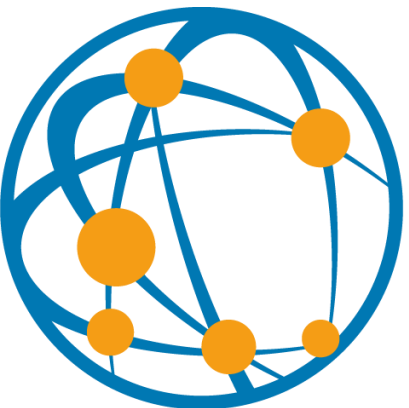
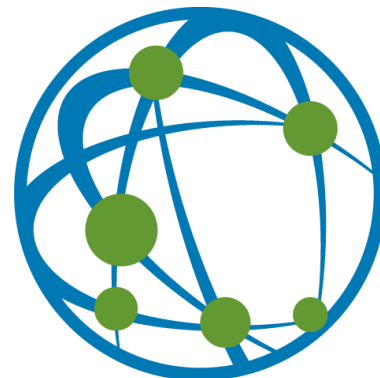


# How to use the Parathyroid carcinoma module in Core registry



**EuRRECa**

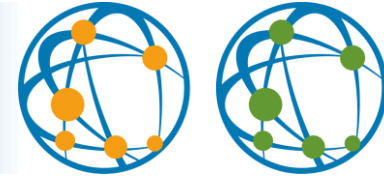
European Registries for  
Rare Endocrine Conditions



**EuRR-Bone**

European Registries for Rare  
Bone and Mineral Conditions

# Register in 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.

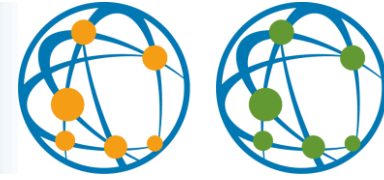
**Upcoming Events**

|           |   |
|-----------|---|
| SEP<br>21 | <b>ESPE 2023 Annual Meeting</b><br>September 21 <sup>st</sup> - September 23 <sup>rd</sup> , 2023 |
| MAY<br>11 | <b>ECE 2024 Annual Meeting</b><br>May 11 <sup>th</sup> - May 14 <sup>th</sup> , 2024              |
| MAY<br>24 | <b>ECTS 2024 Congress</b><br>May 24 <sup>th</sup> - May 28 <sup>th</sup> , 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

# Login in Core registry



Follow the self-registration link:

 **EuRECa**  
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

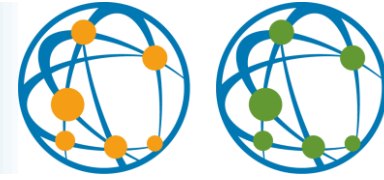
Filter Centres by Country (optional)

\* 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 in Core registry



Go to <https://eureb.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<sup>st</sup> - September 23<sup>rd</sup>, 2023
- MAY 11** ECE 2024 Annual Meeting  
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

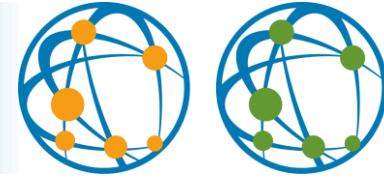
e-REC

Core-Registry

Information

Login to Core registry using this button and your credentials

# Login in 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](#)

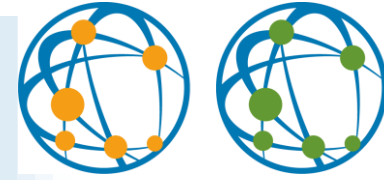
New Users

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



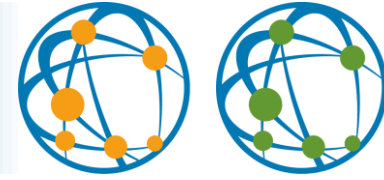
Click here



Condition Group



# Fill in common data elements



## Add Patient

Fields marked with \* are mandatory

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

Mandatory fields →

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  
"Calcium and  
Phosphate"

