EURORDIS
RARE DISEASES EUROPE

Creating a European rare disease federation

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1. Building a federation

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Action plans

Actions plans are the specific means by which objectives are accomplished. They incorporate five factors.

Action plans identify the resource requirements necessary to accomplish an objective. When all action plans are viewed together, management can determine how many objectives they can actually accomplish over a given period of time. If sufficient resources are not available, more must be found and allocated, and/or the objectives must be changed/limited/edited, which may be facilitated by an objective prioritization process. **It is far better to modify an objective to a point that it can be accomplished than to leave unrealistic expectations in the plan.**

You and your group need to revisit the Action Plan often. If it is a two-year, three-year, five-year Action Plan, one does not wait until the end of the term to see 'if things got accomplished', but one must review at least quarterly the strengths and weaknesses and buttress up, if necessary, any areas that need extra support.

1. The specific step or activity/action.
2. The person who will be held responsible for seeing that each step or action is completed. (Quite often this point is left out, at least officially, and any problems that happen over time with this step or action can be left unresolved due to no-one 'owning' the issue. Appoint a leader or volunteer!)
3. When these steps or actions are to be carried out – timelines.
4. The resources that need to be allocated in order to carry out each step or action.
5. The feedback mechanisms needed to be able to track the progress of a step or action (performance indicator) and to know when it has been completed.

Creating the structure

Where to register a pan-European organisation

It would be lovely to have an EU-recognised system that gives non-profit status Europe-wide to associations. Right now, that is not the case* So is there a "best" country to set up the Pan-European organisation?

Our advice is to locate in a country **where there is a strong local group** that can do the majority of work that needs to be done by the European group (registration, opening a bank account).

Some organisations prefer to have their headquarters in Brussels, for the address, for the easier connection to EU organisms, and for central location. But all this is non-technical, i.e. the EU does not recognise any group better because they are in Brussels, and as long as they can somehow show that they have members in half + 1 of member countries and can be considered "representative" of some certain population.

Here the countries where the majority of EURORDIS member federations are registered

Belgium	18
Netherlands	7
Germany	7
France	6
UK	4

***A statute for European cross-border associations**

Commissioned by the European Parliament's Policy Department for Citizens' Rights and Constitutional Affairs at the request of the JURI Committee, this study provides a comparative analysis of the main laws on non-profit organizations in force in some selected European countries, before going on to discuss a potential legislative initiative of the European Union on the subject. The study sets out the different options available and concludes that the European Union should introduce a European.

Look for other national groups

The decision to try to organize a European federation for a rare disease normally begins from one of the National Groups, looking for a bigger visibility at the European level.

In most of the cases, this group has relations with other similar groups in Europe, but, in some cases, there is only a small number of groups.
If your disease is a very rare one, it is possible that there are no national associations in most of the European countries.

The first task is to search for other groups in Europe willing to participate in the Federation.

Ways to find other groups:

1) The Orphanet database www.orpha.net allows to search for patient organisations across Europe by disease (nearly 6000 diseases are referenced on this database)

2) The EURORDIS list of National Rare Disease Alliances. You can write to all these Alliances asking them for national groups related to your disease.

3) Internet search. You can search online, trying to find other groups related to your disease, and contact them directly. The main problem in this case will be the language, because the same Rare Disease can have different names in each country. As an example, the HSP (Hereditary Spastic Paraplegia) is called PEF (Paraparesia Espastica Familiar) in Spain, Strümpell-Lorrain disease in France. You can find the translation of most rare disease's names on orpha.net.

Membership

European (or International) federations are **organisations that federate national patient organisations**, across Europe and sometimes across the world.

Membership is organisational and delegates for meetings or candidates for election to Board of Directors or Executive Committee are nominated by their group individuals (patients, families…). They should be members of the national associations and these national groups should represent their members in the European association. It may be different for very rare diseases, where the number of patients in a country may be very limited. For these isolated people it may be necessary to be a member of a European association because a national group may not have enough members to function and or achieve a lot

Some federations choose to accept individual members. Of course, voting rights cannot be the same for a patient organisation, representing a number of patients in their country/region, and individuals.

