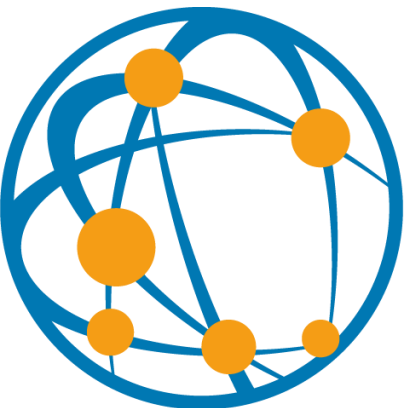
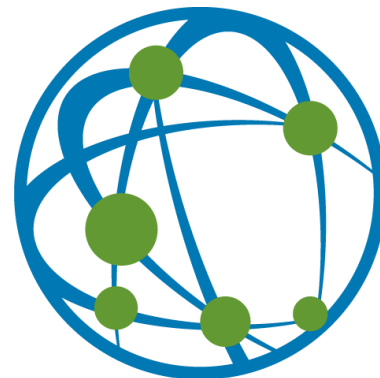


How to use the Melorheostosis module in the Core registry



EuRRECa

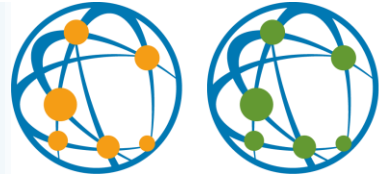
European Registries for
Rare Endocrine Conditions



EuRR-Bone

European Registries for Rare
Bone and Mineral Conditions

Melorheostosis module

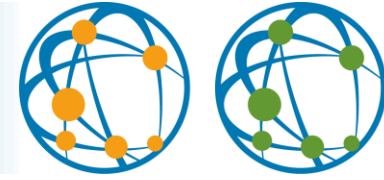


This condition-specific module is open for the following diagnoses:

- Melorheostosis (ORPHA2485),
- Melorheostosis with osteopoikilosis (ORPHA1879),
- Buschke-Ollendorff syndrome (ORPHA1306)
- Isolated osteopoikilosis (ORPHA166119)

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

Register in the Core registry



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

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

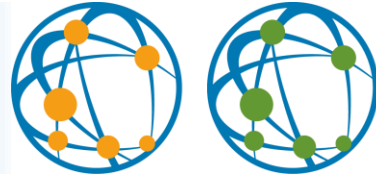
SEP 21	ESPE 2023 Annual Meeting September 21 st - September 23 rd , 2023
MAY 11	ECE 2024 Annual Meeting May 11 th - May 14 th , 2024
MAY 24	ECTS 2024 Congress May 24 th - May 28 th , 2024

Navigation menu: Home, About, News, Registries, Patients, Contact, Access →


Dropdown menu: 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](#):

 **EuRRECa**
European Registries for
Rare Endocrine Conditions

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

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

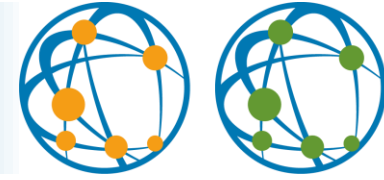
Filter Centres by Country (optional)

* Centre

You need an access to 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/>

The screenshot shows the top navigation bar of the website. On the left are the logos for EuRECa (European Registries for Rare Endocrine Conditions) and EuRR-Bone (European Registries for Rare Bone and Mineral Conditions). To the right is a search bar with the placeholder text 'What are you looking for?'. Below the logos is a large banner image with the word 'MEDICAL' and 'more data,'. At the bottom of the banner is a navigation menu with links: Home, About, News, Registries, Patients, and Contact. To the right of the menu is a green 'Access ->' button. Below this button is a dropdown menu with three items: 'e-REC', 'Core-Registry', and 'Information'. The 'Core-Registry' item is circled in red, and an orange arrow points to it from the right.

Welcome

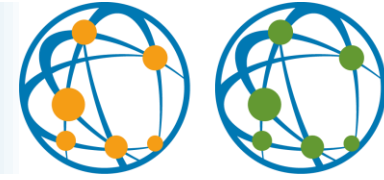
The European Registries for Rare Endocrine and Bone Conditions consists of EuRECa and EuRR-Bone. The registries are aimed at maximising the opportunity for all patients, health care professionals, and researchers to participate and use high quality, patient-centred registries for rare endocrine and bone/mineral 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 21st - September 23rd, 2023
- MAY 11** ECE 2024 Annual Meeting
May 11th - May 14th, 2024
- MAY 24** ECTS 2024 Congress
May 24th - May 28th, 2024


