



Resources

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Resources

EURORDIS

- European Organisation for Rare Diseases (EURORDIS) www.eurordis.org

Rare Disease Day

- www.rarediseaseday.org

Relevant European Regulations

- Regulation (EC) No 141/2000 of the European Parliament and of the Council of 16 December 1999 on orphan medicinal products <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:32000R0141:EN:HTML>
- Regulation (EC) No 1901/2006 of the European Parliament and of the Council of 12 December 2006 on medicinal products for paediatric use and amending Regulation (EEC) No 1768/92, Directive 2001/20/EC, Directive 2001/83/EC and Regulation (EC) No 726/2004
- Regulation (EC) No 1394/2007 of the European Parliament and of the Council of 13 November 2007 on advanced therapy medicinal products and amending Directive 2001/83/EC and Regulation (EC) No 726/2004; http://ec.europa.eu/health/files/eudralex/vol-1/reg_2007_1394/reg_2007_1394_en.pdf

European Medicines Agency

- European Medicines Agency (EMA): www.ema.europa.eu
- EMA Patients' and Consumers' web pages: http://www.ema.europa.eu/ema/index.jsp?curl=pages/partners_and_networks/general/general_content_000317.jsp&mid=WC0b01ac058003500c
- European regulation on orphan medicinal products: 10 years of experience and perspectives (2011) *Nature Reviews: Drug Discovery* 10: 341-349

European Commission and Council Documents On Rare Diseases

- COM (2008) 679 Communication from the Commission to the European Parliament, the Council the Economic and Social Committee and the Committee of the Regions on Rare Diseases: Europe's challenges.
- Council Recommendation of 8 June 2009 on an action in the field of rare disease.
- Special Eurobarometer 361- European awareness of Rare Diseases (http://ec.europa.eu/health/rare_diseases/docs/ebs_361_en.pdf)

European/International Research Consortia

- European Committee of Experts on Rare Diseases (EUCERD) <http://www.eucerd.eu/>
- International Rare Diseases Research Consortium (IRDiRC) http://ec.europa.eu/research/health/medical-research/rare-diseases/irdirc_en.html
- ERA-Net for Research Programmes on Rare Diseases (E-RARE) www.e-rare.eu
- Seventh Framework Programme for Research and Technological Development cordis.europa.eu/fp7/home_en.html
- The EU Framework Programme for Research and Innovation (Horizon 2020) <http://ec.europa.eu/research/horizon2020>

- European Project for Rare Diseases National Plans Development (EUROPLAN) <http://www.euoplanproject.eu>

Orphanet

- Orphanet: www.orpha.net

Online Communities

- RareConnect <http://www.rareconnect.org/>

Training Initiatives for Patients

- EURORDIS Summer School: <http://www.eurordis.org/training-resources>
- European Patients' Academy on Therapeutic Innovation (EUPATI) www.patientsacademy.eu
- EMA training website and documents – [http://www.ema.europa.eu/ema/index.jsp?curl=pages/partners_and_networks/general/general_content_000575.jsp&mid=WC0-b01ac058077ce81#In-house training sessions](http://www.ema.europa.eu/ema/index.jsp?curl=pages/partners_and_networks/general/general_content_000575.jsp&mid=WC0-b01ac058077ce81#In-house%20training%20sessions)

NORD

- www.rarediseases.org

Rare Disease Day US

- www.rarediseaseday.us

NORD Physician Guides

- www.nordphysicianguides.org

NIH Genetic and Rare Diseases Information Center (GARD)

- <http://rarediseases.info.nih.gov/gard>

NIH Center for Advancing Translational Sciences

- <http://www.ncats.nih.gov/>

NIH Office for Rare Diseases Research

- <http://rarediseases.info.nih.gov/>

FDA Patient Network

- <http://www.fda.gov/ForPatients/default.htm>

Gene Reviews

- <http://www.ncbi.nlm.nih.gov/books/NBK1116/>

FDA Office of Orphan Products Development

- <http://www.fda.gov/AboutFDA/CentersOffices/OfficeofMedicalProductsandTobacco/OfficeofScienceandHealthCoordination/ucm2018190.htm>