The EU would be more sympathetic to a European group that has a large membership base, made of local and national groups that in terms of numbers can be seen as 'meaningfully representative'.

Can there be multiple members from any one country?

Generally, one country/ national organisation/ vote seems the most desired goal. However, what if there are two or three local groups for the same disease who compete (and maybe do not agree with each other)?

We encourage a policy of one group per country. However, in special circumstances where this has not been possible, we have to recognise the reality of life on the ground but would advise that each country still only has one vote so the groups have to decide on a common response or not vote at all.

Pro & cons of setting up a European federation

Over the years an increasing number of European umbrella organizations for specific rare diseases have appeared. The history of these federations seems to be quite different, depending on the size of the group, the economic possibilities, the objectives of the creation and other contributing factors. Due to modern communication tools and technologies, people and patient groups can more easily contact each other, and cooperation has become easier, less time consuming and cheaper.

If a small group of national rare disease organisations is considering the creation of a federation or a national organisation, it is strongly recommended to discuss and agree the main intentions. The question of creating or joining such a Federation depends very much on the desired goals of this step forward.

Objectives or possible advantages of a European federation

± Contact between people from different countries sharing the same disease

± learning from each other – for daily living and other issues

± giving advice and support

± Collection and publication of information about the disease on an international level

± Collection of data

± Common website + networking – "together we are strong!"

± Cooperation with, networking for, and training of medical professionals

± Setup of common projects

± Creation of common standards of care, rehabilitation and treatment

± Collaboration with European Reference Networks and ePAGs

± Political representation of common interests on European or international level

± Promotion of research on all aspects of the disease

± Transfer of knowledge and equipment, access to treatment and support for people in poorly developed countries

± Support for small national groups

± Exchange of "best practise examples" and guidelines for certain procedures

± Collaboration with the European Medicines Agency

± Possible financial support from the European Commission, only granted to European umbrella organisations

Possible disadvantages, problems with or reasons against a federation:

— If the main reason for the creation of a Federation is the contact between individuals, it might be easier and advisable to join and use other existing networks like Rare Connect or Facebook groups.

— Funding – a European Federation will need financial resources, the access to external subsidies will most probably be difficult, especially during the starting period. This will result in the need to ask the national members for economic support of the Federation's operational costs, e.g. an annual membership fee that could be a burden for small national organizations. Costs to attend annual meetings, workshops or European conferences are high and could be too high for certain groups

— Language barriers: problems to use a common language and to find national representatives with the according language skills

— Lack of human resources: as in general, volunteers are rare, the creation of a European umbrella might be difficult due to the lack of a competent and capable representatives

2 How to fund a European federation

Code of good practice

The valuable and serious work of patient groups and the service they provide needs to be recognised, valued and supported. However, most groups are struggling to find sufficient, diversified resources to fulfil their mission and objectives and remain independent, whether funding comes from corporate or public sources. Patients' organisations are keen to work in a constructive manner together with all stakeholders to ensure that the credibility of patients' groups is safeguarded.

For this reason, patient organisations have developed the following transparent and robust **Code of Good Practice to guide the relations between patient organisations and the industry.**
We encourage all patient organisations to adopt this Code when engaging in a dialogue, working partnership, joint initiative, and/or when accepting support from any funding source.

Read the full paper here

Cross border tax relief

In a landmark decision, the European Court of Justice ruled on 27 January 2009 that **national restrictions on tax relief** for cross border donations to charities in other European Union Member States **are unlawful**. This decision has significant implications for all charities throughout the EU.
The case was brought by a German resident who donated items to a Portuguese charity. The German tax authorities rejected his claim for a tax deduction when considering the donation on the basis that the beneficiary of the gift was not a charitable body established in Germany. German law allows a deduction for tax purposes in respect of donations to charitable bodies established in Germany but excludes this relief in respect of donations to charitable bodies in other Member States.

The European court of Justice ruled that the restriction imposed by the German authorities constituted a restriction of the free movement of capital, which is prohibited by EU law.

This ruling should result in a change of law in EU countries that impose similar restrictions.

