Information factsheet for
Patients living with a rare disease and their relatives

EMRaDi
EUREGIO MEUSE-RHINE
— RARE DISEASES

LIVING WITH A RARE DISEASE IS NOT RARE!

RARE DISEASES are often chronic, highly complex, progressive and severely disabling, frequently affecting life expectancy and generating specific care needs. Due to their low prevalence, little is known about most rare diseases. As a result, they are difficult to diagnose and their symptoms under-recognized in healthcare and social systems.

30 MILLION CITIZENS
AFFECTED IN THE EU

6000 - 8000 different
rare diseases

For each RD,
fewer than 1 out of 2000 people affected

Important needs
and complex care
of patients

Geographically scattered
expertise

ACCESS TO CARE

- **FOR MANY RARE DISEASES, THE BURDEN OF COORDINATING** the different aspects of the care pathway is high – either before diagnosis and looking for the right health care professional (HCP), or after the diagnosis and setting up the treatment and (para)medical support required for the rare disease (RD).
- **THE MULTIDISCIPLINARY NATURE OF RD CARE, THE NUMEROUS VISITS AND HCPs** involved as well as the challenges of the transition could be facilitated by a care coordinator. The recommended coordinator could offer centralisation and bridge all of the different needs of patients and relatives. Hospitals and centres for RDs could offer such a support in the form of a coordinating medical specialist, a social worker or liaison nurse/case manager. Other HCPs might also be consulted or involved to take on this task.

  To learn more about the expertise of different centres and their varying degrees and ways in which they aim to coordinate care for RD patients, please find the contact details of University hospitals' RD centres enclosed in this factsheet.
- **PRIMARY CARE PRACTITIONERS** - General Practitioners (GPs) and paediatricians – are also very important at all stages of your patient pathway as they have a very good overview of your overall personal and family situation.

ACCESS TO INFORMATION ON RDs

ACCESSING ACCURATE AND CORRECT INFORMATION THAT IS EASY UNDERSTANDABLE CAN BE VERY DIFFICULT.

- **HCPs** are there to inform you on every aspect of your pathway and you should never hesitate to ask them questions.
- Each country has an **umbrella patient association** for RDs, in partnership with EURORDIS, the European umbrella for RD patient organisations. This national umbrella can help you to get in touch with a specific patient association for your RD or, in case none exists, it can help you to find fellow patients/relatives.
- As a starting point, a **list of contacts and sources** can be found at the bottom of this factsheet.
- **Online communities and social media** also exist and can be great sources of information and support. **Rareconnect.org** is an online network of RD communities in partnership with EURORDIS.

IF YOU WISH TO ACCESS INFORMATION ON THE INTERNET – whether for personal use or to pass on to others to increase their awareness - the most reliable European source of medical information on your RD is Orphanet - **The Portal for RDs and Orphan Drugs (www.orpha.net).** There, you can also find centres of expertise, patient organisations and lots of other important info. In Germany, the Netherlands and Belgium, specific information is also available - see the information sources below.

SUPPORT FOR ADMINISTRATIVE PROCEDURES AND FINANCIAL ASPECTS

IN BELGIUM, health insurance funds are a good source of information for reimbursement questions. RDs are exceptional situations for health insurance funds but they are there to offer support to patients and relatives with administrative procedures and financial aspects such as access to reimbursement, allocations, financially sustainable treatments and specific assistance for accessing the Special Solidarity Fund, which can offer, in particular cases, additional financial support to RD patients.

IN GERMANY, the situation is quite scattered and difficult to navigate. Patient associations are a good place to get help. The Centres of Expertise for RDs also offer support in these fields for their patients. Nevertheless, a lot of classic institutions are not specialised in RDs. Some of the support for administrative procedures and financial aspects will be provided by the social welfare offices of local municipalities, such as disability status or house adaptations. Other areas of support will be provided by health insurance funds, such as access to medical equipment.

IN THE NETHERLANDS, most healthcare services for RDs are reimbursed based on the national healthcare package, which applies to all citizens. For more information regarding administrative and financial procedures you can contact your health insurer and/or your hospital (finance department).

SOCIAL SERVICES (either located within the hospitals, the health insurance funds and/or the municipalities) are a good source of information and support to help you with your access to care, reimbursements and administrative procedures – disability status, adaptations to the house, medical equipment, etc.

