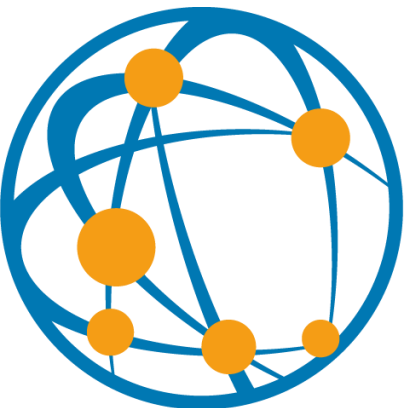
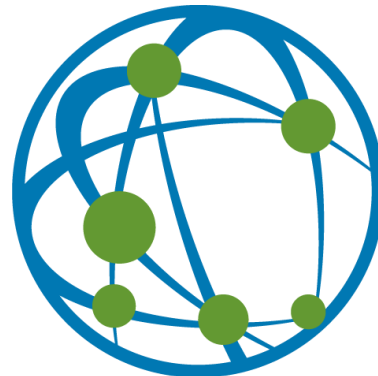


Using the Rare Obesity module in the Core Registry



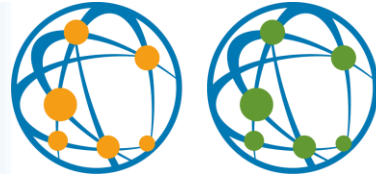
EuRRECa

European Registries for
Rare Endocrine Conditions



EuRR-Bone

European Registries for Rare
Bone and Mineral Conditions

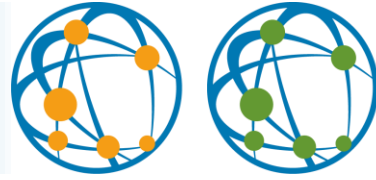


This condition-specific module is open for the following diagnoses

- Syndromic Genetic Obesity **ORPHA240371**
 - Prader-Willi syndrome **ORPHA739**
 - Prader-Willi-like syndrome **ORPHA398073**
 - Beckwith-Wiedemann Syndrome **ORPHA116**
 - Bardet-Biedl syndrome **ORPHA110**
 - And **other diagnoses**: check our [Core Registry diagnosis and conditions dictionary](#) for the full list
- Non-Syndromic Genetic Obesity **ORPHA98267**
 - Congenital Leptin Resistance **ORPHA179490**
 - Leptin receptor gene deficiency **ORPHA179494**
 - Melanocortin 4 receptor deficiency **ORPHA71529**
 - Prohormone convertase I deficiency **ORPHA71528**
 - Pro-opiomelanocortin deficiency **ORPHA71526**
 - CEP19 deficiency **ORPHA397615**
 - Obesity due to congenital leptin deficiency **ORPHA66628**
 - SIM1 deficiency **ORPHA369873**
 - Severe early-onset obesity-insulin resistance syndrome due to SH2B1 deficiency **ORPHA329249**

In this guide, we will show you how to use the module step by step

Register in the Core registry



Go to <https://eurreb.eu/>

EuRRECa
European Registries for
Rare Endocrine Conditions

EuRR-Bone
European Registries for Rare
Bone and Mineral Conditions

What are you looking for?

MEDICAL

more data,

Home About News Registries Patients Contact

Access →

Welcome

The European Registries for Rare Endocrine and Bone Conditions consists of EuRRECa and EuRR-Bone. The registries are aimed at maximising the opportunity for all patients, health care professionals, and researchers to participate and use high quality, patient-centred registries for rare endocrine and bone/mineral conditions. They work closely together and with Endo-ERN and ERN BOND and are supported by patients, researchers, clinicians, scientific societies, patient societies to build this database.

