EURORDIS

RRID:SCR_003814
Type: Tool

Proper Citation

EURORDIS (RRID:SCR_003814)

Resource Information

URL: http://www.eurordis.org/

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Description: EURORDIS is a non-governmental patient-driven alliance of patient organizations and individuals active in the field of rare diseases, dedicated to improving the quality of life of all people living with rare diseases in Europe. It is a not-for-profit organization and represents more than 479 rare disease organizations in 45 different countries (of which 25 are EU Member States), covering more than 4,000 rare diseases. It is therefore the voice of the 30 million patients affected by rare diseases throughout Europe. EURORDIS aims at improving the quality of life of people living with rare diseases in Europe through advocacy at the European level, support for research and drug development, networking patient groups, raising awareness and other actions designed to fight against the impact of rare diseases on the lives of patients and family. EURORDIS' training programs and resources are designed to strengthen the capacity of rare disease patients' representatives. Training empowers patients' representatives to advocate effectively for rare diseases at both the local and EU level. Key issues affecting patients of Rare Diseases on which we actively work: * Sustaining rare diseases as an EU public health priority * Making Rare Diseases A Public Health Priority In All Member States * Rare Diseases: An International Public Health Priority * Improving Access To Orphan Drugs * Improving Access To Quality Care * Promoting cross-border healthcare and patient mobility * Bridging Patients And Research * Genetic testing and newborn screening

Abbreviations: EURORDIS

Synonyms: EURORDIS - Rare Diseases Europe

Resource Type: nonprofit organization
**Funding Agency:** French Muscular Dystrophy Association, European Union, members, corporate foundations, health industry

**Resource Name:** EURORDIS

**Resource ID:** SCR_003814

**Alternate IDs:** nlx_143535, grid.433753.5, Wikidata: Q5412882

**Alternate URLs:** https://ror.org/019w4mg02

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**Ratings and Alerts**

No rating or validation information has been found for EURORDIS.

No alerts have been found for EURORDIS.

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**Data and Source Information**

**Source:** SciCrunch Registry

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**Usage and Citation Metrics**

We found 33 mentions in open access literature.

**Listed below are recent publications.** The full list is available at RRID.


Iotova V, et al. (2020) Educational and knowledge gaps within the European Reference Network on Rare Endocrine Conditions. Endocrine connections.


