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EURORDIS SUPPORT TO VOLUNTEERS IN THE ERNs and EMA (and beyond!)

23 May 2025

European Patient Advocacy Group

EURORDIS
RARE DISEASES EUROPE

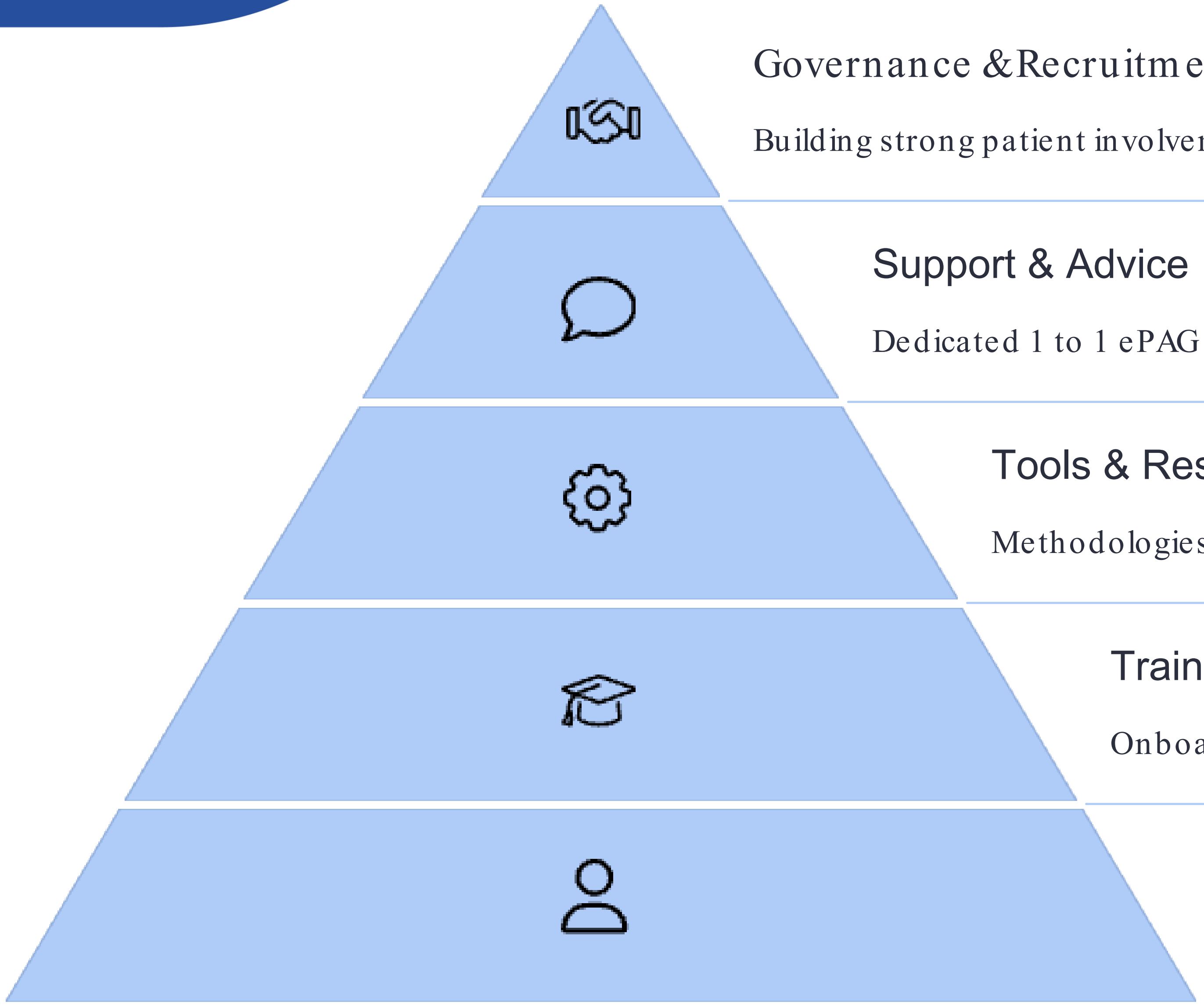
Empowering Rare Disease ePAG advocates: EURORDIS Support Framework

EURORDIS provides comprehensive support to patient advocates in European Reference Networks (ERNs) through the European Patient Advocacy Groups (ePAGs).

