

# BECOME A MEMBER



## INFORMATION ON YOUR ORGANISATION

Name of association  
Full postal address including country

Telephone number  
General email address of your organisation  
Website

### CONTACT AT YOUR ORGANISATION

*All information from EURORDIS will be sent to this contact*

Name  
Telephone number  
Email

### MEMBERS AND BUDGET

Number of members in your association  
Disease(s) represented  
Date association was established  
Legal status  
Annual budget (in €)

### BOARD OF DIRECTORS

Number of Board Members  
Number of Board Members who are patients or family of a patient

### MAIN ACTIVITIES AND GOALS OF YOUR ORGANISATION

#### FUNDRAISING

How do you raise money for your association?  
(i.e. membership fees, fundraising, sponsorships, etc.)

Is your association a member of a National Alliance for Rare Diseases and/or any international organisations? Yes No

**If yes, please provide details**

Do you receive financial support from pharmaceutical companies? Yes No  
% of this financial support of your revenue:  
Number of pharmaceutical/biotech companies funding your organisation:

**PRIVACY STATEMENT:** We store your personal details securely in the EURORDIS contact database. We will only use them to provide the service(s) that you have requested and communicate with you in the way(s) you have agreed to. We will not pass on your details to anyone else and we will only share them if required to do so by law.

## MEMBER NEWS:

Yes, I would like to subscribe to the free bi-monthly Member News

## ARE YOU APPLYING FOR:

Full membership or Associate membership

(See below for criteria of full and associate membership)

## FULL MEMBERSHIP

### PATIENT ORGANISATIONS\*:

- That are **rare disease** organisations according to EU prevalence criteria (5/10 000) as defined in the: EU Regulation on Orphan Medicinal Products (1999), Commission Communication on Rare Diseases (2008), Council Recommendation on an Action on Rare Diseases (2009)
  - From a **European country** (48 countries as defined by EURORDIS based on definitions by the EU, the Council of Europe and the WHO-Europe)
  - With **governing boards made up of a majority of rare disease patients** or of family members of patients
  - That are **financially independent**, particularly from the pharmaceutical industry (max. 50% of funding from several companies)
  - Holding **non-profit statuts**
  - With proven activities such as patient support and/or advocacy activities and/or research
- ✓ **Full members are entitled to vote at the General Assembly and to be candidates to the Board of Directors.**

### MEMBERSHIP FEES FULL MEMBERS:

Income €	Fee €	Income €	Fee €
< 5.000	25	750.000 - 999.999	1000
5.000 - 10.000	50	1.000.000 - 2.999.999	1250
10 000 -99 999	100	3.000.000 - 4.999.999	2000
100.000 - 249.999	200	5.000.000 - 19.999.999	5000
250.000 - 499.999	400	> 20.000.000	10.000
500.000 - 749.999	600		

### ANNUAL REVIEW PROCESS FOR REGULAR RE-ASSESSMENT OF FULL MEMBERS:

A self-reported update form and request for an annual report & composition of the Organisation's Board of Directors is sent to the following organisations every year:

- 1 Member organisations that present a candidate to the EURORDIS Board elections
- 2 National Alliances & European Federations
- 3 Full members that joined EURORDIS 10 years before the year of the last update

## ASSOCIATE MEMBERSHIP

### PATIENT ORGANISATIONS THAT DO NOT COMPLY WITH ALL THE CRITERIA FOR FULL MEMBERSHIP CAN BECOME ASSOCIATE MEMBERS'

Patient organisations that have been recently (less than 1 year) created are invited to apply for "full membership", but will qualify for a provisional status as "associate member".

**FEE FOR ASSOCIATE MEMBERS: 50 €** (independent of income)

## PLEASE SEND THE FOLLOWING DOCUMENTS WITH YOUR APPLICATION:



Statutes of association/constitution



List of your Board of Directors, indicating for each person if they are a patient or family member of a patient



Most recent Annual Report (including financial statement)



Please send your completed application form, together with the necessary supporting documents, to [anja.helm@eurordis.org](mailto:anja.helm@eurordis.org).  
More information on becoming a EURORDIS member: [www.eurordis.org/content/become-member](http://www.eurordis.org/content/become-member)

*Your application will be examined by our staff and submitted at the next Board of Directors or Board of Officers meeting.*

\* One, or all, of these criteria could be waived in exceptional cases, due to the particularity of patient-driven organisations and of rare diseases, as well as for historical or contextual reasons.