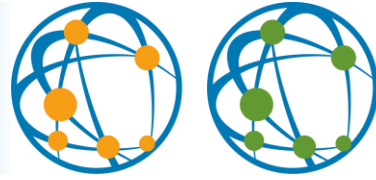
Upcoming Events

SEP 21	ESPE 2023 Annual Meeting September 21 st - September 23 rd , 2023
MAY 11	ECE 2024 Annual Meeting May 11 th - May 14 th , 2024
MAY 24	ECTS 2024 Congress May 24 th - May 28 th , 2024



e-REC
Core-Registry
Information

If you have no account yet, you can request the access [here](#) or choose “information” from the “access” button

Register in the Core registry



Follow the [self-registration link](#):

e-Reporting of Rare Conditions (e-REC) and Core Registry

New User Registration Request

Fields marked with * are mandatory

* Application Role Requested ☐ e-REC Reporter ☐ Core Registry Clinical Contributor

Title

* Surname

* Given Name

Middle Names

* Email (and User Name)

Password must be at least 8 characters
Password must contain both lower and upper case letters
Password must contain at least one numeric character
Password must contain at least one of the following symbols: @ # ! ? € \$ % & _ + - =

* Password

* Confirm Password

Telephone

I am the Centre Lead for this Centre ☐

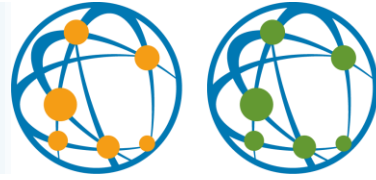
Filter Centres by Country (optional)

* Centre


You need an access to the Core registry to use the module

Fill in the mandatory information.
Your request will be approved as soon as possible.

Login to the Core registry



Go to <https://eureb.eu/>



What are you looking for?



more data,

[Home](#) [About](#) [News](#) [Registries](#) [Patients](#) [Contact](#) [Access](#)

Welcome

The European Registries for Rare Endocrine and Bone Conditions consists of EuRRECa and EuRR-Bone. The registries are aimed at maximising the opportunity for all patients, health care professionals, and researchers to participate and use high quality, patient-centred registries for rare endocrine and bone/mineral conditions. They work closely together and with Endo-ERN and ERN BOND and are supported by patients, researchers, clinicians, scientific societies, patient societies to build this database.

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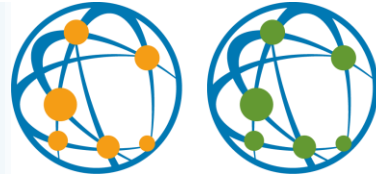
e-REC

Core-Registry


Information


Login to the Core registry using this button and your credentials

Login to the Core registry




Choose clinician login and then provide your credentials:


**EuRRECa**
European Registries for
Rare Endocrine Conditions

**EuRR-Bone**
European Registries for Rare
Bone and Mineral Conditions

Core Registry



**EuRRECa**
European Registries for
Rare Endocrine Conditions

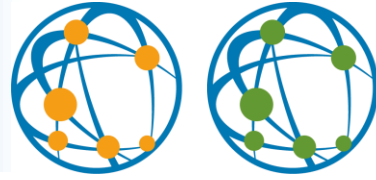
**EuRR-Bone**
European Registries for Rare
Bone and Mineral Conditions

Core Registry

Provide your credentials and 6 digit PIN,
if needed, [reset your password](#)