Our mission is to empower advocates with knowledge, tools, and connections they need to partner effectively with health professionals.

We believe in creating a powerful community of informed patient representatives who can drive meaningful change in rare disease care.

Five Pillars of Support



Governance & Recruitment

Building strong patient involvement and representation

Support & Advice

Dedicated 1 to 1 ePAG support and guidance when needed

Tools & Resources

Methodologies, guides, templates, good practices

Training

Onboarding webinars twice a year & EURORDIS Open Academy

Peer Learning

Transversal working groups for collaboration, peer learning and support across ePAG groups

Our support framework addresses all aspects of effective advocacy. We help advocates build their skills, knowledge, and networks.

Examples of Resources for ePAG Advocates

Governance Templates

Templates and structures for effective collaboration with healthcare professionals

Speak Up Toolkit

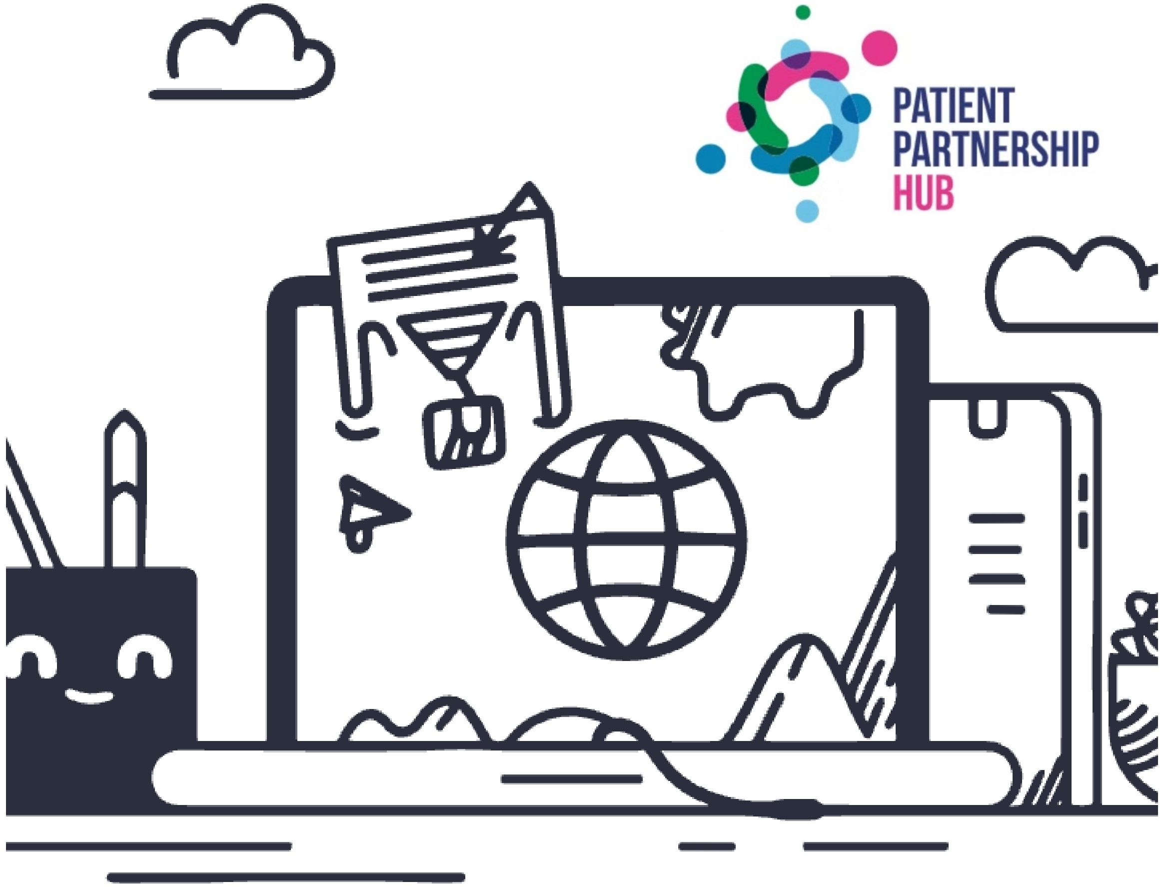
A guide and tools to support development of good surveys and other methodologies to capture the patient community's voice

