EURORDIS – RARE DISEASES EUROPE: A COMMUNITY OF PEOPLE LIVING WITH A RARE DISEASE

EURORDIS Membership Meeting 2021

Yann Le Cam
Chief Executive Officer

EURORDIS.ORG

Our purpose

OVER
6000
distinct rare diseases

Affects between
3.5% -
5.9%

of the population in the course of their lives

Each one affects fewer than
1 IN
2000
PEOPLE

NO
CURE
for the vast majority of diseases and few treatments available

All together, an estimated
30
MILLION PEOPLE
are living with a rare disease in Europe and
300
MILLION
worldwide

72%
of rare diseases are genetic

ONSET OF
70%
of rare diseases is in childhood

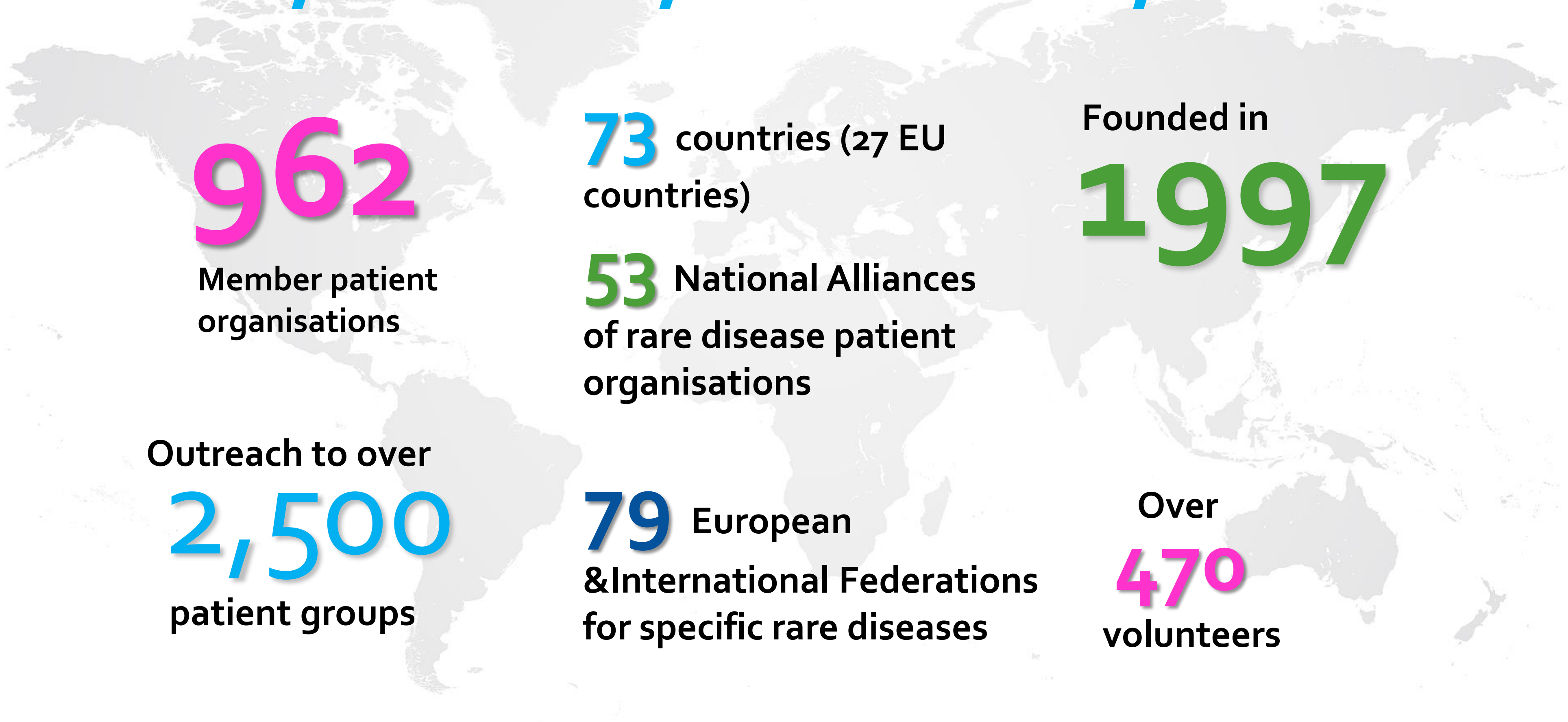
Our vision

To enable better lives and cures for people living with a rare disease

Our mission

To work across borders and diseases to improve the lives of people living with a rare disease