> **Health insurance funds and social services can support and explore with you whether you benefit from all the rights you are entitled to** (specific status and access to care and reimbursement, including homecare, social and psychological services)

PSYCHOLOGICAL SUPPORT

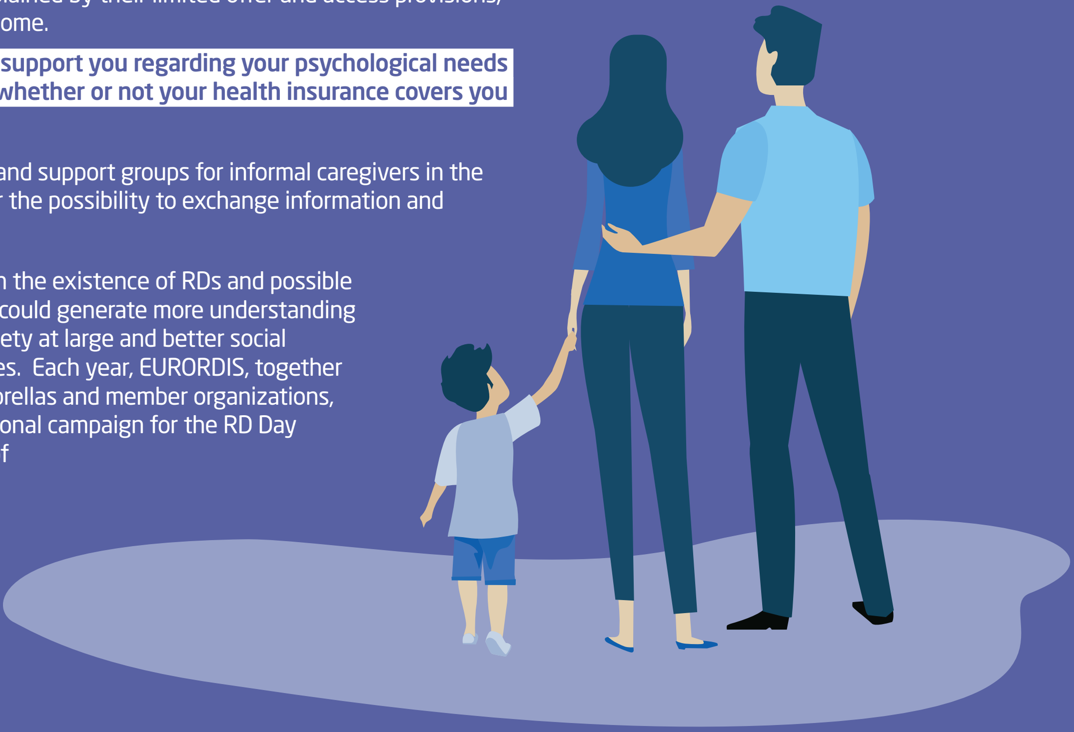
THE PSYCHOLOGICAL ASPECTS OF RDs AND (THE BURDEN OF) CARE RESPONSIBILITIES CAN BE ADDRESSED WITH DIFFERENT FORMS OF PSYCHOLOGICAL SUPPORT.

- Different reimbursement schemes exist and could be applicable. Psychological support services are often underused because medical professionals do not offer them routinely and patients and relatives do not request them at a larger scale. This could also be explained by their limited offer and access provisions, which can be burdensome.

  Your HCP is there to support you regarding your psychological needs and check with you whether or not your health insurance covers you for reimbursement.

- Patient associations and support groups for informal caregivers in the different regions offer the possibility to exchange information and experiences.

- Raising awareness on the existence of RDs and possible psychological burden could generate more understanding and support from society at large and better social inclusion of RD families. Each year, EURORDIS, together with the national umbrellas and member organizations, organize the international campaign for the RD Day (always the last day of February).



CROSS-BORDER CARE ACCESS

DUE TO THE SPECIFICITIES OF RDs, IT MIGHT BE BENEFICIAL TO SEEK SPECIFIC EXPERTISE ABROAD.

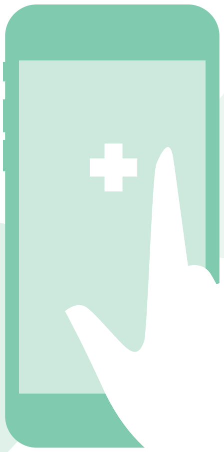
- **Before going abroad to receive healthcare (CBHC), consulting your health insurance fund** first is highly recommended.

- **Your medical specialist** can provide you with assistance to check the different possibilities, required authorizations and reimbursement conditions.

- Further information for treatment/care and reimbursement can be requested at the **National Contact Points for CBHC**. Initial Information is provided on the NCP websites, which give a broad overview about issues relevant to cross-border care.
  More specific information tailored to your personal situation, and information on specific procedures or treatment centres can also be requested by phone or using the contact form at the National Contact Point.

CONTACT DETAILS AND SOURCES OF INFORMATION

As a patient, with or without diagnosis, and as a relative or informal caregiver, it is important to have access to the best information and expertise possible.
Important bodies and sources of information in the Euregio Meuse-Rhine and in Europe are summarized here.



UNIVERSITY HOSPITALS AND CENTRES OF EXPERTISE FOR RDs

Each country has set up Centres of Expertise and of References for RDs.

