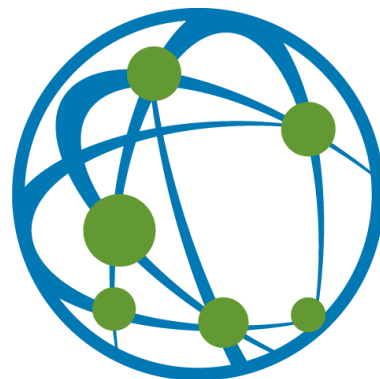


Using the Pseudohypoparathyroidism Conditions module in the Core registry



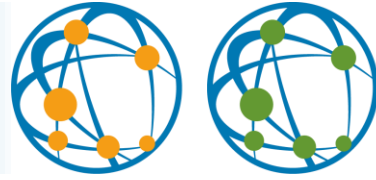
EuRRECa

European Registries for
Rare Endocrine Conditions



EuRR-Bone

European Registries for Rare
Bone and Mineral Conditions

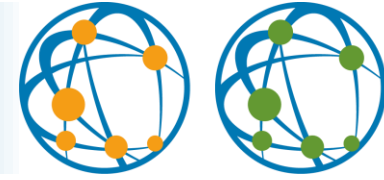


This condition-specific module is open for the following diagnoses

- Pseudohypoparathyroidism (iPPSD) **ORPHA97593**
- Pseudopseudohypoparathyroidism (iPPDS2) **ORPHA79445**
- Pseudohypoparathyroidism type 1A (IPPSD2) **ORPHA79443**
- Pseudohypoparathyroidism type 1B (IPPSD3) **ORPHA94089**
- Pseudohypoparathyroidism type 1C (IPPSD2) **ORPHA79444**
- Pseudohypoparathyroidism type 2 **ORPHA94090**
- Pseudohypoparathyroidism with Albright hereditary osteodystrophy **ORPHA457059**
- Pseudohypoparathyroidism without Albright hereditary osteodystrophy **ORPHA457062**
- Acrodystostosis Type 1 (iPPDS4) **ORPHA950**
- Acrodystostosis Type 2 (iPPDS5) **ORPHA950**
- Blomstrand chondrodysplasia (iPPSD1) **ORPHA50945**
- Eiken disease (iPPSD1) **ORPHA79106**
- Hypertension and brachydactyly Syndrome (iPPSD6) **ORPHA1276**
- Pseudohypoparathyroidism, all known genes excluded (iPPSDx) **ORPHA97593**

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

Register in the Core registry

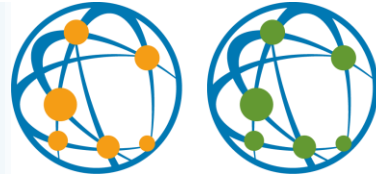


Go to <https://eurreb.eu/>


The screenshot shows the EURREB website homepage. At the top 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 navigation menu with links for Home, About, News, Registries, Patients, and Contact. A green "Access" button is located to the right of the navigation menu. A dropdown menu is open under the "Access" button, showing three options: "e-REC", "Core-Registry", and "Information". The "Information" option is circled in red, and an orange arrow points from this circle to a text box on the right. The main content area features a large graphic with the word "MEDICAL" and the text "more data,". Below the graphic is a "Welcome" section with a paragraph of text. To the right of the "Welcome" section is an "Upcoming Events" section with three event listings: "ESPE 2023 Annual Meeting" (September 21st - September 23rd, 2023), "ECE 2024 Annual Meeting" (May 11th - May 14th, 2024), and "ECTS 2024 Congress" (May 24th - May 28th, 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](#):

 **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

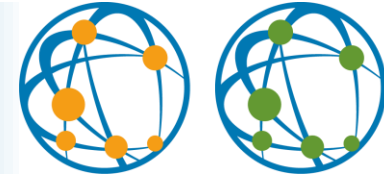
Filter Centres by Country (optional)

* 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 header of the website includes the logos for EuRECa (European Registries for Rare Endocrine Conditions) and EuRR-Bone (European Registries for Rare Bone and Mineral Conditions). A search bar is located on the right with the placeholder text 'What are you looking for?'. The navigation menu contains links for Home, About, News, Registries, Patients, and Contact. A green 'Access ->' button is positioned above a dropdown menu that lists 'e-REC', 'Core-Registry', and 'Information'. The 'Core-Registry' option is highlighted with a red circle, and an orange arrow points to it from the right side of the image.