A diverse and wide movement, one voice: members, alliances, federations, advocates



962
Member patient organisations

73 countries (27 EU countries)

53 National Alliances of rare disease patient organisations

Founded in
1997

Outreach to over
2,500
patient groups

79 European &International Federations for specific rare diseases

Over
470
volunteers

Our values

Professional

Patients first

Innovative

Collaborative

Courageous

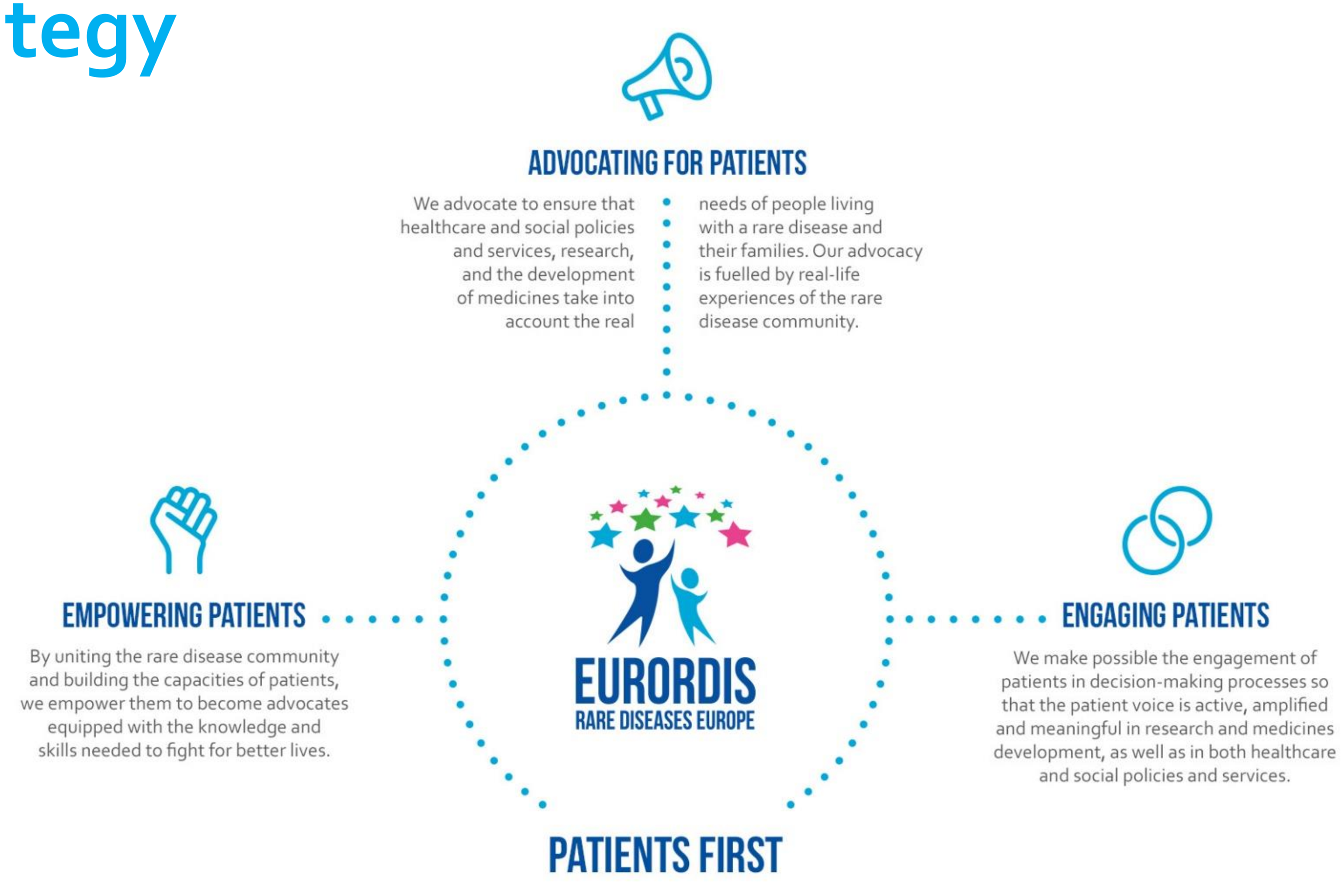
Authentic

Values that guide EURORDIS in all it does

As well as embracing the common European values of **democracy, mutual respect, solidarity, social justice** and **equality** EURORDIS is also guided by the following values:

- **Patients first** – EURORDIS puts patients first and endeavours to do what's right for patients and their families. In order to maintain its **legitimacy** in representing the needs, concerns and realities of its constituents EURORDIS stays independent from all other stakeholders with an interest in rare diseases.
- **Authentic** – EURORDIS is **credible** in representing the patient voice because its positions are based on contributions from its members and a wide range of PLWRD. EURORDIS' ensures that its volunteers are people who understand what it is to be affected by a rare disease.
- **Authoritative** – EURORDIS strives for excellence in all that it does and to represent the patient perspective with the **professionalism** it deserves. EURORDIS believes in building its positions on the basis of available evidence drawn both from the scientific literature and the experiences of PLWRD.
- **Courageous** – EURORDIS has a strong sense of integrity and is **straightforward** in representing the needs, concerns and desires of PLWRD.
- **Collaborative** – EURORDIS recognises that common problems are often solved more effectively by finding synergies and promoting collective action. EURORDIS is **respectful** of the fact that many stakeholders can help improve the lives of PLWRD and therefore is open to collaboration with like-minded organisations that share its vision and goals.
- **Innovative** – EURORDIS is a **visionary** organisation that is highly entrepreneurial in seeking out and implementing new ways to serve PLWRD.

Our Strategy



ADVOCATING FOR PATIENTS

