

## LIST CENTRES FOR HUMAN GENETICS

### **CENTRE FOR HUMAN GENETICS - CHU SART-TILMAN**

Sart Tilman Bâtiment B 35 • 4000 Liège  
04 242 52 52  
[www.chuliege.be/jcms/c2\\_17345740/fr/](http://www.chuliege.be/jcms/c2_17345740/fr/)

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### **INSTITUT DE PATHOLOGIE ET DE GÉNÉTIQUE (IPG)**

Avenue Georges Lemaître 25 • 6041 Gosselies  
071 47 30 47  
[www.ipg.be](http://www.ipg.be)

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### **CENTRE FOR HUMAN GENETICS - UCL**

Avenue Hippocrate 10 • 1200 Bruxelles  
02 764 67 74  
<https://www.saintluc.be/fr/service/service-de-genetique-humaine-contacts>

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### **CENTRE FOR HUMAN GENETICS - ULB**

Hôpital Erasme  
Route de Lennik 808 • 1070 Bruxelles  
02 555 64 30  
[www.ulbgenetics.be](http://www.ulbgenetics.be)

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### **CENTER FOR MEDICAL GENETICS - UZ ANTWERPEN**

Prins Boudewijnlaan 43 bus 6 • 2650 Edegem  
03 275 97 74  
[www.genetica-antwerpen.be](http://www.genetica-antwerpen.be)

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### **CENTER FOR MEDICAL GENETICS - UZ BRUSSEL VUB**

Laarbeeklaan 101 • 1090 Brussel  
02 477 60 71  
<https://www.uzbrussel.be/web/centrum-voor-medische-genetica/home>

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### **CENTRE FOR HUMAN GENETICS - UZ LEUVEN**

Herestraat 49 • 3000 Leuven  
016 34 59 03  
[www.uzleuven.be/nl/centrum-menselijke-erfelijkheid](http://www.uzleuven.be/nl/centrum-menselijke-erfelijkheid)

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### **CENTER FOR MEDICAL GENETICS - UZ GENT**

C. Heymanslaan 10 • 9000 Gent  
09 332 36 03  
<https://www.uzgent.be/nl/zorgaanbod/mdspecialismen/CMGG/Paginas/default.aspx>

In collaboration with:



## WANT TO KNOW MORE ABOUT RARE DISEASES?

Orphanet ([www.orpha.net](http://www.orpha.net)) is the international portal site for rare diseases. This website provides scientific information about more than 6.000 known rare diseases for all audiences. Orphanet provides information on specialized services such as patient organizations and national and international research plus new initiatives regarding rare diseases. You can contact the Belgian Orphanet team via: [orphanetbelgium@sciensano.be](mailto:orphanetbelgium@sciensano.be)

## CENTRAL REGISTRY FOR RARE DISEASES

### Sciensano

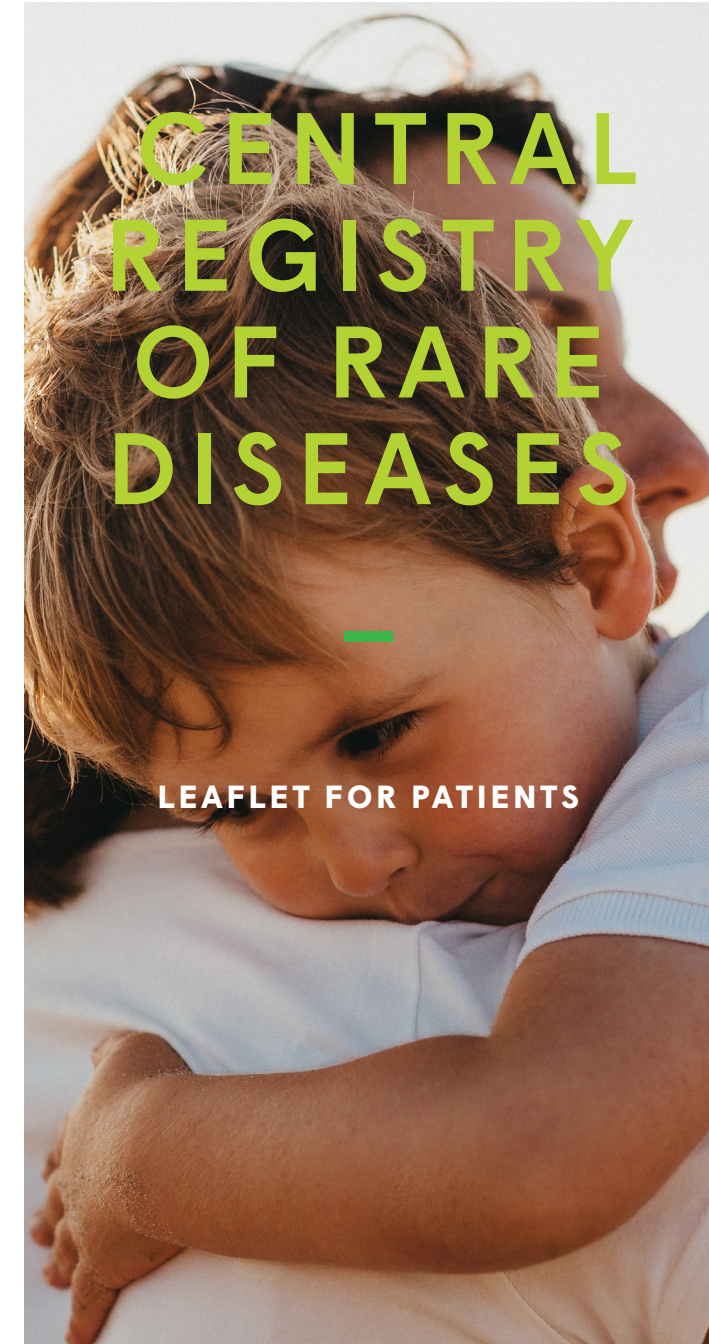
Rue Juliette Wytsmanstraat 14 • 1050 Brussels  
Epidemiology and Public Health  
Health Services Research • Unit Rare Diseases