You will need to download
OTP authenticator

Add a new patient



Core Registry

Dashboard

Patients

Centres

Centre Users

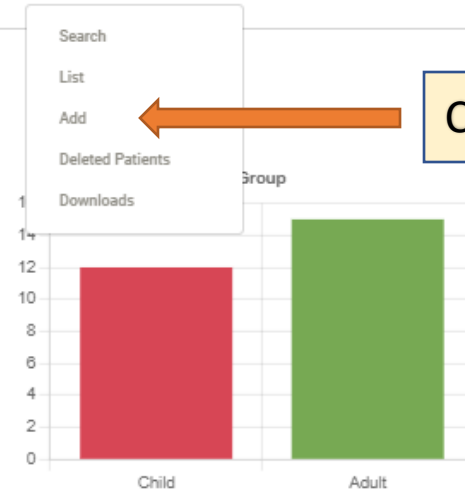
Clinician Dashboard

Patients in Centre: EuRR-Bone-Test

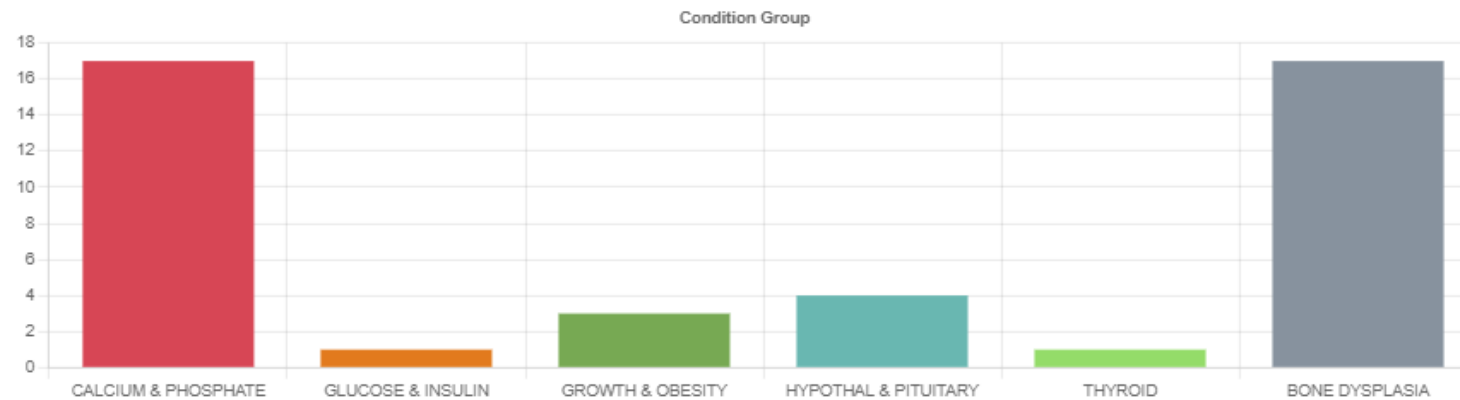
Patients registered by you: 2

Patients registered in your centre: 27

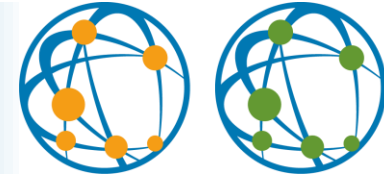
Patients with outstanding actions: 0



Click here



Fill in the Common Data Elements



Mandatory fields

Fields marked with * are mandatory

- * Consent for Core Registry
- * Date of Birth
- * Condition Group (select all that apply)

Select **“Growth and Obesity”**



Pseudonymised ID (e.g. SPIDER)

Sex at Birth

Current Gender

Country of Birth

Country of Usual Residence

Patient Follow-up Status

Date of Death

Primary Cause of Death

Can be contacted for research purposes by clinician responsible for patient

Data can be shared for research purposes

Can be contacted for collecting Patient Reported Outcomes

Patient would like access to Core Registry

Consent for Newsletters

☒ Opt-in [?](#) ☐ Opt-out [?](#)

dd-mm-jjjj

☐ ADRENAL [?](#) ☐ CALCIUM & PHOSPHATE [?](#) ☐ GLUCOSE & INSULIN [?](#) ☐ GENETIC ENDOCRINE TUMOURS [?](#) ☒ GROWTH & OBESITY [?](#)
☐ HYPOTHAL & PITUITARY [?](#) ☐ SEX DEVELOPMENT [?](#) ☐ THYROID [?](#) ☐ BONE DYSPLASIA [?](#)

☐ Male ☐ Female ☐ Other ☒ Unknown

☐ Male ☐ Female ☐ Non-binary ☐ Other ☐ Asked but unknown

NETHERLANDS

NETHERLANDS

☐ Patient active ☐ Patient inactive ☐ Patient care suspended ☐ Patient care terminated ☐ Deceased ☒ Unknown

dd-mm-jjjj

- Select -

☐ Yes ☐ No ☐ Not Known

☐ Yes ☐ No ☐ Not Known

☐ Yes ☐ No ☐ Not Known

☐ Yes ☐ No ☐ Not Known

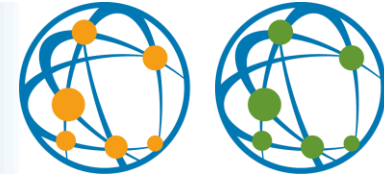
☐ Yes ☐ No ☐ Not Known



SAVE

Save

Go to the Patient Condition section



Edit Patient

Patient ID -



Edit To Do

Fields marked with * are mandatory

* Consent for Core Registry

* Date of Birth

* Condition Group (select all that apply)