Welcome

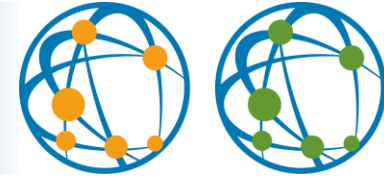
The European Registries for Rare Endocrine and Bone Conditions consists of EuRECa and EuRR-Bone. The registries are aimed at maximising the opportunity for all patients, health care professionals, and researchers to participate and use high quality, patient-centred registries for rare endocrine and bone/mineral 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.eurreb.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](#)

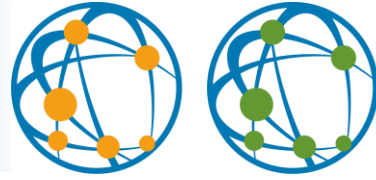
New Users

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

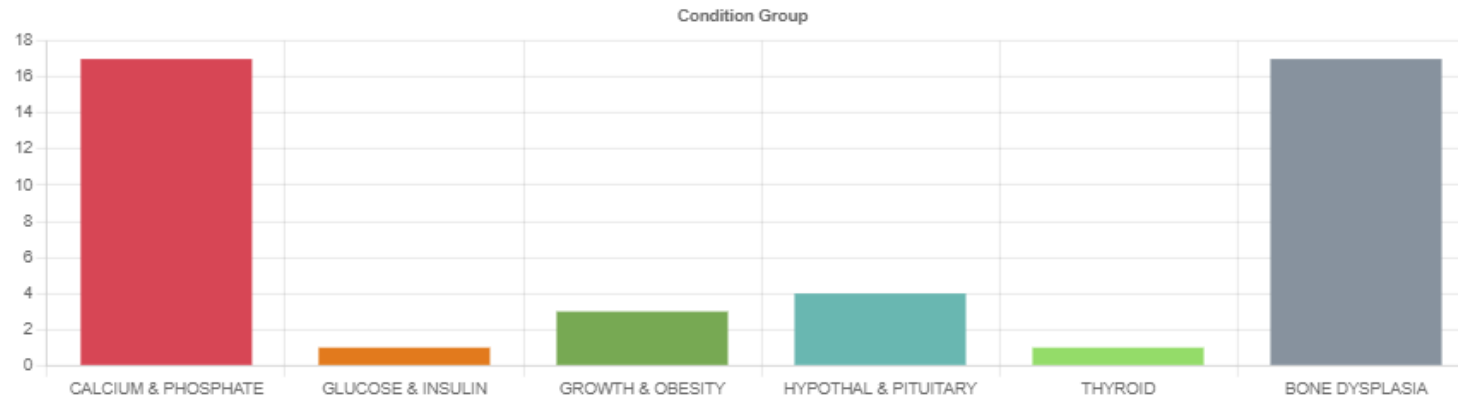
Patients registered in your centre: 27

Patients with outstanding actions: 0

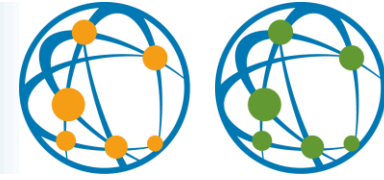
- Search
- List
- Add
- Deleted Patients
- Downloads



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)

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-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

Yes No Not Known

Yes No Not Known

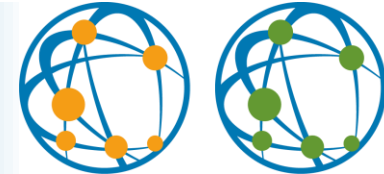
Yes No Not Known

Select "Calcium & Phosphate"

SAVE

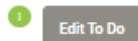
Save Cancel

Go to the Patient Condition section



Edit Patient

Patient ID - 2647



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

Can be contacted for collecting Patient Reported Outcomes

Patient would like access to Core Registry

Consent for Newsletters

CALCIUM & PHOSPHATE

BONE DYSPLASIA

Patient Access

Generic Outcomes

Diagnosis-specific Outcomes

Audit

Patient List

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

Yes No Not Known

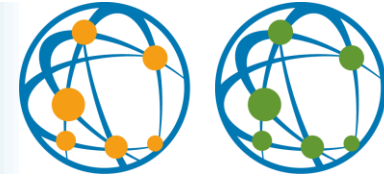
Yes No Not Known

Yes No Not Known

Save

A navigation menu will appear, click on "Calcium & Phosphate"