Patient Journeys

Methodology and templates to map patient community care needs

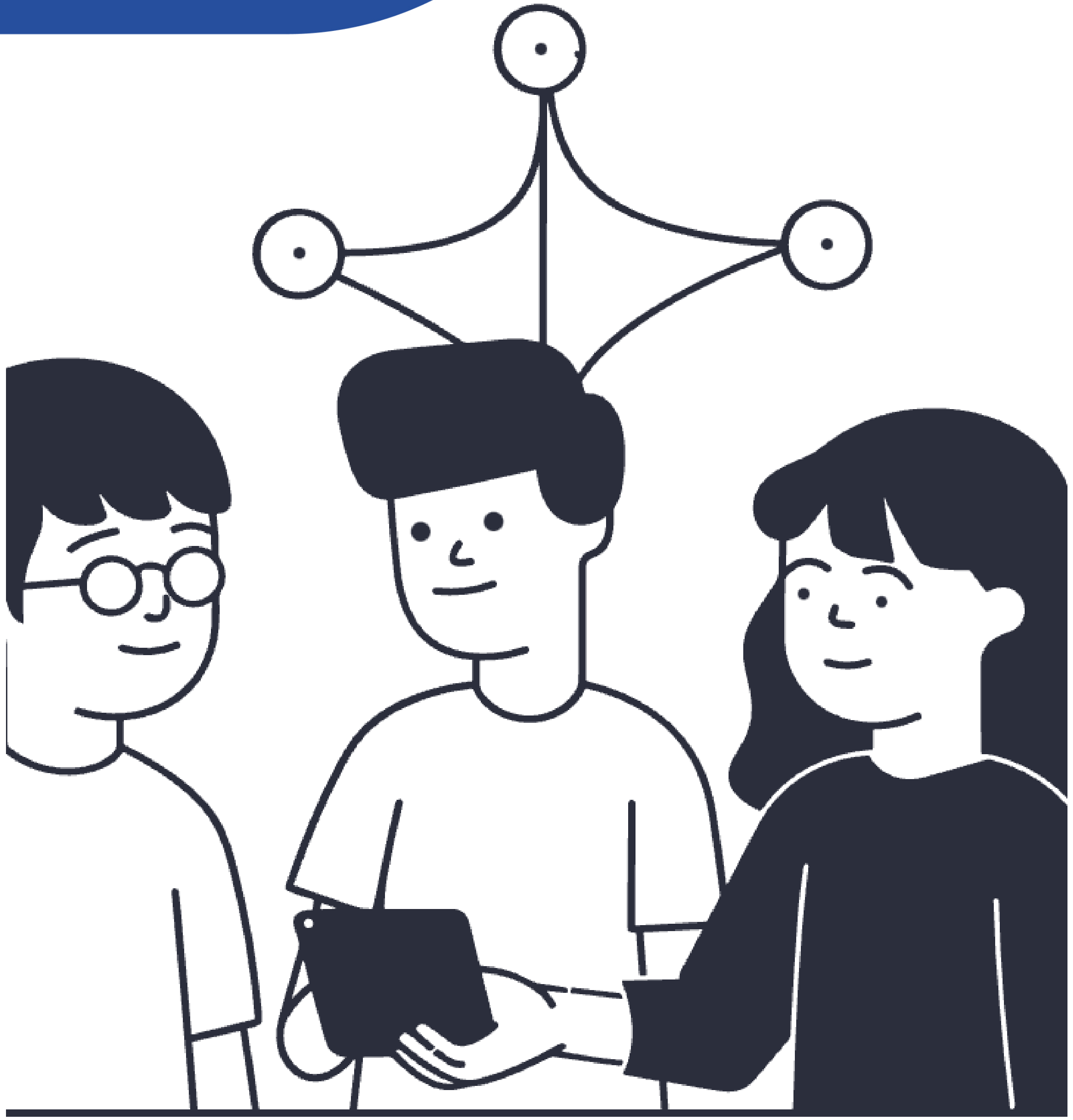
Patient Partnership Webinars

Webinars to showcase patient partnership in action in the ERNs/healthcare



One-stop resource. All tools and resources easily accessible in one place.

Fostering Peer Learning Communities



Over 120 ePAG advocates collaborate in these cross-ePAG groups

ePAG Steering Committee

Leadership group ensuring coordinated approach to patient partnership across all ERNs. Meets on a quarterly basis to discuss strategy and to identify shared needs and priorities.

Transversal Topic-based Working Groups

Groups addressing shared challenges: ERNs evaluation and monitoring; Patient Partnership WG (CoPs in 2025).

Communities of Practice

Informal discussion forums on practical issues related to the implementation of patient partnership like economic inclusion/reimbursement, meeting accessibility in ERNs or patient involvement in development of care pathways (JARDIN)

EURORDIS ERN & Healthcare Team

Core Team

The ERN & Healthcare team provides dedicated support to all ePAG advocates. Inés Hernando (Director) and Nora Lázaro (Patient Engagement Manager) lead these efforts.

Our team brings expertise in patient engagement, healthcare systems, and advocacy development.

Extended Support

We collaborate with other colleagues across EURORDIS to provide comprehensive assistance. This includes experts in:

- Research & therapeutic development
- Health technology assessment
- Social policy & rare cancer advocacy
- Rare Barometer program

EURORDIS internal taskforces

TAG

Therapeutic Action Group

DITA

Drug ,
Information,
Transparency and
Access (DITA)

HTA

Health
Technology
Assessment

SPAC

Social Poliicy
Action Group

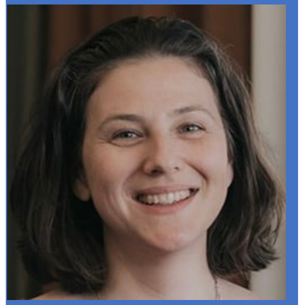
ePAGs

European Patient
Advocacy Groups
(ePAGs)