Only the 3 University hospitals that have participated in the EMRaDi project are mentioned here.
More information on the centres in your region can be found via your health professionals, the European database www.orpha.net and through the patient associations.

In addition, for Germany, the se-atlas - the care atlas for people with RDs - can be consulted (www.se-atlas.de).
In the Netherlands, an overview of the existing Centres of Expertise for RDs can be found at www.nfu.nl (click on 'Patiëntenzorg' and then on '350' in the section 'Erkende expertisecentra') and for some specific diseases on www.erfelijkheid.nl.

IN THE BELGIAN PART OF THE EMR:

CHU de Liège
Centre des Maladies Rares

Avenue de l'Hôpital 1,
4000 LIEGE
Tel.: 0032 (0)4 284 36 40
Fax: 0032 (0)4 242 54 46
E-mail: maladierare@chuliege.be
▶ www.chuliege.be
then click on > 'Les soins aux patients' > 'Consultations' > 'Centre des maladies rares'

IN THE GERMAN PART OF THE EUREGIO MEUSE-RHINE (EMR):

Uniklinik RWTH Aachen
Zentrum für Seltene Erkrankungen Aachen (ZSEA)

Pauwelsstr. 30,
52074 Aachen
Tel.: 0049 (0)241 80-38265
Fax: 0049 (0)241 80-82044
E-mail: zsea@ukaachen.de
▶ www.ZSEA.ukaachen.de

IN THE DUTCH PART OF THE EMR:

Maastricht UMC+
Polikliniek Klinische Genetica

Postbus 5800,
6202 AZ Maastricht
P. Debyelaan 25,
6229 HX Maastricht
Tel.: 0031 (0)43 3875855 (08.30 - 17.00 uur)
E-mail: polikliniek.klinischegenetica@mumc.nl
▶ klinischegenetica.mumc.nl/

UMBRELLA PATIENT ASSOCIATIONS FOR RDs (NATIONAL)

IN GERMANY:

Achse

▶ www.achse-online.de/
Tel.: +49-30-3300708-0
E-mail: info@achse-online.de

IN BELGIUM:

RaDiOrg - Rare Diseases Belgium

▶ https://www.radiorg.be/fr/
info@radiorg.be - +32 478 727 703
National helpline via the contact form, in coordination with Orphanet Belgium.
Additional initiative for French-speaking patients: the "Rare Disease Line" from Rare Disorders Belgium (secretariat@rd-b.be) > 0800 9 2802 (free call)

IN THE NETHERLANDS:

VSOP

▶ www.vsop.nl/
Tel.: +31 35 6034040
E-mail: vsop@vsop.nl

▶ www.zichtopzeldzaam.nl
▶ www.zeldzameaandoening.nl

This factsheet is part of the EMRaDi final report and is based on its global results.
EMRaDi (acronym of "Euregio Meuse-Rhine Rare Diseases") is an INTERREG-funded cross-border project on RDs, the initial phase of which took place between October 2016 and March 2020 in the Euregio Meuse-Rhine. For more information, you can access the complete report at **www.emradi.eu**.

EURORDIS-RARE DISEASES EUROPE

▶ www.eurordis.org

European non-profit alliance of 884 RD patient organisations from 72 countries that work together to improve the lives of the 30 million people living with a RD in Europe.

▶ RareConnect.org

The online network of RD communities that brings together thousands of patients, families and groups who might otherwise be isolated.

HEALTH INSURANCE FUNDS

Your health insurance fund can support you in all the aspects mentioned in this factsheet.
Visiting its webpages can also provide you with information on the social support available in your region.

ORPHANET - THE PORTAL FOR RARE DISEASES AND ORPHAN DRUGS

▶ www.orpha.net

Orphanet provides medical descriptions of rare diseases and directories of professionals and institutions, medical laboratories, centres of expertise and patient associations.

EUROPEAN REFERENCE NETWORKS (FOR RDs)

▶ ec.europa.eu/health/ern_en

To influence the decision-making process, EURORDIS encourages patient organisations to participate in European Reference Networks. Patient organisations can represent their interests through European Advocacy Groups (ePAGs) in ERNs.

EMRADI - RARE DISEASES IN THE EUREGIO MEUSE-RHINE

▶ www.emradi.eu

(INTERREG V-A EMR project)

CROSS-BORDER HEALTHCARE: NATIONAL CONTACT POINTS

National Contact Points are a source of information for cross-border healthcare (CBHC) in cooperation with health insurance funds.

Manual, **Checklist** and **toolbox** for patients (edited by the European Commission).

EU website on cross-border healthcare.

IN GERMANY:

▶ www.eu-patienten.de

E-mail: info@eu-patienten.de

IN BELGIUM:

▶ www.crossborderhealthcare.be

E-mail: information@crossborderhealthcare.be

IN THE NETHERLANDS:

▶ www.cbhc.nl

The EMRaDi partners can also support you in your CBHC via their specific information material.

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