

Partners & Collaborators



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Discover who we are

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SCAN ME



Want to learn more about rare diseases?

Orphanet (www.orpha.net) is the international portal dedicated to rare diseases. This website provides scientific information on more than 6,400 known rare diseases, accessible to all audiences.

Orphanet also offers information on specialized services, such as patient organizations, national and international research, as well as new initiatives related to rare diseases.

You can contact the Belgian Orphanet team at the following address:
orphanetbelgium@sciensano.be



Central Registry of Rare Diseases (CRRD)



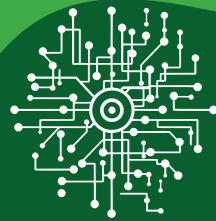


RARE, BUT NOT ALONE !

In Europe, a disease is considered rare when it affects fewer than 1 in 2,000 people. With more than 6,400 rare diseases, thousands of patients are affected in Belgium.

The Central Registry of Rare Diseases (CRRD) aims to:

- ✓ Improve understanding of the prevalence of rare diseases in Belgium
- ✓ Support research and recruitment for clinical trials
- ✓ Inform health policies and reimbursement decisions
- ✓ Improve the quality of care through benchmarking



DATA & CODIFICATION

One of the major challenges in recording rare diseases is the underuse of appropriate coding systems.

The Orphanet nomenclature (ORPHAcodes) is an internationally recognized system that provides specific, standardized, and consistent coding of rare disease diagnoses in electronic medical records and registries.

Its use is strongly recommended for data exchange and statistical analysis at both national and international levels.



WHAT IS THE CRRD ?

The CRRD is a database holding a limited set of data from patients affected by a rare disease who have consulted a specialist in Belgium about their disease.

WHY IS THE CRRD IMPORTANT ?

Enables descriptive epidemiological studies.

Supports research on care needs and availability.

Facilitates genetic and phenotype-genotype studies.

Contributes to European-level data collection.



WHAT DATA IS COLLECTED?

The CRRD gathers a select set of data, including patient demographics, details about the diagnosis and diagnostic journey, as well as information on consultations and referrals to specialists.



BUILDING A STRONGER CRRD

Expansion since 2024:

Including data from rare disease functions in addition to the genetic centers in order to expand patient coverage.

Alignment with Standards:

The CRRD is evolving to meet European guidelines and Belgium's e-Health Action Plan, driving digital healthcare progress.

JOIN THE EFFORT

Register Your Patients:
Contribute to the CRRD and support RD research.

Advocate for ORPHAcodes:
Promote ORPHAcodes for better data accuracy and consistency across Europe!



NEXT STEPS & COLLABORATIONS

- Broadening data collection to include additional healthcare providers.
- Incorporating genetic test results into the registry.

Strengthening collaborations at both national and international levels.