Login to 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


[Click here for Patient Login](#)

[Click here for Clinician Login](#)

For further information visit www.eureb.eu



 **EuRRECa**
European Registries for
Rare Endocrine Conditions

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

Core Registry

Clinician Login

User Name

Password

Forgotten password? To reset your password please click on the following [Reset Password link](#)

6 digit PIN from your mobile device

Click on the following link for further information about OTP authentication: [OTP Authentication](#)

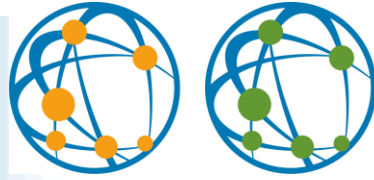
New Users

To request access to the system please click on the following [Self-Registration link](#)

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

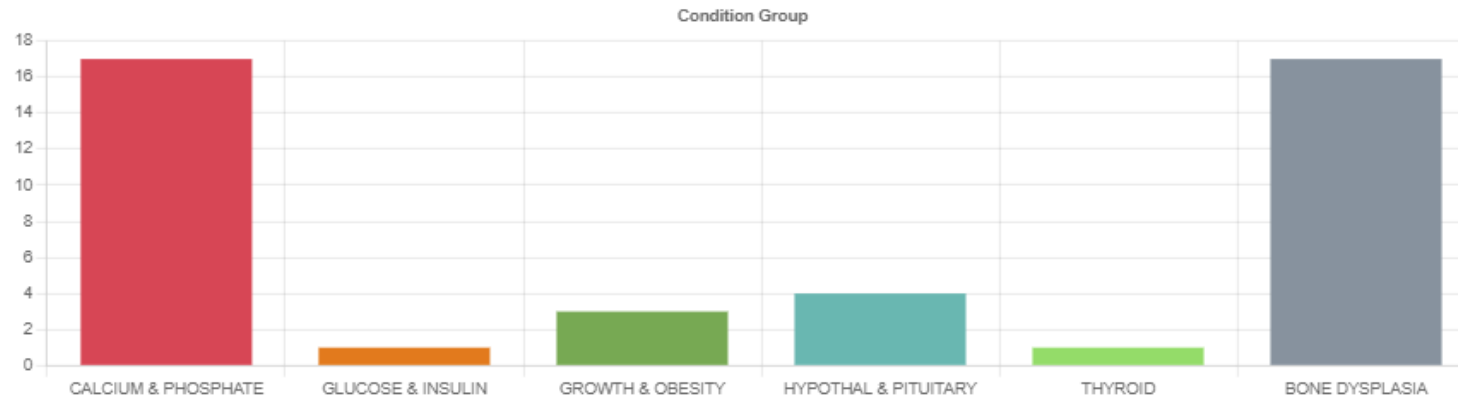
Patients registered in your centre: 27

Patients with outstanding actions: 0

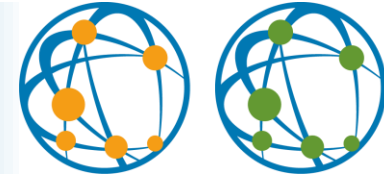
- Search
- List
- Add
- Deleted Patients
- Downloads



Click here



Fill in the Common Data Elements



Mandatory fields →

Add Patient

Fields marked with * are mandatory

* Consent for Core Registry

* Date of Birth

* Condition Group (select all that apply)

If applicable →

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

Save

Cancel

Choose "Bone dysplasia" →

Opt-in [?] Opt-out [?]

ADRENAL [?] CALCIUM & PHOSPHATE [?] GLUCOSE & IN:

BONE DYSPLASIA [?]

Male Female Other Unknown

Male Female Non-binary Other Asked but unknc

NETHERLANDS

NETHERLANDS

Patient active Patient inactive Patient care suspended

mm/dd/yyyy

- Select -

Yes No Not Known

Yes No Not Known

Yes No Not Known

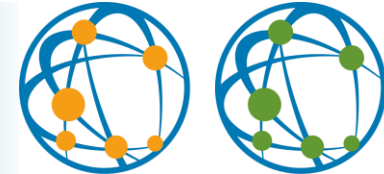
Yes No Not Known

Yes No Not Known

SAVE



Go to condition group section



Core Registry

Dashboard Patients Centres Centre Users Mariya Cherenko - EuRR-Bone-Test

Edit Patient

Patient ID - 4275



Edit To Do

Fields marked with * are mandatory

* Consent for Core Registry

Opt-in Opt-out

* Date of Birth

* Condition Group (select all that apply)

