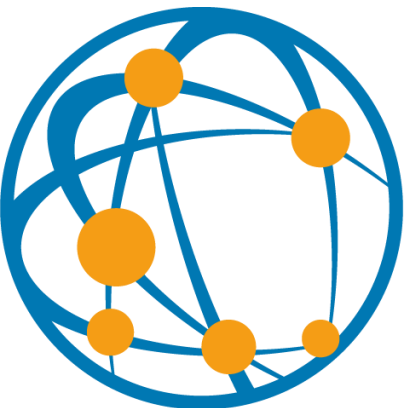
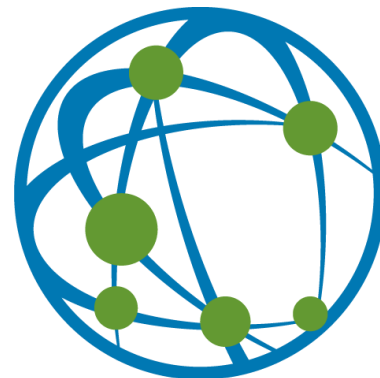


# How to use the FD/MAS module in the Core registry



**EuRRECa**

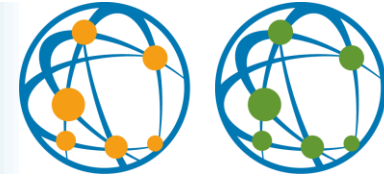
European Registries for  
Rare Endocrine Conditions



**EuRR-Bone**

European Registries for Rare  
Bone and Mineral Conditions

# 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?

Home About News Registries Patients Contact

Access →

e-REC  
Core-Registry  
Information

## Welcome

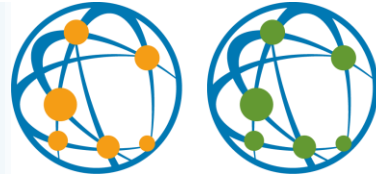
The European Registries for Rare Endocrine and Bone Conditions consists of EuRRECa and EuRR-Bone. The registries are aimed at maximising the opportunity for all patients, health care professionals, and researchers to participate and use high quality, patient-centred registries for rare endocrine and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

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

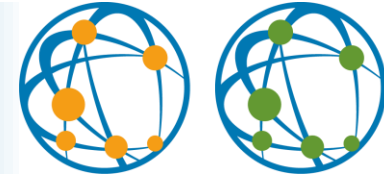
Filter Centres by Country (optional)

\* Centre

You need an access to 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 text 'What are you looking for?'. Below the logos is a large banner with a blue background and the word 'MEDICAL' in a glowing font. At the bottom of the banner is the text 'more data,'. Below the banner is a navigation menu with links for Home, About, News, Registries, Patients, and Contact. To the right of the menu is a green 'Access ->' button. Below the 'Access ->' 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

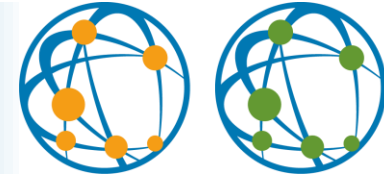
The European Registries for Rare Endocrine and Bone Conditions consists of EuRECa and EuRR-Bone. The registries are aimed at maximising the opportunity for all patients, health care professionals, and researchers to participate and use high quality, patient-centred registries for rare endocrine and bone/mineral 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  
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May 11<sup>th</sup> - May 14<sup>th</sup>, 2024
- MAY 24** ECTS 2024 Congress  
May 24<sup>th</sup> - May 28<sup>th</sup>, 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](http://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](#)

