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Eurordis has published a founding paper on rare diseases "Rare Diseases: Understanding This Public Health Priority", available in English, French, Italian, German, and Spanish (see www.eurordis.org or contact Eurordis).

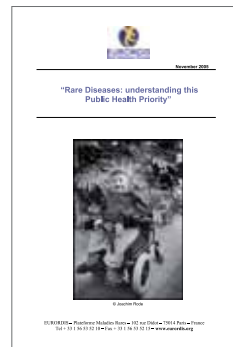
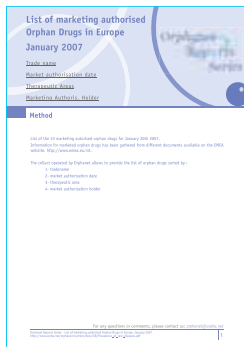
Eurordis publishes the latest figures on rare diseases in a report called "The Prevalence of Rare Diseases". This report is published jointly with Orphanet (www.orpha.net) on a quarterly basis.



EURORDIS
Rare Diseases Europe

WHAT IS A RARE DISEASE?

MALADIES RARES • ENFERMEADES RARAS
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EURORDIS represents about 300 rare disease organisations in over 30 countries, covering more than 1,000 rare diseases. EURORDIS fights for the right of rare disease patients to benefit from timely diagnosis, quality healthcare and treatments, and social integration in an equitable way across the various European countries.



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Eurordis - Rare Diseases Europe
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Rare Diseases Europe

WHAT IS A RARE DISEASE?

**A disease or disorder is defined as rare in Europe when it affects less than 1 in 2,000 citizens (Orphan Drug Regulation 141/2000) .
Rare diseases may affect 30 million European Union citizens.**

CHARACTERISTICS OF RARE DISEASES

- Rare diseases are often chronic, progressive, degenerative, and often life-threatening
- Rare diseases are disabling: the quality of life of patients is often compromised by the lack or loss of autonomy
- High level of pain and suffering for the patient and his/her family
- No existing effective cure
- There are between 6,000 and 8,000 rare diseases
- 75% of rare diseases affect children
- 30% of rare disease patients die before the age of 5
- 80% of rare diseases have identified genetic origins. Other rare diseases are the result of infections (bacterial or viral) , allergies and environmental causes, or are degenerative and proliferative.

Rare diseases are characterised by a broad diversity of disorders and symptoms that vary not only from disease to disease, but also from patient to patient suffering from the same disease.

Relatively common symptoms can hide underlying rare diseases, leading to misdiagnosis.

RARE DISEASE PATIENTS FACE COMMON PROBLEMS:

- Lack of access to correct diagnosis
- Delay in diagnosis
- Lack of quality information on the disease
- Lack of scientific knowledge of the disease
- Heavy social consequences for patients
- Lack of appropriate quality healthcare
- Inequities and difficulties in access to treatment and care

HOW CAN THINGS CHANGE?

- By implementing a comprehensive approach to rare diseases
- By developing appropriate public health policies
- By increasing international cooperation in scientific research
- By gaining and sharing scientific knowledge about all rare diseases, not only the most "frequent" ones
- By developing new diagnostic and therapeutic procedures
- By raising public awareness
- By facilitating the networking of patient groups to share their experience and best practices
- By supporting the most isolated patients and their parents to create new patient communities or patient groups
- By providing comprehensive quality information to the rare disease community

EUROPEAN REGULATIONS AND POLICIES IN PLACE IN FAVOUR OF RARE DISEASE PATIENTS:

- EU Regulation on Orphan Medicinal Products (1999)
- EU Regulation on Paediatric Drugs (2006)
- Programme of Community Action in the Field of Public Health (2007-2013)
- EU 7th Framework Programme for Research (2007-2013)