NBS WG

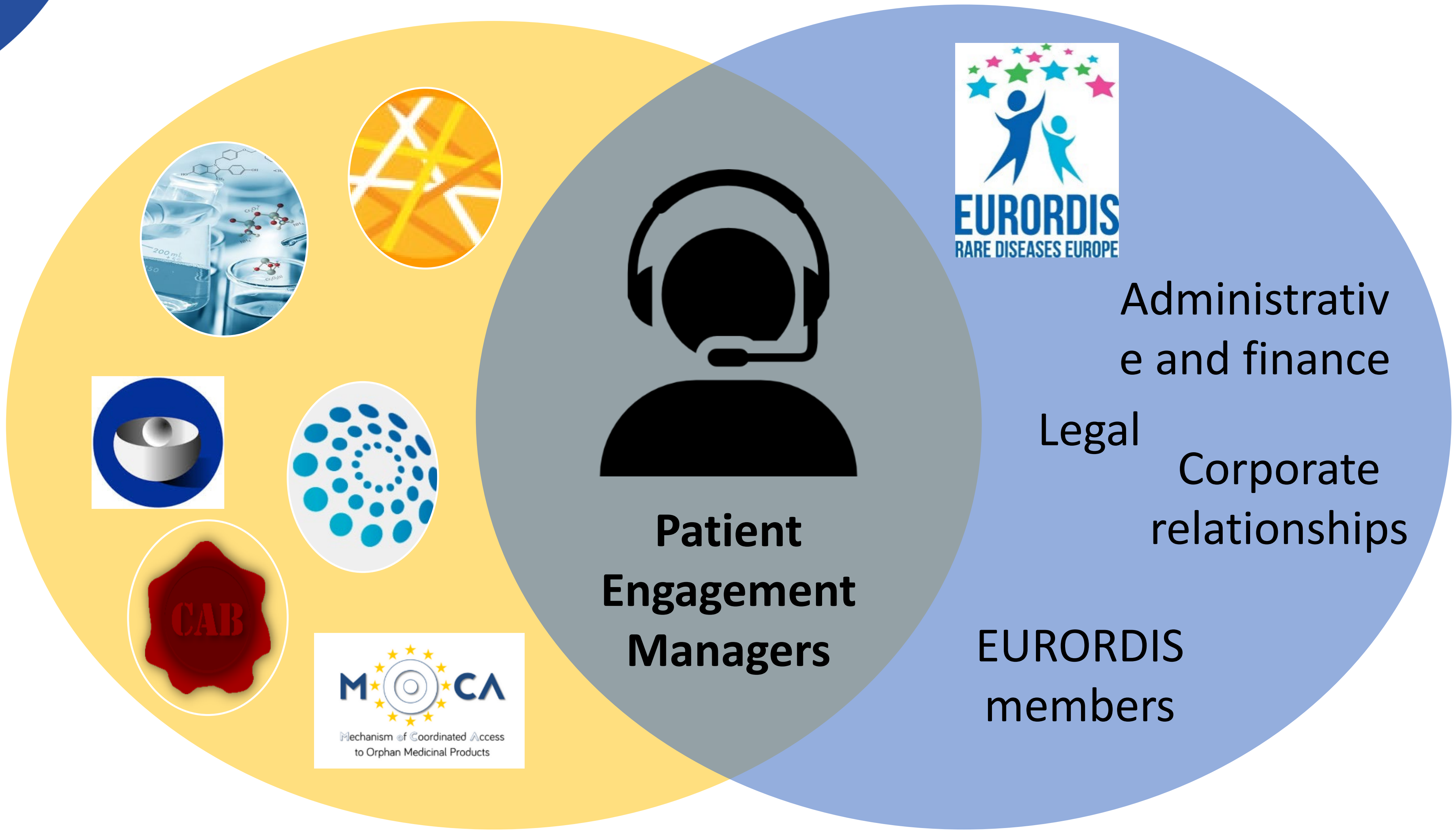
Newborn
screening
working group

DAG



Digital and Data
Advisory Group

EURORDIS Internal taskforces and working groups



Patient Engagement Managers

Administrative and finance

Legal

Corporate relationships

EURORDIS members

Single point of contact centralizing external and internal interactions

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Newborn Screening Working Group

35+ Members

17 countries

Multidisciplinary WG

Meeting/ 2 months (1h 30 min)

Patient experts
Clinicians
Screen4Care partners
Genetic counselors
Members of the National Committees of NBS
Academics
Psychologists
Ethicists
Researchers
Policymakers

- Discussing NBS Policy & Research European landscape
- Harmonising NBS approaches in Europe
- Identifying challenges and developing solutions