Edit the Patient Condition section



Edit Patient Condition

Core Data Generic Outcomes Documents Audit Patient List

Patient ID · Date of Birth ·
01

 Edit To Do

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 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

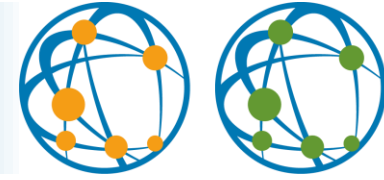
Yes No Not Known

Select a Clinician Responsible for the patient

- Select the “Pseudohypoparathyroidism” as Primary Condition
- Select a Specific Diagnosis from the list

Save Cancel Save

Access the Disease-specific Module

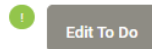


Core Registry

Dashboard Patients ▾ Centres ▾ Centre Users ▾

Edit Patient Condition

Patient ID - 01
Date of Birth



- Core Data
- Generic Outcomes
- Diagnosis-specific Outcomes
- Documents
- Audit
- Patient List



Click here to fill in the disease-specific module

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 First Clinical Manifestations

Primary Condition

Specific Diagnosis

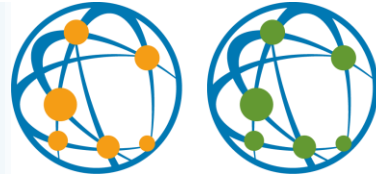
The full hierarchy of Conditions and Specific Diagnoses can be found in the [Core Registry Conditions Dictionary](#)

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

Fill in a Disease-specific outcome



Core Registry

Dashboard

Patients ▾

Centres ▾

Users ▾

Centre Users ▾

Patient Users ▾

Reference Data ▾

Mariya Cherenko - Li

Diagnosis-specific Outcomes

Core Data

CALCIUM & PHOSPHATE

Generic Outcomes

Audit

Patient ID

Date of Birth -

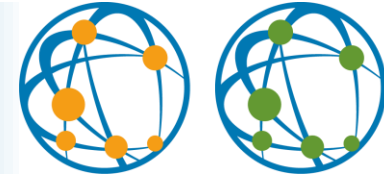
Calcium and Phosphate

No Outcomes found

New Outcome

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

Fill in the data into the module and save



Patient ID - Date of Birth Condition Group - Calcium and Phosphate

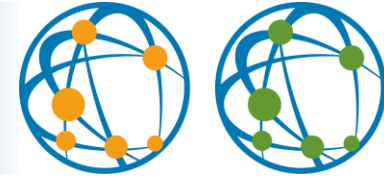
Questionnaire: iPPSD outcome questionnaire v3 - iPPSD outcome questionnaire v3

New Outcome

Date of Birth	<input type="text"/>	e-REC ID	<input type="text"/>	Primary Condition	Pseudohypoparathyroidism
Current Gender	<input type="text"/>	Clinician Responsible for Patient	<input type="text"/>	Specific Diagnosis	Pseudohypoparathyroidism (iPPSD)
				Date of Diagnosis	<input type="text"/>

Perinatal features	Genetic findings	Endocrine Status	Auxology parameters	Clinical findings	Clinical musculoskeletal features	Radiological musculoskeletal features	Other Radiological findings	Therapy	Surgical interventions
Assessment Date	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Age at Assessment Date	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Gene variant (cDNA)	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Gene variant (protein)	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Gene	<ul style="list-style-type: none"><input type="checkbox"/> PTH1R<input type="checkbox"/> GNAS, maternal allele<input type="checkbox"/> GNAS, paternal allele<input type="checkbox"/> GNAS, parental allele not known<input type="checkbox"/> abnormal methylation at least at GNAS A/B DMR<input type="checkbox"/> PRKAR1A<input type="checkbox"/> PDE4D<input type="checkbox"/> PDE3D<input type="checkbox"/> Other<input type="checkbox"/> No genetic analysis<input type="checkbox"/> Unknown								

Give the Patient access to the Core Registry



Core Registry

Dashboard Patients Centres Users Centre Users Patient Users Reference Data

CALCIUM & PHOSPHATE

Patient Access

Generic Outcomes

Diagnosis-specific Outcomes

Audit

Patient List

Edit Patient

Patient ID -



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

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

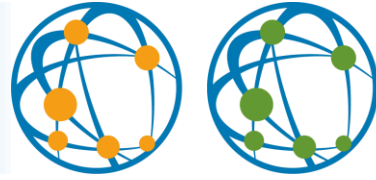
mm/dd/yyyy

Primary Cause of Death

- Select -

Give 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/>