Opt-in <sup>?</sup>  Opt-out <sup>?</sup>

mm/dd/yyyy

- CALCIUM & PHOSPHATE <sup>?</sup>  GLUCOSE & INSULIN <sup>?</sup>  GENETIC ENDOCRINE TUMOURS <sup>?</sup>  GROWTH & OBESITY <sup>?</sup>  
 HYPOTHAL & PITUITARY <sup>?</sup>  SEX DEVELOPMENT <sup>?</sup>  THYROID <sup>?</sup>  BONE DYSPLASIA <sup>?</sup>

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 -

Yes  No  Not Known

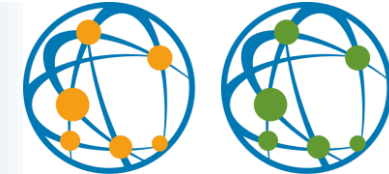
Yes  No  Not Known

Yes  No  Not Known

Yes  No  Not Known

Yes  No  Not Known

# Go to condition group section



## Edit Patient

Patient ID - 4626



Fields marked with \* are mandatory

\* Consent for Core Registry

\* Centre

\* 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

Can be contacted for collecting Patient Reported Outcomes

Patient would like access to Core Registry

Consent for Newsletters

Opt-in  Opt-out

EB51 - Leiden-LUMC

mm/dd/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

mm/dd/yyyy

- Select -

Yes  No  Not Known

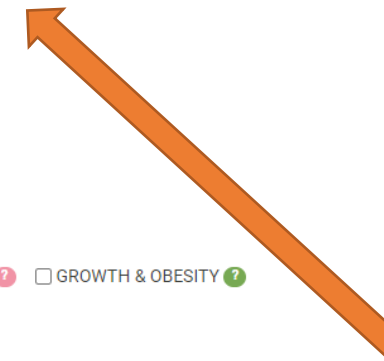
Yes  No  Not Known

Yes  No  Not Known

Yes  No  Not Known

Yes  No  Not Known

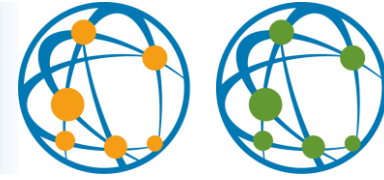
CALCIUM & PHOSPHATE Generic Outcomes Documents Audit Patient List



Click here to fill in the "calcium and phosphate" tab



# Fill in primary condition and specific diagnosis



## Edit Patient Condition

Core Data

Generic Outcomes

Patient ID - 4626 Date of Birth - [REDACTED]

Edit To Do

### Calcium and Phosphate

Senior Clinician < 18 - N/A

Senior Clinician ≥ 18 - N/A

If REC ID  
applicable

First Contact with Centre

mm/dd/yyyy

Clinician Responsible for Patient

Not Assigned

Select a Clinician Responsible for the patient

Date of First Clinical Manifestations

mm/dd/yyyy

Primary Condition

Specific Diagnosis

Select the Primary condition -  
“Hyperparathyroidism including  
parathyroid cancer” and for Specific  
diagnosis - “Parathyroid carcinoma” or  
“Hyperparathyroidism-jaw tumor  
syndrome”

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

Date of Diagnosis

Participation in Detailed Disease Registry

Yes  No  Not Known

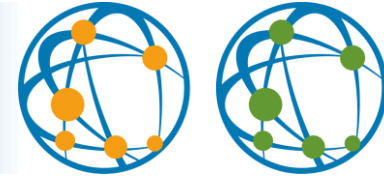
Detailed Disease Registry

Detailed Disease Registry Patient ID



Save Cancel

# Access the Disease-specific Module



Core Registry

Dashboard Patients Centres Users Centre Users Patient Users Reference Data

Mariya Cherenko - Leiden University Medica

Edit Patient Condition

Patient ID - 4167 Date of Birth - [redacted]