Read more about Transnational Giving

European Commission

DG Health - EU4Health programme 2021-2027

The EU4Health programme was adopted as a response to the COVID-19 pandemic and to reinforce crisis preparedness in the EU. The pandemic highlighted the fragility of national health systems. The EU4Health programme will bring a contribution to the long-term health challenges by building stronger, more resilient and more accessible health systems. Health is an investment and, with a €5.3 billion budget during the 2021-27 period, the **EU4Health programme is an unparalleled EU financial support in the health area**. EU4Health is a clear message that public health is a priority for the EU and it is **one of the main instruments to pave the way to a European Health Union.**

DG Research - Horizon Europe

Horizon Europe is the EU's key funding programme for research and innovation with a budget of €95.5 billion. It tackles climate change, helps to achieve the UN's Sustainable Development Goals and boosts the EU's competitiveness and growth. The programme facilitates collaboration and strengthens the impact of research and innovation in developing, supporting and implementing EU policies while tackling global **challenges. It supports creating and better dispersing of excellent knowledge and technologies.**

Financial Management

All organisations need money. Alongside staff, money is the one thing that takes up most management
Good financial management involves the following four building blocks:

Keeping Records

Firstly, the foundation of all accounting is basic records that describe your earnings and spending. This means the contracts, letters for money you receive and the receipts, and the invoices for things that you buy.

These basic records prove that every transaction has taken place. They are the cornerstones of being accountable. You must make sure that all these records are carefully filed and kept safe.

You must also make sure that you write down the details of each transaction. Write them down in a 'cashbook' – which is a list of how much you spent, on what and when.

If you are keeping your basic records in good order and writing down the details of each transaction in a cashbook then you cannot go far wrong.

Internal Control

Make sure that your organisation has proper controls in place so that money cannot be misused. Controls always have to be adapted to different organisations.

Some controls that are often used include:

- Keeping cash in a safe place (ideally in a bank account).
- Making sure that all expenditure is properly authorised.
- Following the budget.
- Monitoring how much money has been spent on what every month.
- Employing qualified finance staff.
- Having an audit every year.
- Lastly, carrying out a 'bank reconciliation' every month – which means checking that the amount of cash you have in the bank is the same as the amount that your cashbook tells you that you ought to have.

This last control is particularly important. It proves that the amounts recorded in the cashbook and the reports based on it are accurate.

Budgeting

For good financial management, you need to prepare accurate budgets, in order to know how much money you will need to carry out your work. A budget is only useful if it is worked out by carefully forecasting how much you expect to spend on your activities.

The first step in preparing a good budget is to identify exactly what you hope to do and how you will do it. List your activities, then plan how much they will cost and how much income they will generate.

Financial Reporting

The fourth building block is writing and reviewing financial reports. A financial report summarises your income and expenditure over a certain period.

Financial reports are created by adding together similar transactions. For instance, this might mean adding together all the money you spent on fuel, new tyres and vehicle insurance and calling them "Transport Costs".

Financial reports summarise the information held in the cashbook. This is normally done using a system of codes, to allocate transactions to different categories. Donors might often define these categories.

Financial support by commercial companies

The EURORDIS Policy on financial support by Commercial Companies" define a set of principles, which can help other patient organisations to define their own rules and principles.

Download here: Policy On Financial support by Commercial Companies

Fundraising

A ***donation*** is made to an organization (or a specific activity such as a conference) with an **objective** in mind, sometimes simply to get a good image. This is critical to understand when we approach a potential sponsor – why are they donating? What advantages can they obtain? It is equally important to maintain professionalism within the Patient organisation, to build adequate trust with the potential donor. Transparency and accountability should be an integral part your association.

1 First steps

Make sure to write a proposal that is within the limits of the organization's capacities and competencies and within the limits of the budget requested.

Most funding organization have clear guidelines, instructions and guides on their funding procedure; check their website for that information

2 Finding sponsors

Carefully look at who you're approaching, research your target to find the right fit

Look at the sponsor's previous philanthropic activities and its programmes/projects, and align your request around them

Remember that it is easier to get money for one event, rather than a long-term project.