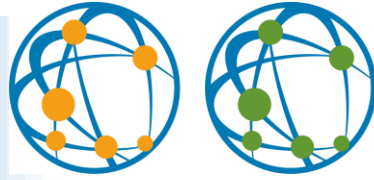
New Users

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

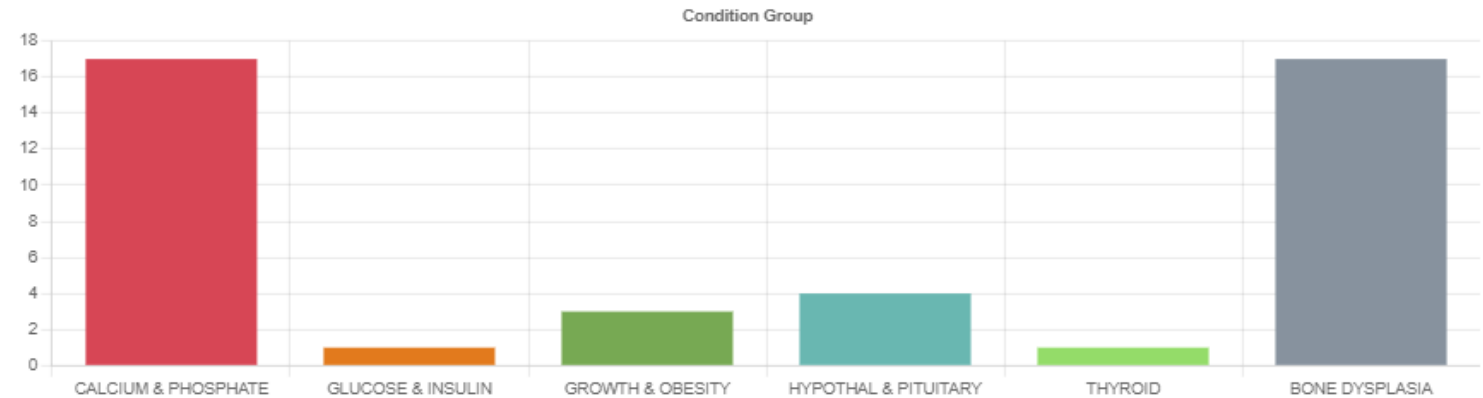
Patients registered in your centre: 27

Patients with outstanding actions: 0

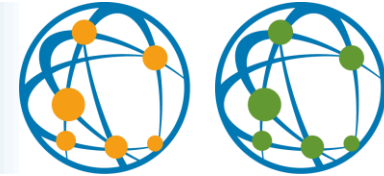
- Search
- List
- Add
- Deleted Patients
- Downloads



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

Save Cancel

Choose "Bone dysplasia"

Opt-in  Opt-out

[Redacted]

- ADRENAL
- CALCIUM & PHOSPHATE
- GLUCOSE & IN
- BONE DYSPLASIA

[Redacted]

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

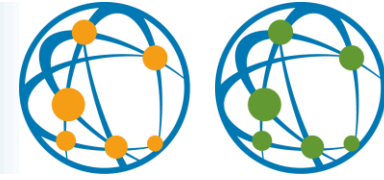
Yes  No  Not Known

Yes  No  Not Known

Yes  No  Not Known

Yes  No  Not Known

# Go to the 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

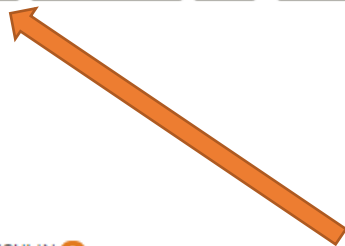
Yes  No  Not Known

BONE DYSPLASIA

Generic Outcomes

Audit

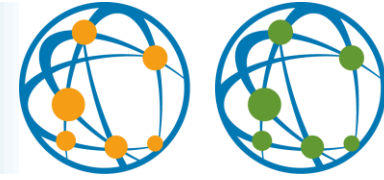
Patient List



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

Core Data Patient Access Generic Outcomes Audit Patient List

## Edit Patient Condition

Patient ID  Date of Birth -   
11-11

### 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

Select a Clinician Responsible for the patient

Date of Condition Onset

Select the Primary condition - "PBD with disorganized development of skeletal components", for Specific diagnosis – choose from the list

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

Detailed Disease Registry

Detailed Disease Registry Patient ID

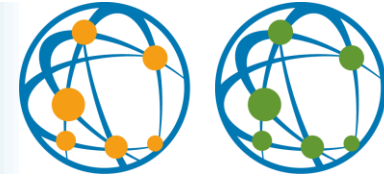
Biobank Sample Available for Research

Yes  No  Not Known

Biobank Details

↓

# Access the Disease-specific Module



Core Registry

Dashboard Patients - Centres - Centre Users -

Mariya Cherenko - EuRR-Bone

## Edit Patient Condition

Patient ID [redacted] Date of Birth [redacted] 11-11

[Edit To Do](#)

