



EURORDIS

Board of Directors Election

Call for candidates

Annual General Assembly

15 May 2025

1. EURORDIS Board of Directors – Extract of the EURORDIS By-Laws

According to EURORDIS by-laws:

“The number of directors is at least 6 and not more than 18.

The established practice at EURORDIS is between **12 to 15 directors**.

The number of directors is decided for the coming year by the Board of Directors; members are informed through the call for candidates to the Board; report is made to the Annual General Assembly when announcing the results of elections to the Board.

A third of the Board of Directors is to be renewed by election every year.

EURORDIS Board of Directors – May 2024 -May 2025

This is the list of the Board members since the last elections held at the Annual General Assembly on May 22nd, 2024.

The Board of Directors currently consists of 15 Directors.

PRESIDENT

Ms Avril Daly	Retina International	Ireland
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DIRECTORS

Ms Anna Arellanesova	Rare Diseases Czech Republic	Czechia
Ms Simona Bellagambi	UNIAMO – Rare Diseases Italy	Italy
Mr Alain Cornet	Lupus Belgium	Belgium
Ms Dorica Dan	Romanian Prader Willi Association	Romania

Mr Daniel de Vicente	FEDER	Spain
Mr Johan de Graaf	Dutch Pituitary Foundation	Netherlands
Mr Tomasz Grybek	Foundation of Borys the Hero	Poland
Ms Kirsten Johnson	The Fragile X Society	UK
Ms Tetiana Kulesha	Rare Diseases Ukraine	Ukraine
Mr Alexandre Mejat	AFM - Téléthon	France
Mr Graham Slater	EAT - Esophageal Atresia Global support groups	UK
Ms Anna Spinou	Hellenic Cystic Fibrosis Association	Greece
Ms Rebecca Tvedt Skarberg	OIFE	Norway
Ms Geske Wehr	European Network for Ichthyosis e.V	Germany

2. Board of Directors elections in May 2025

At the **online General Assembly on 15 May 2025**, we will proceed to the election of 3 Board members. The Board of Directors will consist of 13 directors after the elections. The seats of the outgoing Board members are available for a mandate of 3 years. The 5 outgoing Board members are:

Representative	Organisation	Country
Kirsten Johnson	Fragile X Society	UK
Tetiana Kulesha	Rare Diseases Ukraine	Ukraine
Graham Slater	EAT – Esophageal Atresia Global	UK
Rebecca Tvedt Skarberg	OIFE	Norway
Geske Wehr	European Network for Ichthyosis e.V.	Germany

The process to nominate candidates for election to the Board of Directors is explained in Appendix 1. The main criteria to be eligible to be a director are described in Appendix 2.

Each Board member represents the interest of rare disease patients from all European countries; they do not represent the interest of their own country, disease, or association. It is the individual representative, who is elected on the Board of EURORDIS, not the member organisation.

Please complete the candidate nomination form (Form A) and return it to EURORDIS.

Please note that all candidate nominations for the position of member of the Board of Directors must be received before 30 April 2025.

Each organisation that is a full member of EURORDIS and has paid the membership fee for 2025 represents one vote. The voting will be done online through a dedicated platform managed by Alphavote.

If you require further information, please contact anja.helm@eurordis.org

EURORDIS Directors

How to nominate a candidate for the elections

To nominate candidates for election to the Board of Directors, or to vote in the election, your organisation must be a full member of EURORDIS and be up to date with membership fees. If you are unsure of your organisation's current membership status, contact Anja Helm (anja.helm@eurordis.org) for clarification.

The legal representative of your organisation must complete and sign the "Nomination of a candidate for the Board of Directors' election" form (Form A) and return it to EURORDIS before 30 April 2025.

Each candidate must email to EURORDIS (anja.helm@eurordis.org) a brief description of themselves in English, their involvement with rare diseases and what they can bring to EURORDIS' Board; this will be distributed with the list of candidates. Candidates should make a 3-minute presentation at the online General Assembly, in English, in support of their candidacy; in case of unavoidable absence a video recording will be shown.