We advocate to ensure that healthcare and social policies and services, research, and the development of medicines take into account the real needs of people living with a rare disease and their families. Our advocacy is fuelled by real-life experiences of the rare disease community.

EMPOWERING PATIENTS

By uniting the rare disease community and building the capacities of patients, we empower them to become advocates equipped with the knowledge and skills needed to fight for better lives.

ENGAGING PATIENTS

We make possible the engagement of patients in decision-making processes so that the patient voice is active, amplified and meaningful in research and medicines development, as well as in both healthcare and social policies and services.

PATIENTS FIRST

Research Policy & Activities

Development & Access to Therapies

Healthcare Policy & Services

Social Policy & Services

Our Strategic Objectives 2015-2020

1

EURORDIS in 2020 **has consolidated its position as the organisation of reference** for rare diseases both in EU and in Europe for its legitimate membership base and its credible European patient voice.

2

EURORDIS in 2020 is facilitating the effective **implementation of European legislations** (regulations such as those on orphan medicines, paediatric use of medicines, advanced therapies, transparency; directives such as Patient’s Right to Cross Border Health Care, Clinical Trials, Data Protection) **and policy strategies** (e.g. Commission Communication & Council Recommendation on Action in Rare Diseases**,** Commission Communication on Orphan Medicines, Communication on Cancer Control) at **European and national levels** (e.g. National Plans on Rare Diseases) in more **policy areas – research, public health, healthcare, social, digital, rights** - for the benefit of patients and families.

3

EURORDIS in 2020 is **empowering its member patient organisations and volunteers** through more and enriched information, education and capacity building, all working to reinforce their autonomy.

4

EURORDIS in 2020 is **more sustainable** in terms of **governance and of human, financial and organisational resources**; EURORDIS' resources have grown through a **diversification of public and private funding** (corporate, foundations, events, donors, fee-based services); EURORDIS has reinforced its **volunteer base** and **long-term leadership capacities;** EURORDIS has consolidated its **multi-cultural multi-skilled staff** and established a **human resource management**; EURORDIS is innovating advanced quality governance.