Pseudonymised ID (e.g. SPIDER)

Sex at Birth

Current Gender

Country of Birth

Country of Usual Residence

Patient Follow-up Status

Date of Death










Primary Cause of Death

Can be contacted for research purposes by clinician responsible for patient

Data can be shared for research purposes

☒ Opt-in  ☐ Opt-out 

dd-mm-yyyy 

☐ ADRENAL  ☐ CALCIUM & PHOSPHATE  ☐ GLUCOSE & INSULIN  ☐ GENETIC ENDOCRINE TUMOURS 
☒ GROWTH & OBESITY  ☐ HYPOTHAL & PITUITARY  ☐ SEX DEVELOPMENT  ☐ THYROID  ☐ BONE DYSPLASIA 

☐ Male ☐ Female ☐ Other ☒ Unknown


☐ Male ☐ Female ☐ Non-binary ☐ Other ☐ Asked but unknown

NETHERLANDS 

NETHERLANDS 

☐ Patient active ☐ Patient inactive ☐ Patient care suspended ☐ Patient care terminated ☐ Deceased ☒ Unknown

dd-mm-yyyy

- Select - 

☐ Yes ☐ No ☐ Not Known

☐ Yes ☐ No ☐ Not Known

GROWTH & OBESITY

Generic Outcomes

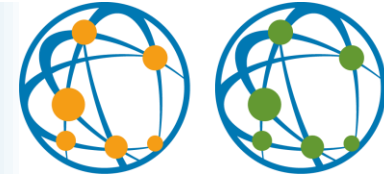
Documents

Audit

Patient List

A navigation menu will appear, click on **“Growth and Obesity”**

Edit the Patient Condition section



EuRECa
European Registries for
Rare Endocrine Conditions



EuRR-Bone
European Registries for Rare
Bone and Mineral Conditions

Core Registry

Dashboard Patients ▾ Centres ▾ Centre Users ▾

Edit Patient Condition

Core Data

Generic Outcomes

Documents

Audit

Patient List

Patient ID - Date of Birth -

01



Edit To Do

Growth and Genetic Obesity

Senior Clinician < 18 - N/A

Senior Clinician ≥ 18 - N/A

e-REC ID

First Contact with Centre

Clinician Responsible for Patient

Date of First Clinical Manifestations

Select a Clinician Responsible
for the patient

Primary Condition

Specific Diagnosis

- Select -

- Silver-Russell Syndrome
- Noonan Syndrome
- GH Resistance syndromes
- Overgrowth Syndrome
- Syndromic Genetic Obesity
- Non-Syndromic Genetic Obesity

The full hierarchy of Conditions and Specific Diagnoses can be found in the

How Was Diagnosis Reached

Date of Diagnosis

Participation in Detailed Disease Registry

☐ Yes ☐ No ☐ Not Known

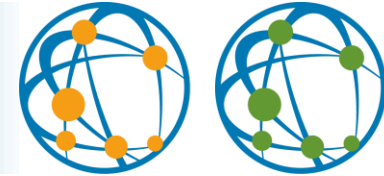
- Select either “Syndromic or Non-Syndromic Genetic Obesity”
- Select a Specific Diagnosis from the list

Save

Cancel

Save

Access the Condition-specific Module



Edit Patient Condition

Patient ID
01

Date of Birth -



Edit To Do

Growth and Genetic Obesity

Senio - N/A

Senior Clinician ≥ 18 - N/A

e-REC ID

First Contact with Centre

Clinician Responsible for Patient

Date of First Clinical Manifestations

Primary Condition

Specific Diagnosis

The full hierarchy of Conditions and Specific Diagnoses can be found in the [Core Registry Conditions Dictionary](#)

How Was Diagnosis Reached

☐ Clinical ☐ Biochemistry ☐ Genetic ☐ Histology ☐ CT ☐ MRI ☐ PET ☐ USS ☐ X-Ray ☐ Other ☐ Not Known