Core Data

**CALCIUM & PHOSPHATE**

Patient Access

Generic Outcomes

Diagnosis-specific Outcomes

Documents

Audit

Patient List

## Calcium and Phosphate

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

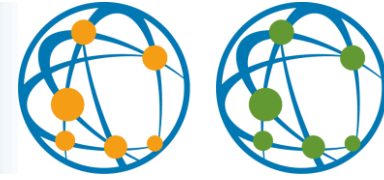
Yes  No  Not Known

Detailed Disease Registry

Detailed Disease Registry Patient ID

Click here to fill in the diagnosis-specific outcomes

# Fill in the new outcome



Diagnosis-specific Outcomes

Core Data **CALCIUM & PHOSPHATE** Generic Outcomes Documents Audit Patient List

Patient ID - 4626 Date of Birth [REDACTED]

Calcium and Phosphate

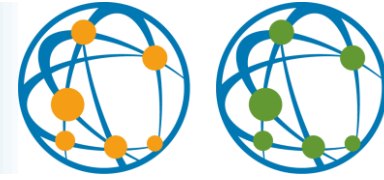
No Outcomes found

New Outcome Language

[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 Users Centre Users Patient Users Reference

## Add Diagnosis-specific Outcome

Patient ID - 4165 Date of Birth - [redacted] Condition Group - Calcium and Phosphate

Questionnaire: Parathyroid cancer

New Outcome

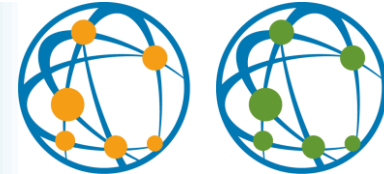
|                |            |                                   |                 |  |
|----------------|------------|-----------------------------------|-----------------|--|
| Date of Birth  | [redacted] | e-REC ID                          |                 | Primary Condition                                |
| Current Gender | Male       | Clinician Responsible for Patient | Mariya Cherenko | Hyperparathyroidism including parathyroid cancer |
|                |            |                                   |                 | Specific Diagnosis Parathyroid carcinoma         |
|                |            |                                   |                 | Date of Diagnosis                                |

General Diagnosis Imaging at time of diagnosis Medical treatment Surgery and histology PHPQoL Recurrence 1 Recurrence 2 Next recurrences PHPQoL recurred

### General

|                           |   |  |   |
|---------------------------|---|--|---|
| Assessment Date           | ? | mm/dd/yyyy   | 🗓 |
| Smoking habit             | ? | - Select -   | ▼ |
| Packyear                  | ? |  |   |
| Alcohol intake            |   | <input type="radio"/> yes <input type="radio"/> no <input type="radio"/> unknown |   |
| Units of alcohol per week | ? |  |   |
| Height (cm)               | ? |  |   |
| Weight (kg)               | ? |  |   |
|                           | ? |  |   |

# Give an access to the platform to your patient



Core Registry

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

CALCIUM & PHOSPHATE

Patient Access

Generic Outcomes

Diagnosis-specific Outcomes

Audit

Patient List

## Edit Patient

Patient ID - [redacted] 1 Edit To Do

Fields marked with \* are mandatory

\* Consent for Core Registry

Opt-in ?  Opt-out ?

\* Date of Birth

[redacted]

\* Condition Group (select all that apply)

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

EUPID (European Patient ID)

test Cherenko2

Sex at Birth

Male  Female  Other  Unknown

Current Gender

Male  Female  Non-binary  Other  Asked but unknown

Country of Birth

NETHERLANDS

Country of Usual Residence

NETHERLANDS

Patient Follow-up Status

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

Date of Death

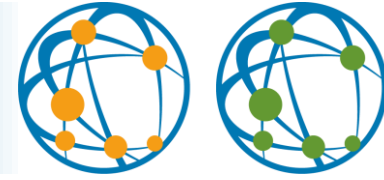
mm/dd/yyyy

Primary Cause of Death

- Select -

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

# 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/>