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

Pseudonymised ID (e.g. SPIDER)

Sex at Birth

Male Female Other Unknown

Current Gender

Male Female Non-binary Other Asked but unknown

Country of Birth

Country of Usual Residence

Patient Follow-up Status

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

Date of Death

Primary Cause of Death

Can be contacted for research purposes by clinician responsible for patient

Yes No Not Known

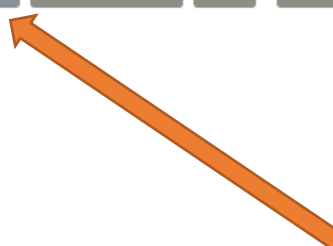
Data can be shared for research purposes

Yes No Not Known

Can be contacted for collecting Patient Reported Outcomes

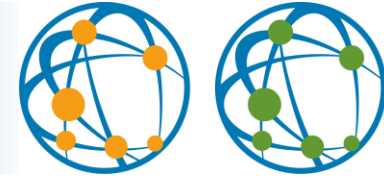
Yes No Not Known

BONE DYSPLASIA Generic Outcomes Audit Patient List



Click here to fill in the bone dysplasia tab

Edit the Patient Condition section



Core Registry

Dashboard

Patients

Centres

Centre Users

Mariya Cherenko - EuRR-Bone-Test

Edit Patient Condition

Core Data

CALCIUM & PHOSPHATE

Patient Access

Generic Outcomes

Diagnosis-specific Outcomes

Audit

Patient List

Patient ID - 551 Date of Birth

- [Redacted]



Edit To Do

Bone Dysplasia

Senior Clinician < 18 - N/A

Senior Clinician ≥ 18 - N/A

If applicable →

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 the Primary condition - "PBD with increased bone density", for Specific diagnosis – choose from the list

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

Detailed Disease Registry

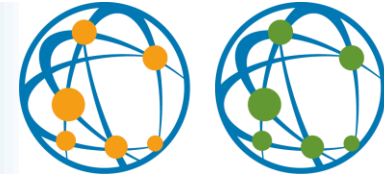
Detailed Disease Registry Patient ID



Save

Cancel

Access the Disease-specific Module



Core Registry

Dashboard Patients Centres Users Centre Users Patient Users Reference

Edit Patient Condition

Core Data Patient Access Generic Outcomes **Diagnosis-specific Outcomes** Audit Patient List

Patient ID - 4270 Date of Birth

- [Redacted]

! Edit To Do

Bone Dysplasia

Senior Clinician < 18 - N/A

Senior Clinician ≥ 18 - N/A

e-REC ID

First Contact with Centre

04/12/2022



Clinician Responsible for Patient

Natasha Appelman-Dijkstra



Date of First Clinical Manifestations

01/01/2020



Primary Condition

Primary bone dysplasia with increased bone density



Specific Diagnosis

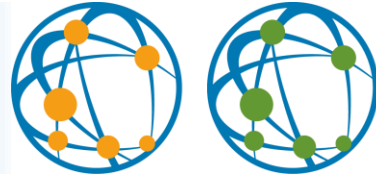
Melorheostosis



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

Click here to fill in the disease-specific module

Fill in a Disease-specific outcome



Core Registry

Dashboard Patients Centres Users Centre Users Patient Users Reference Data

Diagnosis-specific Outcomes

Core Data

BONE DYSPLASIA

Patient Access

Generic Outcomes

Audit

Patient List

Patient ID - 4270 Date of Birth -

Bone Dysplasia

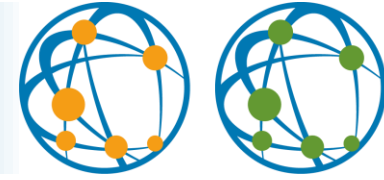
Supplemental material to complete this module

No Outcomes found

New Outcome

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

Fill in the data into the module and save



Add Diagnosis-specific Outcome

Patient ID - [redacted] Date of Birth - [redacted] Condition Group - Bone Dysplasia

Questionnaire: Melorheostosis, Buschke-Ollendorff syndrome, Isolated osteopoikilosis

New Outcome

Date of Birth	[redacted]	e-REC ID		Primary Condition	
Current Gender	Male	Clinician Responsible for Patient	Natasha Appelman-Dijkstra	Primary bone dysplasia with increased bone density	
				Specific Diagnosis	Melorheostosis
				Date of Diagnosis	2022-04-12

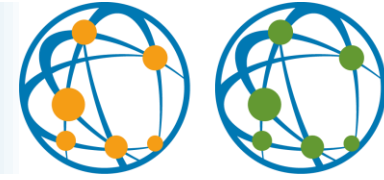
General Clinical features Genetic analysis Fractures Surgery Medication MSK-HQ BPI

Family ID ?