Board of Directors

- 12 members; expanding to 15; 14 today
- Presented by their PO member; elected as individuals, trustees of EURORDIS
- Diversity of countries and diseases
- Diversity of disease specific patient organisation, national alliances and European federations
- Mix of duration of tenure, for stability, shared vision and culture, renewal
- Long term leadership
- Direct contact: Who we Are?/Board/each profile

EURORDIS Board of Directors

Board of Officers

Terkel Andersen
President

Avril Daly
Vice-President

Geske Wehr
General Secretary

Alain Cornet
Treasurer

Dorica Dan
Officer

Directors

Maria Montefusco

Elizabeth Vroom

Jayne Spink

Alba Ancochea

Lieven Bauwens

Simona Bellagambi

Birthe Byskov Holm

Alexandre Mejat

Vlasta Zmazek

Staff

- **47 full time or part time + self employed and interns.**
- **Based across Europe**. Offices Paris, Brussels, Barcelona + working from home in Germany, Romania, Serbia, France and the UK.
- **Wide diversity** of nationality, languages, culture, age; High level educational background and experience, multi-lingual; Share common functions.
- **Direct contact:** Who we are? / Staff / email address under each profile which presents the background, function, priority areas of work

Staff Members


Ariane Weinman
Public Affairs Senior Manager


Erwan Berjonneau
Research Executive Rare Barometer

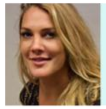

Matteo Scarabelli
Patient Engagement Manager - HTA


Marta Campabadal
Patient Engagement Manager


Yann Le Cam
Chief Executive Officer


Clara Hervás
Public Affairs Manager


Michael Wilbur
Chief Operating Officer


Lenja Wiehe
Patient Engagement Manager Healthcare


Sandra Pavlovic
RareConnect Outreach Manager


Stanislav Ostapenko
Communications Manager


Marie Meunier
Senior Executive Assistant to the CEO


Kostas Aligiannis
Public Affairs Manager


Adrien Ruez
Operations Junior Manager


Anne-Laure Aslanian
Patient Engagement Manager Healthcare


Lara Chappell
Strategic Communications and Marketing Director


Erik Ruiz
Communications Junior Manager


Zoe Alahouzou
Deputy to the Chief Executive Officer


Anna Kole
Public Health Policy Director - Rare2030 Lead


François Houÿez
Information & Access to Therapies Director


Maria Cavaller
Patient Engagement Manager


Sharon Ashton
Events Director


Davor Duboka
Web Technology Manager


Flaminia Macchia
RDI Executive Director


Julien Delaye
Public Health Policy Junior Manager


Virginie Hivert
Therapeutic Development Director


Virginie Bros-Facer
Scientific Director


Martina Bergna
Events Manager


Patrice Régnier
Chief Financial Officer


Anja Helm
Senior Manager of Relations with PO


Karolina Hanslik
Project Senior Manager - Rare Impact


Inés Hernando
ERN and Healthcare Director


Gulcin Gumus
Research and Policy Project Manager


Céline Schwob
Corporate Relations Senior Manager


Susan Foster
HR Support and Budget Manager


Valentina Bottarelli
PA Director & Head of Advocacy


Katarzyna Radwan
Team Assistant & Office Manager


Matt Bolz-Johnson
ERN & Healthcare Advisor


Raquel Castro
Open Academy Director, Social Policy Director


Anne-Mary Bodin
Resource Development Assistant


Annie Rahajarizafy
Accounting Manager


Simone Boselli
Public Affairs Director


Sandra Courbier
Social Research Director - Rare Barometer


Rob Camp
Patient Engagement Senior Manager - CABs


Tamara Kovazh
Open Academy Manager


Jo Marshall
Corporate and Donor Relations Assistant


Corina Puls
Office Manager

Volunteers

EURORDIS Volunteers are **playing a crucial role** in **shaping healthcare policy that benefits people with rare diseases**

Who are they?

What is their role?

How do they contribute?

How can you make the most of our networks, information, and training?

EURORDIS
RARE DISEASES EUROPE

Thank you!

Yann Le Cam

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