Join Eurordis advocacy!
The Drug Information, Transparency and Access Task Force

An Eurordis task force of volunteers

This activity is funded by the Health Programme of the European Union

Regulation of medicines =

Pilot projects, mentoring, PCWP

How to conduct clinical trials in the EU?
Single arm trials vs Place controlled?
Role of patients in the desi and conduct of trials?

ACT EU, ICH guidelines, CTIS

Patient Experience Data
Patient engagement, Patie Preferences Elicitations studies, Patient data…

EMA Reflection Paper, IHI projects…

Involvement in EMA decision-making
Early Dialogue CHMP, Scientific Advisory Groups, Oral explanation, document review, CoI…

Patient information
Electronic package leaflet, risk minimisation measures / patient card, medici overviews, campa label us

Web-RADR app, SCOPE JA,

Shortages of medicine
Analysis of causes, information to patient catalogues, risk assessm plans, impact for patients, of critical medicines

Common Position 45 organisations, list of proposals, CMA

And much more!
Pilot for drug repurposing, Big data, AI, raw data, EMA communication, third party contributions…

This activity is funded by the Health Programme of the European Union

This activity is funded by the Health Programme of the European Union

Aleksandra Leijenhorst, NLD
Limb-Girdle Muscular Dystrophy

Karen Druckman, SWI
Hereditary Hemorrhagic Telangiectasia






Ilaria Galetti, ITA
Systemic sclerosis (FESCA)

Irena Bibic, CRO
Dravet Syndrome

Alan Timothy, GBR
rare lung diseases

Russell Wheeler, GBR / FRA
Leber's Hereditary Optic Neuropathy

Evy Reviers, BEL
Amyotrophic lateral scl.

Florian Innig, GER
Achondroplasia

Michela Onali, ITA
GNE myopathies

Daniel de Vicente, SPA
Niemann-Pick B

Janet Bloor, GBR
Duchenne UK and RACC

Jean-Ch. Fidalgo, FRA
Amyloidosis






And
Kees Deijl, NLD

About the task force

- Members are appointed by the Board of Directors
  - As they contribute shaping Eurordis positions
- For a mandate of 3 years
- We meet every month online (90 minutes)
  - And once a year face-to-face
- Members participate in conferences and can volunteer to EMA working groups

- Anne-Mary Bodin is coordinating organisational aspects and reports
- All minutes are public

- Next call: June 2025!
  - Summer School participants
  - Or if you express your interest!

This activity is funded by the Health Programme of the European Union

Your objectives

- Development and implementation of new legislations: your opinion?
- Awareness of patients / authorisation and use of medicines (committees, WPs…)
- Guidance documents
- Advice in relation to product-specific matters – excepted confidential information
- Transparency of the regulatory procedures, involvement of patients
- Information on access to medicines (i.e. compassionate use, placing on the market)

This activity is funded by the Health Programme of the European Union

Thank you!

François Houÿez, Director of Treatment Information and Access, EURORDIS

francois.houyez@eurordis.org

This activity is funded by the Health Programme of the European Union