### MORE INFORMATION

<https://rarediseases.sciensano.be>  
or via [CRRD@sciensano.be](mailto:CRRD@sciensano.be)



[www.sciensano.be](http://www.sciensano.be)



## **ONE IN A MILLION? BUT TOGETHER WE CAN BE STRONG!**

A disease is considered to be rare when it affects less than 1 in 2.000 of the population. Yet, the total number of patients affected by a rare disease is large, as currently more than 6.000 different rare diseases are known.

We want to ask you to contribute to this registry to allow a better mapping of patients with a rare disease in Belgium, to optimise quality of care and to facilitate clinical research.

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## **WHAT IS THE CENTRAL REGISTRY OF RARE DISEASES?**

The Central Registry of Rare Diseases 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.

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## **WHAT DATA IS COLLECTED?**

The Central Registry of Rare Diseases collects a limited number of variables: demographical data of the patient (age, sex, postal code,...), data on the diagnosis and path to diagnosis and finally information on the consultation and the referral to other specialists.

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## **HOW IS THE DATA PROTECTED?**

Data of patients is encrypted before being sent and stored in a protected environment. Only anonymized data will be used for the report.

## **WHAT IS THE GOAL OF THE REGISTRY?**

- Epidemiological research to ascertain how many patients are affected by a rare disease in Belgium (which types of rare diseases are present, where are patients treated, etc.)
- Support healthcare organization decisions
- Participation of patients in clinical trials and facilitation of research

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## **WHY IS IT SO IMPORTANT THAT YOUR DATA IS COLLECTED?**

Currently, almost no data is available for those patients affected by a rare disease, it is not even known how many of these patients there are in Belgium or which diseases they suffer from. This makes it difficult to fine tune the healthcare for these patients. Thanks to your participation and the participation of fellow sufferers in this registry, we can follow this specific group of patients and optimize their care.

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## **INTERESTED IN CLINICAL TRIALS?**

The registry also supports the development of orphan drugs by facilitating participation of patients to clinical studies. Patients affected by very specific rare diseases are important for the development of new treatments but recruitment of those patients is very difficult. The Registry can act as a facilitator and hence accelerate the development of new therapies. If you allow registration, your specialist can contact you in case patients with your condition are required for participation to a clinical trial.

## **WHO IS RESPONSIBLE FOR THE PROCESSING OF MY DATA?**

Sciensano, a scientific institution of the Belgian federal government, is responsible for processing of the data. Its main task is to conduct scientific research in order to support health policy. The final aim is the optimization of the quality of care. Sciensano also provides expertise and services related to public health.

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## **SHOULD YOU GIVE YOUR CONSENT TO BE ENROLLED IN THIS REGISTRY?**

The Commission for the Protection of Privacy has decided that the consent of the patient is not necessary for registration in the Registry (authorization in deliberation No. SCSSH/13/224 of 22/10/2013 and No. SCSSH/15/107 of 16/06/2015 of the Sector Committee of the Social Security and Health).

Nevertheless, it is possible - upon your explicit request - to refuse the registration of your data. You can also indicate if you don't want to participate to clinical trials. Please contact your physician for this.