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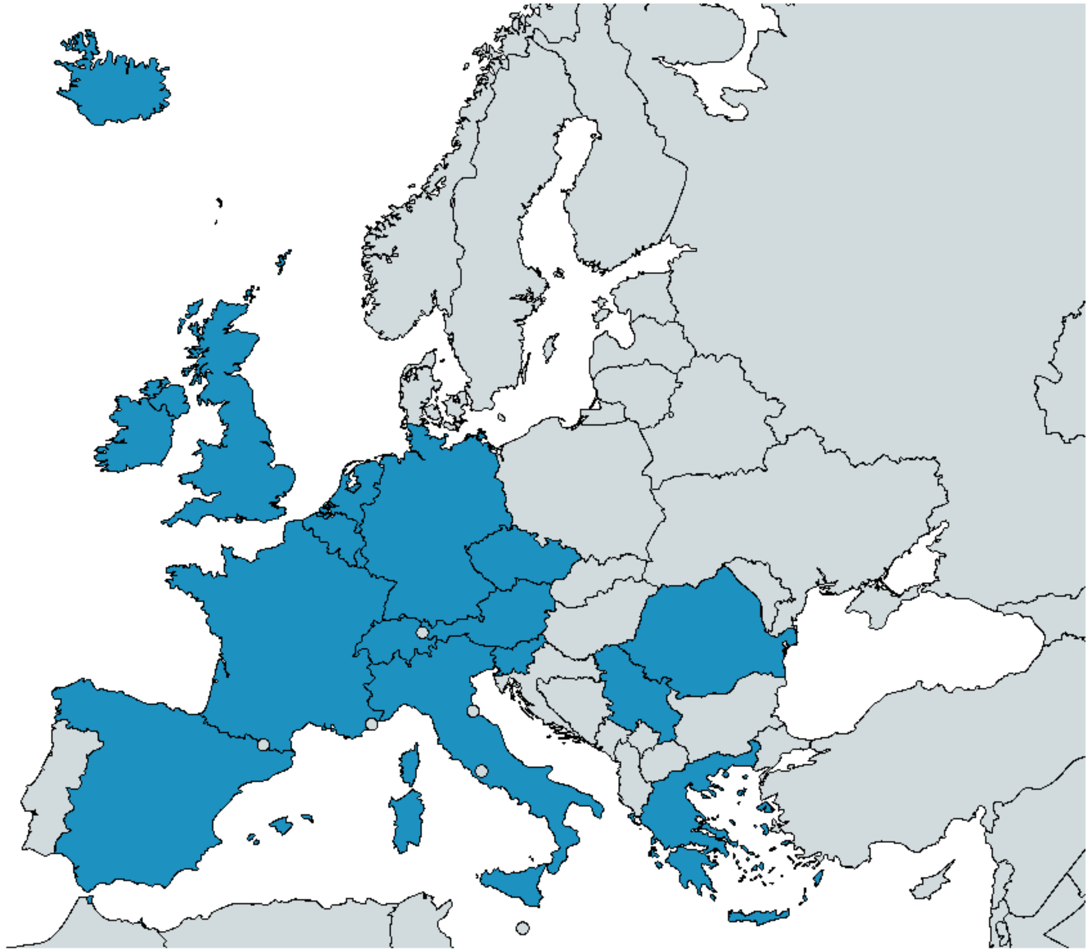
