engaging in a dialogue, working partnership, joint initiative, and/or when accepting funding in relation to EDRIC's activities..

In order to fulfil its mission to safeguard and promote the interest of all those affected by dysmelia, EDRIC's activities fall into three distinct pillars:

- A vibrant and multi-lingual online community to enable people with the same or similar impairments to share information, solve problems and support each other
- A comprehensive expert forum that brings together all of the expertise - medical, ergonomic, commercial, scientific, educational/informative - around dysmelia
- A constantly updated, multi-lingual document library or information centre that captures all of the research, clinical knowledge and peer solutions of relevance to those affected by dysmelia

To carry out these activities successfully, EDRIC uses this Code to guide its practices and present a professional and courteous organisation.

EDRIC is governed by a set of statutes that set out the organisation's purpose and objectives. These are available in English, French, German, Spanish, Italian and Swedish on the organisation's website at the following link:

<http://www.dysnet.org/legal/notices/>

EDRIC's Board members, officers, employees and contractors must observe these statutes in the execution of their duties. EDRIC further encourages its member organisations to adopt and abide by its policies - especially this Code of Good Practice and its Position Statement on Collaboration with the Private Sector.

We owe it to our member organisations across Europe and beyond, who have placed their trust in us, to act in a fully democratic, independent and transparent manner, according to the highest standards of good governance. We derive our legitimacy from our membership, our statutes and our democratically elected board, the majority of whose members have first-hand experience of living with dysmelia.

Summary:

This policy covers three broad areas:

1. The arrangements governing the operation of the Board as well as EDRIC's officers and contractors,
2. Openness and transparency in all of EDRIC's operations, and
3. The use of social media to communicate with interested parties.

1. The Board, Officers and Contractors

The Board should be clear about its strategic and leadership roles, and of its key functions which cannot be delegated. These should include as a minimum:

- a) ensuring compliance with the objects, purposes and values of the organisation, and with its statutes and policies;
- b) setting or approving policies, plans and budgets to achieve those objectives, and monitoring performance against them;
- c) ensuring the solvency, financial strength and good performance of the organisation;
- d) ensuring that the organisation complies with all relevant laws, regulations and requirements of its regulators;
- e) dealing with the appointment (and if necessary the dismissal) of the organisation's Chief Operating Officer;
- f) agreeing or ratifying all policies and decisions on matters which might create significant risk to the organisation, financial or otherwise.

The Board must ensure that the organisation's vision, mission and values and activities remain true to its objects.

Board members are bound by an overriding duty, individually and as a Board, to act reasonably at all times in the interests of the organisation and of its present and future members.

Board members must ensure that they remain independent, and do not come under the control of any external organisation or individual.

The Board should collectively be responsible and accountable for ensuring and monitoring that the organisation is performing well, is solvent, and complies with all of its obligations.

The Board must ensure that the organisation complies with:

- a) its own governing documents;

- b) the requirements of its regulators and relevant legislation, and in particular that it submits annual returns, reports and accounts as required by law;
- c) any statutory or regulatory requirements relating to maintenance of financial records, and external audit of its accounts;
- d) the requirements of all other statutes, authorities and regulations governing its work.

The Board should have policies, procedures and reporting mechanisms in place to ensure compliance with applicable legislation.

The Board must avoid undertaking activities which might place the organisation's members at undue risk.

The Board must exercise special care when investing the organisation's funds, or borrowing funds for it to use, and must comply with the organisation's governing document and any other legal requirements in doing so.

The Board should obtain advice from professional advisers or others on all matters where there may be material risk to the organisation, or where the Board members may be in breach of their duties.

The Board should take ultimate responsibility for dealing with and managing conflicts that may arise within the organisation. This includes conflicts arising between Board members, staff, the Chief Operating Officer or members.

The Board should have clear responsibilities and functions, and should compose and organise itself to discharge them effectively.

Individual Board members must not act on their own on behalf of the Board, or on the business of the organisation, without proper authority from the Board.

The Board should organise its work to ensure that it makes the most effective use of the time, skills and knowledge of Board members.

The Board should meet regularly, and ensure that its work is focused on delivering its strategic role.

The Chair of the Board should ensure that all Board members can contribute at meetings, and that the proceedings are not dominated by particular Board members.

Board members should ensure that they receive the advice and information they need in order to make good decisions.

The Board should take professional advice where necessary before making important decisions and should not rely excessively or exclusively on a single source.

The Board members should have the diverse range of skills, experience and knowledge needed to run the organisation effectively.

The Board should make proper arrangements for the supervision, support, appraisal and remuneration of its Chief Operating Officer.