Directors and Officers

Full members of EURORDIS vote for the Directors who make up the Board. The Directors then vote for the Officers – President, Vice Presidents, Treasurer, General Secretary and Deputy General Secretary. In Appendix 2 you will find a full description of what being a director entails.

Reimbursements

It is illegal for Directors to receive payment for their duties. Only reimbursement of expenses incurred for EURORDIS will be reimbursed. Directors make their own economy fare travel arrangements which are reimbursed on production of appropriate receipts. Official forms are available for claiming such expenses, which are reimbursed as swiftly as possible to avoid hardship and inconvenience. In general, hotel bookings are made directly by EURORDIS.

Induction

It is intended that all newly elected Directors receive an appropriate period and level of induction. This induction will be in the form of:

- Description of functions of Directors, President, Vice-Presidents, Treasurer and General Secretary.
- Job Description of the Chief Executive Officer.
- Briefing package with relevant documents.
- Meeting with the CEO, COO, staff, or President, as relevant.



EURORDIS Board of Directors Members Role and Responsibilities

The Terms of Reference of the Board of Directors are providing the roles and responsibilities of the Board of Directors.

Rules & Commitment

- Directors act in the scope of and in accordance with EURORDIS' Statutes and By-Laws and report to the General Assembly.
- The Directors are elected by the Annual General Assembly among individuals nominated by the full members of the Association, for a period of three years. The Board is renewed annually by election of the Directors to fill the seats falling vacant, outgoing Directors are eligible for re-election.
- Each Board member represents the interest of rare disease patients from all European countries; they do not represent the interest of their own country or disease.
- Each full member of EURORDIS can nominate a candidate to serve on the Board, this nomination must be made by the legal representative of the candidate organisation, and the organisation must be up-to-date with their membership fees.
- It is the individual representative, who is elected on the Board of EURORDIS, not the member organisation.
- Directors do not have an alternate and should accept that unjustified absence from two consecutive Board of Directors meetings could result in dismissal.
- Directors should accept that membership of the Board is of an enduring nature and that a minimum of three months' notice of resignation is required.

Role & Responsibilities

Strategic Planning

- Participate in creating and reviewing strategic orientations.
- Review and approve, on an annual basis, the annual work plan (action plan, budget, team chart, governance chart), review annual activity and financial reports.
- Act as a collegiate body with collective responsibility.

Operations

- Attend Board meetings, having read e-mails and papers in advance of meetings.
- Participate in and support appropriate committees within the Board or externally to represent the policies and concerns of EURORDIS.
- To write a short report of all meetings, conferences etc. attended on behalf of EURORDIS, and forward to EURORDIS all presentations made at these events
- To contribute specific skills, interests and contacts to the development of EURORDIS and its aims.

Membership

- To strengthen the membership base in your country, by encouraging membership applications.

- To examine membership applications from candidates from your country or your disease.
- To ensure that the member organisations from your country pay their fees.
- To be responsible of overseeing the admission or the expulsion of members (approved by the BoO) according to EURORDIS statutes

Person Specification (for both BoD and BoO Members)

Essential

- Living with or having personal knowledge of rare disease.
- Fluent English, both spoken and written.
- Ability to commit time to meetings and preparation of meetings (at least twelve whole days equivalent per year).
- Ability to act as EURORDIS representative, to inform of its activities and encourage new membership.
- Ability to work as part of a multi-cultural team.

Desirable (any of the skills below are valuable)

- Knowledge of medical, social or regulatory issues around chronic illness, disability or rare disease.
- Experience of working as a patient advocate and/or within multi-stakeholder committees. Ability/confidence to work effectively at conferences and workshops as speaker or participant.
- Experience of working with the European Commission.
- Experience of project work.
- Ability to participate effectively in teleconferences or similar when face-to-face meetings cannot be scheduled.