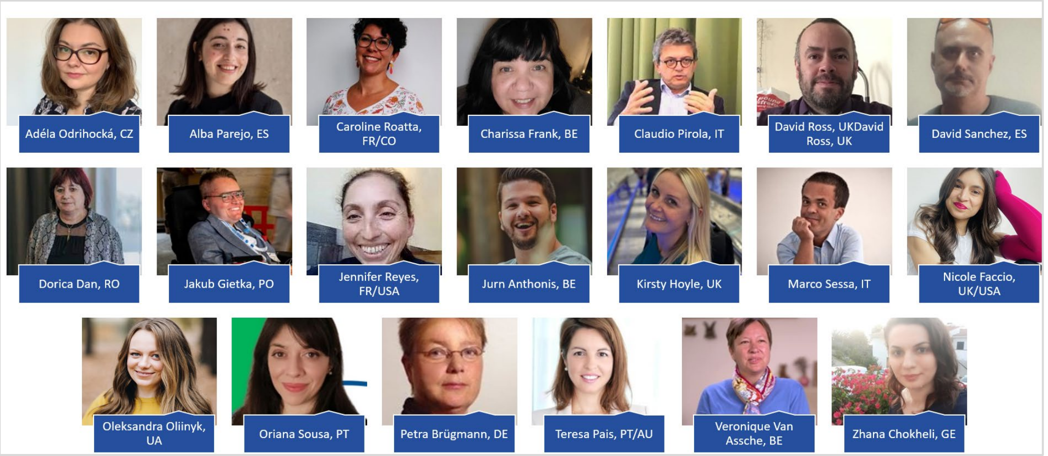
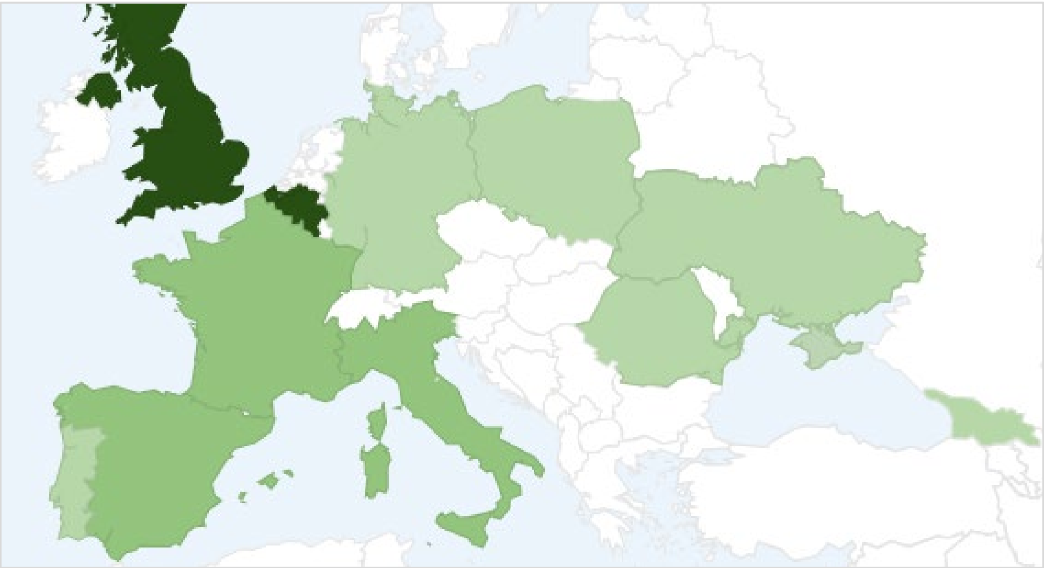