The Board should ensure that formal arrangements are set up for the regular supervision, appraisal and personal development of their Chief Operating Officer.

The Board should periodically carry out strategic reviews of all aspects of the organisation's work, and use the results to inform positive change and innovation.

The Board should set out the functions of sub-committees, officers, the Chief Operating Officer, employees and contractors in clear delegated authorities, and should monitor their performance.

The Board should ensure that staff, volunteers and agents have sufficient delegated authority to discharge their duties. All delegated authorities must have clear limits relating to budgetary and other matters. All delegated authorities must be subject to regular monitoring by the Board.

The Board, individual Board members and officers should act according to high ethical standards, and ensure that conflicts of interest are properly dealt with.

Board members and officers must not benefit from their position beyond what is allowed by the law and is in the interests of the organisation. Board members and officers must be scrupulous to avoid gaining any private benefit from their position, whether financial or other, except:

The organisation should have procedures for Board members and officers to claim legitimate travel and other expenses incurred while carrying out the organisation's business; Board members and officers should not be out of pocket for the work they carry out for the organisation.

Board members and officers should identify and promptly declare any actual or potential conflicts of interest affecting them.

There should be clear guidelines for receipt of gifts or hospitality by Board members and officers. Board members and officers should declare all personal gifts received and hospitality accepted while on the organisation's business, or from people or organisations connected with the organisation; such declarations should be recorded in Board minutes.

Board members and officers should not accept gifts with a significant monetary value or lavish hospitality

Board members and officers should under no circumstances accept gifts or hospitality where this could be seen as being likely to influence the decisions of the Board.

2. Openness and Transparency

The Board should be open, responsive and accountable to EDRIC's members, partners and others with an interest in its work.

Communication and Consultation: EDRIC should identify those with a legitimate interest in its work (stakeholders), and ensure that there is a strategy for regular and effective communication with them about the organisation's achievements and work.

Openness and accountability: the Board should be open and accountable to stakeholders about its own work, and the governance of the organisation.

Stakeholder involvement: the Board should encourage and enable the engagement of key stakeholders in the organisation's planning and decision-making.

EDRIC and its member organisations should only accept funds for activities that are consistent with its mission and objectives. Member organisations that receive funding from any source, including industry or governmental bodies, should at all times remain open, honest and transparent concerning the amounts and sources of such funding. Public documents of EDRIC and its member organisations, e.g. annual reports and websites, should clearly illustrate such information and be fully accessible. For the sake of transparency, funders should also receive public acknowledgement for their support. Acknowledgement should be attributed to the funding person or organisation itself, but not to a specific product or project.

3.Social Media

EDRIC engages directly with members of the dysmelia community using its own DysNet website together with a plethora of social media channels: Facebook, Twitter, LinkedIn, YouTube, Google+, Pinterest, Flickr and its multi-lingual online forum, RareConnect, which is hosted by EURORDIS and NORD, the rare disease umbrella bodies for Europe and North America respectively.

There are two types of social media activity that are covered by this policy:

1. Communication for or on behalf of EDRIC or its members that is designed to propagate key messages or engage with campaigns supported by the Board, and
2. Personal social media activity, done for friends and contacts, but not under or in the name of DysNet, EDRIC or its members.

1.Communication on behalf of EDRIC/EDRIC members:

- a. EDRIC/DysNet has a number of social media accounts in its own name. These must only be used to promote policies, messages and campaigns that are consistent with EDRIC's aims and/or authorised by the Board.
- b. Everything else done by individuals who work for EDRIC is done in their own name - it is not owned by the EDRIC, may not normally be linked to or trailed by EDRIC as official communication, and should not purport to come from the EDRIC.

2. Personal social media activity, done for friends and contacts, but not under or in the name of EDRIC:

- a. Individuals are not discouraged from doing any of this, but since they are connected with EDRIC, there are particular considerations to bear in mind. They can all be summarised as: 'Don't do anything stupid'.

- b. Even though individuals are acting in their own personal capacity, they are on show to their friends and anyone else who sees what they write, as a representative of EDRIC.
- c. Individuals are allowed to say that they carry out work for EDRIC, and they can discuss EDRIC and their work publicly. However, their name/title should not contain EDRIC or DysNet in any form. And it should be made clear that the views expressed are personal, and not those of EDRIC.
- d. Care should be taken not to express or sympathise with extreme or offensive views. Individuals should be wary of being seduced by the informality of social media into bringing EDRIC into disrepute.

Remember that you are “speaking” for EDRIC/DysNet when you are working in your official capacity. Do not say anything online that you would not say in a speech in your official capacity. Do not divulge confidential information.