Proband Not Known Yes No

Family history Negative Positive - Maternal Positive - Paternal Positive - Unknown Unknown

Give an access to the platform to your patient



Core Registry

Dashboard Patients Centres Users Centre Users Patient Users Reference Data

Diagnosis-specific Outcomes

Core Data BONE DYSPLASIA Patient Access Generic Outcomes Audit Patient List

Patient ID - 4270 Date of Birth -

Bone Dysplasia

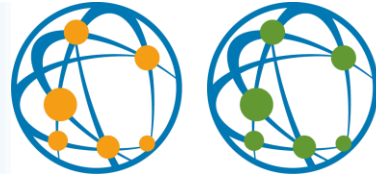
Supplemental material to complete this module

No Outcomes found

New Outcome

Give an access to your patient (in case of consent) - you need to know patient's e-mail for this

Fill in the generic outcomes



Core Registry

Dashboard Patients Centres Users Centre Users Patient Users Reference Data Mariya Cherenko - Leiden Univers

Generic Outcomes

Core Data BONE DYSPLASIA Patient Access Diagnosis-specific Outcomes Audit Patient List

Patient ID - 450 Date of Birth -

EQ-5D BPI-SF PROMIS Profile WHO ICF Patient Reported Outcome Request Settings

Show 10 entries Search:

Created Date	Completed By	Type	Mobility	Self Care	Activity	Pain	Anxiety	EQ VAS	Actions
2022-11-02	Dr. Ana Priego	EQ-5D-5L	2	2	2	2	1	71	
2021-03-24	Dr. Ana Priego	EQ-5D-Y		1	1	2	2	74	
2021-03-24	Dr. Ana Priego	EQ-5D-5L		2	2	1	1	80	

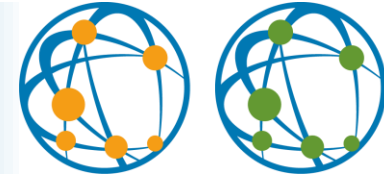
Current Patient EQ-5D Request Settings: EQ-5D-5L every 3 months, starting on 2022-06-30

[Patient EQ-5D Request Settings](#) [Create EQ-5D](#)

Previous 1 Next

Click here to fill in the new generic outcome for your patient: mobility, EQ-5D or other

Choose the frequency for PROMs



Core Registry

Dashboard Patients Centres Users Centre Users Patient Users Reference Data Mariya Cherenko - Le

Generic Outcomes

Core Data BONE DYSPLASIA Patient Access Diagnosis-specific Outcomes Audit

Patient ID - 450 Date of Birth - [REDACTED]

EQ-5D BPI-SF PROMIS Profile WHO ICF Patient Reported Outcome Request Settings

Create or edit requests for the Patient to complete generic questionnaires

Show 10 entries

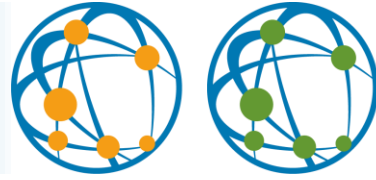
Generic Outcome Questionnaire	Request Frequency (months)	Request Start Date	Actions
WHO-ICF Mobility	9	2022-11-01	Edit Delete

Previous 1

Add Outcome Request

Click here to choose the frequency of email requests to the Patient to self-complete a Patient Generic Outcome Questionnaire

Choose the frequency for PROMs



Core Registry Dashboard Patients Centres

Generic Patient Reported Outcome Request Settings

These settings control the frequency of email requests to the Patient to self-complete a Patient Generic Outcome Questionnaire

Outcome Questionnaire WHO-ICF Mobility

Request Frequency 6 months

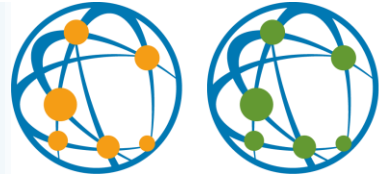
Date of Next Request mm/dd/yyyy

Save Cancel

2022-11-01

Click here to choose the frequency of email requests to the Patient to self-complete a Patient Generic Outcome Questionnaire

Contact us!



Please don't hesitate to contact us by e-mail registries@lumc.nl in case of any questions.

Or join our regularly drop-in sessions <https://eurreb.eu/>