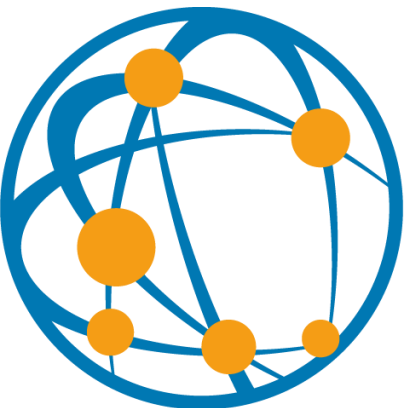
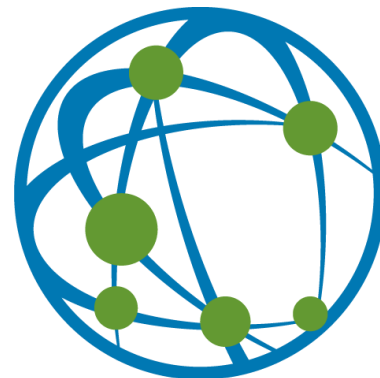


Using the Pituitary Tumour module in the Core Registry



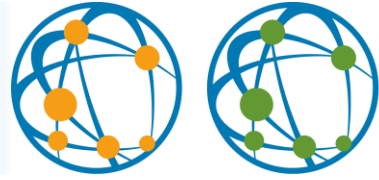
EuRRECa

European Registries for
Rare Endocrine Conditions



EuRR-Bone

European Registries for Rare
Bone and Mineral Conditions

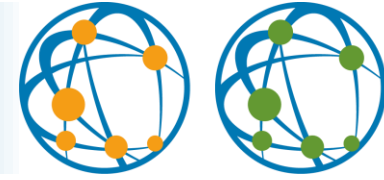


This condition-specific module is open for the following diagnoses

- Pituitary adenoma **ORPHA99408**
- Cushing disease **ORPHA96253**
- Familial isolated pituitary adenoma **ORPHA314777**
- Functioning gonadotropic adenoma **ORPHA91348**
- Functioning pituitary adenoma **ORPHA314753**
- Mixed functioning pituitary adenoma **ORPHA314759**
- Non-functioning pituitary adenoma **ORPHA91349**
- Null pituitary adenoma **ORPHA314790**
- Prolactinoma **ORPHA2965**
- Silent pituitary adenoma **ORPHA314786**
- Somatomammotropinoma **ORPHA314769**
- TSH-secreting pituitary adenoma **ORPHA91347**
- Acromegaly **ORPHA963**
- Pituitary gigantism **ORPHA99725**
- X-linked acrogigantism **ORPHA300373**
- Pituitary carcinoma **ORPHA300385**

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 →

- e-REC
- Core-Registry
- Information

Welcome

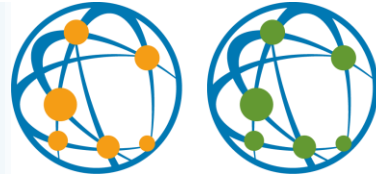
The European Registries for Rare Endocrine and Bone Conditions consists of EuRRECa and EuRR-Bone. The registries are aimed at maximising the opportunity for all patients, health care professionals, and researchers to participate and use high quality, patient-centred registries for rare endocrine and 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	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


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](#):

 **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

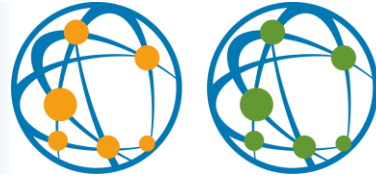
Filter Centres by Country (optional)

* 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 to the Core registry



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

The header of the website includes the logos for EuRRECa (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 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

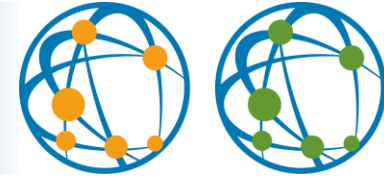
The European Registries for Rare Endocrine and Bone Conditions consists of EuRRECa and EuRR-Bone. The registries are aimed at maximising the opportunity for all patients, health care professionals, and researchers to participate and use high quality, patient-centred registries for rare endocrine and 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
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May 11th - May 14th, 2024
- MAY 24** ECTS 2024 Congress
May 24th - May 28th, 2024


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

[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](#)

[Log in](#)

