Resource Summary Report

Generated by RRID on May 7, 2025

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: French Muscular Dystrophy Association ;
European Union ;
members ;
corporate foundations ;
health industry

Resource Name: EURORDIS

Resource ID: SCR_003814

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

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

Record Creation Time: 20220129T080221+0000

Record Last Update: 20250420T014153+0000

Ratings and Alerts

No rating or validation information has been found for EURORDIS.

No alerts have been found for EURORDIS.

Data and Source Information

Source: SciCrunch Registry

Usage and Citation Metrics

We found 34 mentions in open access literature.

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

Martin S, et al. (2024) Patient preferences in genetic newborn screening for rare diseases: study protocol. BMJ open, 14(4), e081835.

Turner MA, et al. (2022) European research networks to facilitate drug research in children. British journal of clinical pharmacology, 88(10), 4258.

Karin I, et al. (2021) Treat Iron-Related Childhood-Onset Neurodegeneration (TIRCON)-An International Network on Care and Research for Patients With Neurodegeneration With Brain Iron Accumulation (NBIA). Frontiers in neurology, 12, 642228.

Hartmann A, et al. (2021) Is Tourette syndrome a rare condition? F1000Research, 10, 434.

Hachulla E, et al. (2021) French recommendations for the management of systemic sclerosis. Orphanet journal of rare diseases, 16(Suppl 2), 322.

Iotova V, et al. (2021) Educational and knowledge gaps within the European reference network on rare endocrine conditions. Endocrine connections, 10(1), 37.

Brasil S, et al. (2021) Artificial Intelligence in Epigenetic Studies: Shedding Light on Rare Diseases. Frontiers in molecular biosciences, 8, 648012.

Reichel CA, et al. (2021) Rare Diseases of the Oral Cavity, Neck, and Pharynx. Laryngo-rhino- otologie, 100(S 01), S1.

Shah S, et al. (2021) Current Drug Repurposing Strategies for Rare Neurodegenerative Disorders. Frontiers in pharmacology, 12, 768023.

Piperno R, et al. (2021) Mental Well-Being in Patients with Transfusion-Dependent Anemias and Hemochromatosis during the SARS-CoV-2 Pandemic. Mediterranean journal of hematology and infectious diseases, 13(1), e2021024.

Saadoun D, et al. (2021) French recommendations for the management of Takayasu's arteritis. Orphanet journal of rare diseases, 16(Suppl 3), 311.

Masi L, et al. (2021) Bone fragility in patients affected by congenital diseases non skeletal in origin. Orphanet journal of rare diseases, 16(1), 11.

, et al. (2020) 10th European Conference on Rare Diseases & Orphan Products (ECRD 2020). Orphanet journal of rare diseases, 15(Suppl 1), 310.

Vermeulen E, et al. (2020) Involve Children and Parents in Clinical Studies. Clinical and translational science, 13(1), 11.

Li SY, et al. (2020) 5P Strategies for Management of Multiple Endocrine Neoplasia Type 2: A Paradigm of Precision Medicine. Frontiers in endocrinology, 11, 543246.

Vandeborne L, et al. (2019) Information needs of physicians regarding the diagnosis of rare diseases: a questionnaire-based study in Belgium. Orphanet journal of rare diseases, 14(1), 99.

Roy NBA, et al. (2019) The pathogenesis, diagnosis and management of congenital dyserythropoietic anaemia type I. British journal of haematology, 185(3), 436.

Sobrido MJ, et al. (2019) Recommendations for patient screening in ultra-rare inherited metabolic diseases: what have we learned from Niemann-Pick disease type C? Orphanet journal of rare diseases, 14(1), 20.

Wangler MF, et al. (2017) Model Organisms Facilitate Rare Disease Diagnosis and Therapeutic Research. Genetics, 207(1), 9.

Laimer M, et al. (2017) Epidermolysis bullosa House Austria and Epidermolysis bullosa

clinical network : Example of a centre of expertise implemented in a European reference network to face the burden of a rare disease. Wiener klinische Wochenschrift, 129(1-2), 1.