3 Network

Spread the word – let people know about your organisation and your goals.
Talk to your elected officials. Write letters to explain your group and invite them to come see the area with which you are concerned.
Release press statements, or even better, patient testimonies, to the local newspaper.
Find other ways to get your information disseminated. Most local radio, TV or cable stations have time slots set aside for community events, and are looking for ways to fill them

Create a binder with press clippings and a video with interviews that will make you look active and credible

4 Write the proposal

Make sure to write a proposal that is within the limits of the organization's capacities and competencies. In addition, within the limits of the budget requested.

Most funding organization have clear guidelines, instructions and guides on their funding procedure; check their website for that information

When dealing with the pharmaceutical industry or other corporate donors, make sure to stipulate in your letter exactly what the sponsors gets in return for his donation (e.g.: logo on a programme)

Have a look at the EURORDIS Policy on Financial Support by Commercial Companies

Make sure you have fully studied and understood the priorities of the funding organization, and the reasons they are providing funds.

In-kind contributions

EURORDIS has developed a set of principles / recommendations on how to include volunteer activity in financial reporting

Please also read the Q&A sheet for more information

Transparency

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

Read the EURORDIS position paper on Transparency

3 Governance

Board of directors

The role of the Board of Directors is to provide **leadership** and **oversight** of the activities of the association. In both areas, it will strive to represent the interests of members and the broader community.

No action or directive of an individual board member can have any force or effect unless it is approved by the full board.

Board Members are Volunteers and do not receive financial compensation.

Key duties of the Board

- Determine mission and purpose
- Select the executive staff through an appropriate process
- Ensure adequate resources and manage them
- Determine and monitor programs and services
- Enhance public image
- Provide ongoing support and guidance for the Chief Executive Officer

Board Members play a crucial role in non-for-profit organisations. They are the trustees who hold the organization in trust. The ultimate accountability of the organization rests with them. As a part of good governance practice, the Board has to be independent of the Management and should not take up executive role. The CEO and the Management are responsible for execution of the decisions made by the Board. At the same time, the Board has to retain an oversight on the Management so that things are in the right direction.

Even though in some countries it might be legal to pay Board members, this is not considered good practice because board compensation can call into question a non-profit's financial integrity.

It is important to remember that the board of directors holds both the authority and the responsibility for every action the organisation takes. The board can delegate its authority, under certain circumstances.

Checklist for a board information system

Every board must decide for itself exactly what information it needs. For most groups, however, the following checklist is a starting point:

At least two weeks before each board meeting:	**At least two weeks before the board meeting at which it is discussed:**	**After each board meeting:**
○ Agenda ○ Information about issues for discussion ○ Financial information ○ Committee reports	○ Annual budget ○ Audit report ○ Strategic plan	○ Minutes ○ Notice of next meeting ○ **Monthly/Quarterly:** Financial report

Glossary:

Board of Directors:

A group of people chosen to govern the affairs of an organization or institution.

Board of Officers:

At a minimum, three positions are often legally required within a board: president (or chairperson), treasurer and general secretary. These positions can be elected among board members by board members following their election, or by members of the organization at the General Assembly.

Trustee:

a member of a governing board elected or appointed to direct the policies of an institution

Executive Committee:

When a board of directors is large, meets infrequently, or is widely scattered geographically, it may decide to create a smaller group, often called the "**Executive Committee**" that can act for the board as a whole before meetings.

The membership, powers and reporting responsibilities of the Executive Committee need to be carefully laid out in the board's rules (often called the by-Laws). Boards may also hand over specific problems or questions to such a committee for research, decision or action. Doing so must be permitted by the by-Laws. However, the by-laws may set limits on what can be delegated in this way.

By-laws

By-laws are the set of rules under which the organisation will operate.
They typically include such items as:

Number of members, term length, nomination process, committees, and meetings

Fiscal year/accounting cycles, committees, and officers' responsibilities

Methodologies, tools, and strategies, monitoring and evaluation etc.

How to amend the by-laws themselves

For Info:

By-laws are not public documents but making them readily available increases your accountability and transparency and encourages your board to pay closer attention to them. Your board should review them regularly and amend them as your organization evolves.