Social Policy Action Group





20 members, 13 European countries

People with rare diseases or family members

Diverse diseases, disabilities, ages, backgrounds

Some are also experts in social policy and human rights

Support EURORDIS' work to shape policies and practices that improve the access of people living with a rare disease and their families to holistic care, social and human rights.

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Therapeutic Action Group

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- The Therapeutic Action Group (TAG) was created in January 2009.
- Composed of EURORDIS volunteers in the scientific committees and working party at the European Medicines Agency (EMA):
  - 3 representatives from the Committee for Orphan Medicinal Products (COMP);
  - 3 Paediatric Committee (PDCO)
  - 1 Committee for Advanced Therapies (CAT)
  - 1 Pharmacovigilance (PRAC)
  - 1 Patients’ and Consumers’ Working Party (PCWP)
  - 1 Management Board
- These patients’ representatives dedicate their time, experience and expertise to the task of:
  - evaluating dossiers of medicinal products requesting orphan designation, evaluation for use in paediatric patients, evaluation of advanced therapies, as well as ensuring accurate, transparent and available information to patients on authorised medicinal products.
- Commitment:
  - 1h30 min/month + adhoc if needed
  - Mandate is link to EMA Committee mandate
  - Discussions are confidential

Digital and Data Advisory Group (DAG)

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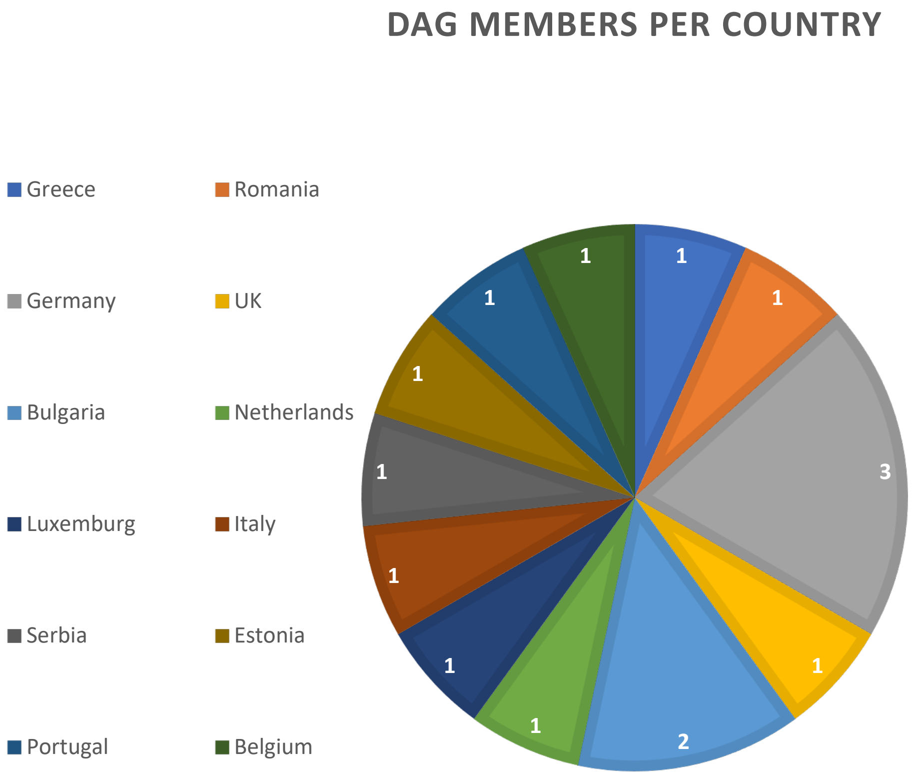

Mission:
To recognize and act upon the opportunities to influence strategic decision making and help EURORDIS assess and bring the views of patients regarding digital and data to the highest level.

Mandate:
To advise EURORDIS on all aspects regarding **Digital Health policies and procedures,** notably through their own experience (individual representation)

To contribute to several EURORDIS positions papers/consultations of European impact, as well as help shape the approach on patient engagement and patient centricity on several European level projects, such as FACILITATE, JARDIN or Screen4Care.

Time engagement for DAG members:

- 4h/month
- 8 to 10 virtual meetings per year
- 3-year mandate

Composition of the group
The DAG is currently comprised of 15 members from 12 countries and is coordinated by Veronica Popa.

EURORDIS.ORG

HTA & DITA TF

- Health Technology Assessment (HTA) task-force
- Drug Information, Transparency, and Access (DITA) task-force

Tomorrow morning specific workshop ☺

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Do you want to join a taskforce?

- Follow EURORDIS social media – Linkedin, facebook, Instagram… ☺
- Read EURORDIS membership news/enews
- Open School newsletter
- Therapeutic report
- Contact the relevant colleague for more information or general **pem@eurordis.org**

Questions?