[Core Data](#) [Patient Access](#) [Generic Outcomes](#) [Diagnosis-specific Outcomes](#) [Audit](#) [Patient List](#)

### Bone Dysplasia

Senior Clinician < 18 - N/A

Senior Clinician ≥ 18 - N/A

e-REC ID

First Contact with Centre

Clinician Responsible for Patient

Date of Condition Onset

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

Detailed Disease Registry

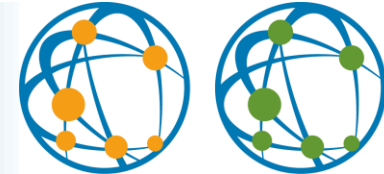
Detailed Disease Registry Patient ID

Biobank Sample Available for Research

Yes  No  Not Known

Click here to fill in the disease-specific module

# Fill in the new 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

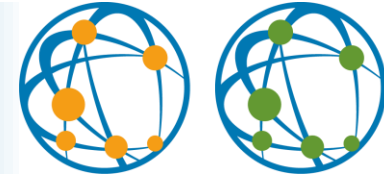
Supplemental material to complete this module

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



Core Registry

Dashboard Patients - Centres - Centre Users -

## Add Diagnosis-specific Outcome

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

Questionnaire: Fibrous dysplasia/McCune Albright module - V2 26/08/22

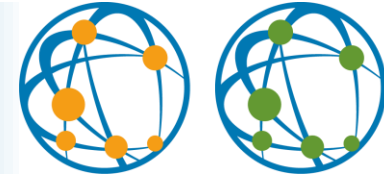
New Outcome

Anthropometry	Basic disease module	Disease characteristics	McCune-Albright syndrome	Craniofacial FD	Therapy
Assessment Date	?	?	?	?	?
Height (cm)	?	?	?	?	?
Height SDS	?	?	?	?	?
Weight (kg)	?	?	?	?	?
Weight SDS	?	?	?	?	?
BMI	?	?	?	?	?
BMI SDS	?	?	?	?	?

Fill in all the tabs which are applicable

Save Back

# Give an access to the platform to your patient



## Edit Patient Condition

Patient ID  Date of Birth -  ! [Edit To Do](#)  
11-11

### Bone Dysplasia

Senior Clinician < 18 - N/A

Senior Clinician ≥ 18 - N/A

e-REC ID

First Contact with Centre

Clinician Responsible for Patient

Date of Condition Onset

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

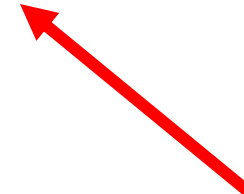
Detailed Disease Registry

Detailed Disease Registry Patient ID

Biobank Sample Available for Research  Yes  No  Not Known

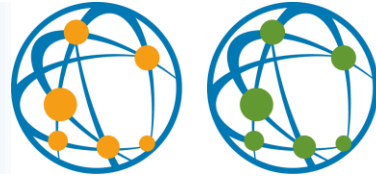
Biobank Details

[Core Data](#) [Patient Access](#) [Generic Outcomes](#) [Audit](#) [Patient List](#)



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	

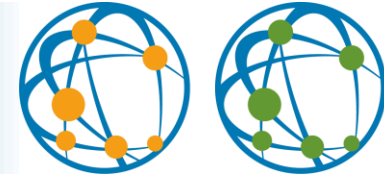
Current Patient EQ-5D Request Settings: EQ-5D-5L every 3 months, starting on 2022-06-30

[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

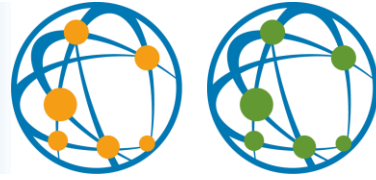
Generic Outcome Questionnaire	Request Frequency (months)	Request Start Date	Actions
WHO-ICF Mobility	9	2022-11-01	Edit Delete

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

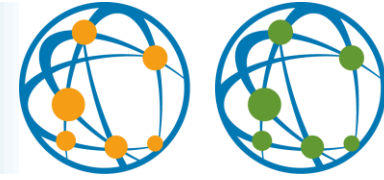
Save Cancel

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](mailto:registries@lumc.nl) in case of any questions.

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