Typical by-laws of a non-profit organisation will contain the following information:

Resources

Examples of governance documents:

See EURORDIS by-Laws here

- Preamble
- Organisation name and acronym
- Organisational logo
- Basic aim and purpose of organization
- Mission statement
- Functions
- Membership (types, conditions/qualifications of members, status, procedure to become members, rights and obligations, termination)
- Advisory board (role and functions, qualifications of board members, authority, elections, members)
- Organisational structure
- Asset management (Finance and property, membership fees)
- Legal status
- Contact address
- Dissolution of the organisation
- Amendments, modifications, revisions of by-laws

Employees & Volunteers

Volunteers are unique to non-profit organizations and are a vital resource in governance, administrative and service capacities. Non-profit organisation's human resource policies must be fair, establish clear expectations and provide for meaningful and effective performance evaluation for both paid employees and volunteers.

- Employees and volunteers should be committed to the mission of the organisation and competently perform the duties they agreed to assume
- The organisation should invest in training to ensure quality management and service
- The employees and volunteers of the organisations should broadly reflect the diversity of their organisation's constituencies.
- The organisation should have a system in place for written evaluation of employees and volunteers by their respective supervisors at least annually
- The organisation should have a system in place for the succession of employees, most notably the executive director.
- New employees and volunteers of the organisation should receive clear orientation to the mission of the group and its policies and procedures, job definitions and expectations and a defined workspace.

Read EURORDIS volunteer charter

General Assembly

The statutes or by-laws of each organization must define the General Assembly and more specifically:

- Duties and responsibilities of the General Assembly
- Who can participate in the general assembly? (in general, the full members of the organization)
- Proxy policy
- Where the General Assembly takes place
- When the General Assembly takes place, and how often
- How the proceedings will be reported
- How the General Assembly decisions will be made
- How and who can present proposals for decision-making, and the procedure for making decisions
- The minimum quorum needed to call for a General Assembly, for the proceedings to take place, and for decisions to be made

See EURORDIUS By-Laws here

Good international practices

EUROPEAN MEDICINES AGENCY
SCIENCE MEDICINES HEALTH

One of the best examples of good international practices certainly are the European Medicines Agency's criteria to be fulfilled by patient and consumer organisations involved in EMA Activities. The organisations should be established at European Union (EU) level, and should fulfil the following criteria:

• Legitimacy:

The organisation should have statutes registered in one of the Member States of the EU. If it is an international organisation not registered in an EU Member State, additional information needs to be provided demonstrating EU focus and activities.

• Structure:

The organisation should have governing bodies that are elected by their members, who shall be patients, their carers, or their elected representatives.

•Accountability and Consultation Modalities:

Statements and opinions of the organisation should reflect the views and opinions of its members and adequate consultation procedures with those members should be in place. In particular, the organisation should ensure that the appropriate flow of information is in place to allow dialogue both ways: from and towards its members.

Additional Information needed for non-EU Member state organisations:

Mission/Objectives: the organisation should have its mission/objectives clearly defined and should agree to have it/them published on the EMEA website

Activities: the organisation should have, as part of its activities, a specific interest in medicinal products which should be documented (e.g. through a report published on the organisation website).

Representability: the organisation should be representative of patients or consumers throughout the EU. Organisations already registered at Community level, e.g. in the EU Health Forum, the Council of Europe, are considered to adequately represent patients or consumers for involvement in EMA activities.

• Transparency:

As a rule, the organisation should be as transparent as possible, e.g. by regularly publishing, on its website, a report on the activities undertaken.

The organisation should also disclose its sources of funding both public and private by providing the name of the public and/or private bodies and their individual financial contribution in terms of percentage of the organisation budget. Any relationship with corporate sponsorship should be clear and transparent. Any conflict of interest should be disclosed to the EMEA. In the case of umbrella organisations, the list of member associations should be publicly available.

Please click here to read the full information and download the application form.

Statutes

The **statutes** (or articles of incorporation, charters, constitutions, articles of association, etc.) are established when the organization files for **incorporation** with the appropriate state agency. A Board of Directors gets its authority from the articles. This governing document specifies, for example, its name, the purpose or mission of the organization, place of business, primary officers, etc.