Date of Diagnosis

Participation in Detailed Disease Registry

☐ Yes ☐ No ☐ Not Known

Core Data

Generic Outcomes

Diagnosis-specific Outcomes

Documents

Audit

Patient List

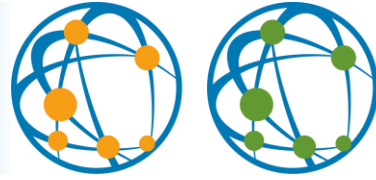


Click here to fill in the
disease-specific module

Save

Cancel

Fill in a Diagnosis-specific outcome



Core Registry

[Dashboard](#)

[Patients](#) ▾

[Centres](#) ▾

[Centre Users](#) ▾

Diagnosis-specific Outcomes

[Core Data](#)

[GROWTH & OBESITY](#)

[Generic Outcomes](#)

[Documents](#)

[Audit](#)

[Patient List](#)

Patient ID - · Date of Birth

Growth and Genetic Obesity

No Outcomes found

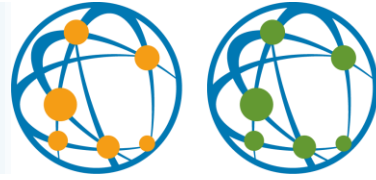
New Outcome Language

English ▾

New Outcome

Click here to fill in the
new outcome for the
disease-specific module

Fill in the data into the module and save



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Bone and Mineral Conditions

Core Registry

Dashboard

Patients ▾

Centres ▾

Centre Users ▾

Add Diagnosis-specific Outcome

Patient ID -

Date of Birth -

Condition Group - Growth and Genetic Obesity

Questionnaire: Rare Obesity - PW & PWL syndrome - V3 Published October/22

New Outcome

Core data fields	Parental data	Genetics	Clinical phenotype	Comorbidities	Medication	Other therapies
Assessment Date		?			dd-mm-jjjj	
Genetic finding Prader-Willi and Prader-Willi-like syndrome					- Select -	
Other (freetext)		?				
Type of genetic variant					- Select -	

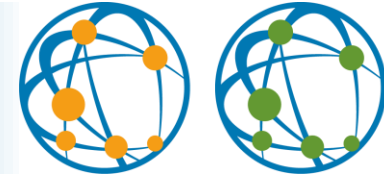
Save

Back



Save

Give the Patient access to the Core Registry



Core Registry

Dashboard Patients Centres Users Centre Users Patient Users Reference Data

Edit Patient

Patient ID -

1 Edit To Do

Fields marked with * are mandatory

* Consent for Core Registry

* Date of Birth

* Condition Group (select all that apply)

Pseudonymised ID (e.g. SPIDER)

Sex at Birth

Current Gender

Country of Birth

Country of Usual Residence

Patient Follow-up Status

Date of Death

Primary Cause of Death

☒ Opt-in ? ☐ Opt-out ?

☐ ADRENAL ? ☒ CALCIUM & PHOSPHATE ? ☐ GLUCOSE & INSULIN ? ☐ GENETIC ENDOCRINE TUMOURS ?
☐ GROWTH & OBESITY ? ☐ HYPOTHAL & PITUITARY ? ☐ SEX DEVELOPMENT ? ☐ THYROID ?
☐ BONE DYSPLASIA ?

☒ Male ☐ Female ☐ Other ☐ Unknown

☒ Male ☐ Female ☐ Non-binary ☐ Other ☐ Asked but unknown

NETHERLANDS ▼

NETHERLANDS ▼

☐ Patient active ☐ Patient inactive ☐ Patient care suspended ☐ Patient care terminated ☐ Deceased ☒ Unknown

mm/dd/yyyy

- Select - ▼

GROWTH & OBESITY

Patient Access

Generic Outcomes

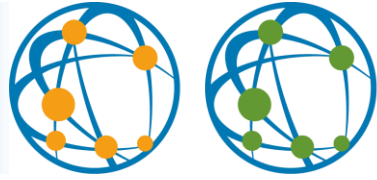
Diagnosis-specific Outcomes

Audit

Patient List

Give access to your patient
*if consent was given in the Common
Data Elements section

Contact us!



Please do not hesitate to contact us by e-mail at registries@lumc.nl in case of any questions

We invite you to join our regularly drop-in sessions <https://eurreb.eu/>