See EURORDIS statutes here

Study: A statute for European cross-border associations

Commissioned by the European Parliament's Policy Department for Citizens' Rights and Constitutional Affairs at the request of the JURI Committee, this study provides a comparative analysis of the main laws on non-profit organizations in force in some selected European countries, before going on to discuss a potential legislative initiative of the European Union on the subject. The study sets out the different options available and concludes that the European Union should introduce a European

4 Advocacy & Communication

Advocacy at a European level

A successful lobbying campaign is multi-layered. However, there are specific elements that will increase the chances of success: Making contacts

Establishing and maintaining contacts with MEPs, Commission officials and national permanent representations of the Member States is of primary importance in any advocacy activity in Brussels. Outlining the benefits of a case to each contact will help gain their support. Allies are easier to find when they have a clear idea of the advantage to them of championing our interests.

The time factor

It is clear from the information above that any lobbying activity has a decreasing chance of success as the decision-making process advances. The sooner you start lobbying, the better.

Persuading an MEP to put forward an amendment to a Commission proposal in first reading can be complicated, but it is feasible and commonly done. On the other hand, it is far more difficult to have a Common Position amended by the Parliament in the second reading.

Media relations

Brussels hosts the world's largest international press corps. The role of the media is crucial in inter-institutional relations in Brussels and in the relations between lobbying groups and decision-makers. Many interest groups have learned to use the press skilfully and have been able to influence the outcome of lobbying campaigns thanks to media support. NGOs, such as Oxfam, Save the Children and Greenpeace, have gained influence and been supported by media campaigns.

Communication & Advocacy tools

Rare Barometer	Rare Barometer Voices is a EURORDIS initiative that aims to make the **voice** of **rare** disease patients stronger. The objective is to transform your opinions and experiences about topics that directly affect you into figures and facts that can be shared with a wider public Rare Barometer has been created to make the rare disease patient voice stronger by ensuring that the patient perspective is entrenched in the advocacy work of EURORDIS and its members. Evidence-based policy equals more effective policy. EURORDIS' strategic positioning at the heart of the policy and regulatory framework in Europe allows us to directly transform patient perspectives into policy and action. The patient input collected through Rare Barometer will help rare disease patients to influence healthcare policies that affect them. It will allow policy and decision makers to be better informed with knowledge only patients and their advocates can bring to the discussion. **Here the results of past surveys that you can use for your advocacy**: https://www.eurordis.org/rare-barometer/english/#surveyResults
Rare Disease Day	Rare Disease Day is the globally coordinated movement on rare diseases, working towards equity in social opportunity, healthcare, and access to diagnosis and therapies for people living with a rare disease. Since its creation in 2008, Rare Disease Day has played a critical part in building an international rare disease community that is multi-disease, global, and diverse– but united in purpose. Rare Disease Day is observed every year on 28 February (or 29 in leap years)—the rarest day of the year. European Federations (EF) are strongly encouraged to participate in the annual Rare Disease Day www.rarediseaseday.org

5 Resources

Advocacy resources:

- Have a look at EURORDIS advocacy work
- Have a look at EURORDIS advocacy resources

Rare Disease Week

Brussel’s Rare Disease Week is a week-long series of events organised by EURORDIS in the lead-up to Rare Disease Day in Brussels, including a series of preparatory webinars. It targets rare disease patient advocates in a view to empower them with knowledge and skills to effectively participate in advocacy activities at the European level and influence the EU decisions that have a direct impact on the lives of people living with a rare disease.

Open Academy online courses :

The EURORDIS Open Academy empowers patient advocates with knowledge and skills to take part in patient engagement roles side-by-side with all stakeholders and to advocate for rare diseases on a European and national level

- Ordinary Legislative Procedure – How are decisions taken by the EU?
- Introduction to the European Union Institutions
- International Advocacy for rare Diseases
- Establishing an international cooperation

CEF (Council of European Federations) Resources

On this page you’ll find a collection of presentations, documents and online trainings that might help you setting up and managing your European federation.

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