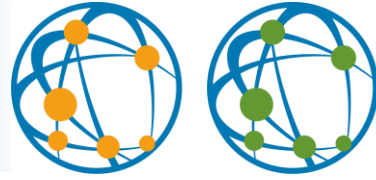
New Users

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

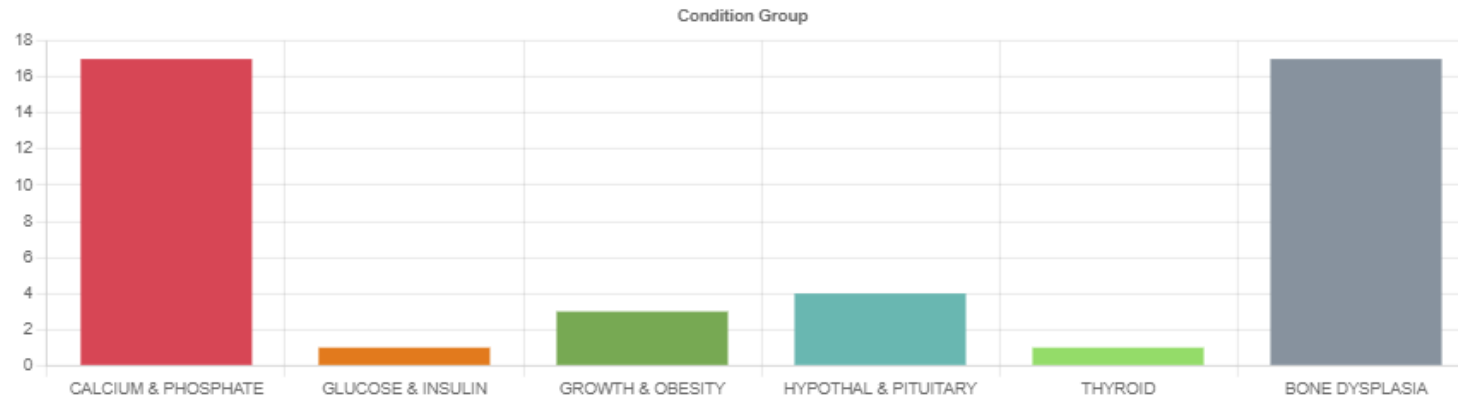
Patients registered in your centre: 27

Patients with outstanding actions: 0

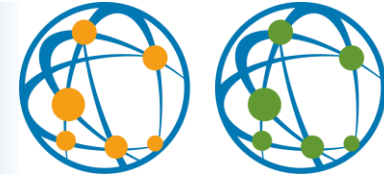
- Search
- List
- Add
- Deleted Patients
- Downloads



Click here



Fill in the Common Data Elements



Edit Patient

HYPOTHAL & PITUITARY Generic Outcomes Documents Audit Patient List

Patient ID - 4517

 **Edit To Do**

Fields marked with * are mandatory

* Consent for Core Registry

* Date of Birth

* Condition Group (select all that apply)

Mandatory fields

Select "Hypothal & Pituitary"

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 

- 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

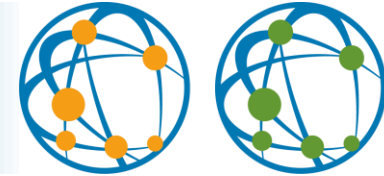
Yes No Not Known

Yes No Not Known

Save

SAVE

Go to the Patient Condition section



Core Registry

Dashboard Patients Centres Centre Users

Edit Patient

Patient ID - 4517



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

- 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

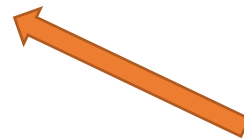
HYPOTHAL & PITUITARY

Generic Outcomes

Documents

Audit

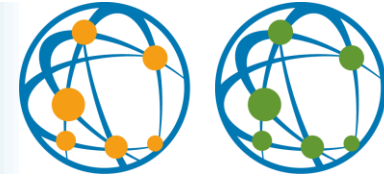
Patient List



A navigation menu will appear, click on **‘Hypothal & Pituitary’**

Save

Edit the Patient Condition section



Edit Patient Condition

Core Data Generic Outcomes Documents Audit Patient List

Patient ID Date of Birth

1 Edit To Do

Pituitary

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

- Select -
- Select -
- Pituitary adenoma
- Cushing disease
- Familial isolated pituitary adenoma
- Functioning gonadotropic adenoma
- Functioning pituitary adenoma
- Mixed functioning pituitary adenoma
- Non-functioning pituitary adenoma
- Null pituitary adenoma
- Prolactinoma
- Silent pituitary adenoma
- Somatotrophinoma
- TSH-secreting pituitary adenoma
- Acromegaly
- Pituitary gigantism
- X-linked acrogigantism
- Pituitary carcinoma

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

How Was Diagnosis Reached

Date of Diagnosis

Participation in Detailed Disease Registry

Detailed Disease Registry

Detailed Disease Registry Patient ID

Biobank Sample Available for Research

Biobank Details

Biobank Patient ID

Save

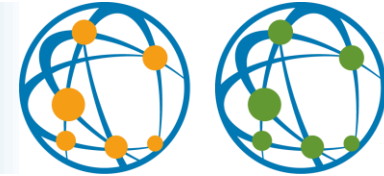
Save

Save

Select a Clinician Responsible for the patient

- Select "Pituitary Adenoma" as Primary Condition
- Select a Specific Diagnosis from the list

Access the Disease-specific Module



Core Registry

Dashboard Patients Centres Centre Users

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

Click here to fill in the disease-specific module

Edit Patient Condition

Patient ID Date of Birth

1 Edit To Do

Pituitary

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

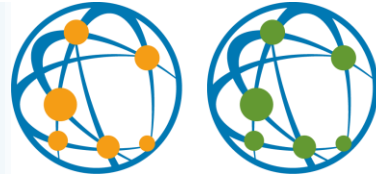
Date of Diagnosis

Participation in Detailed Disease Registry

Yes No Not Known

Save Cancel

Fill in a Disease-specific outcome



Core Registry

Dashboard

Patients ▾

Centres ▾

Centre Users ▾

Diagnosis-specific Outcomes

Core Data

HYPOTHAL & PITUITARY

Generic Outcomes

Documents

Audit

Patient List

Patient ID -

Date of Birth -

Pituitary

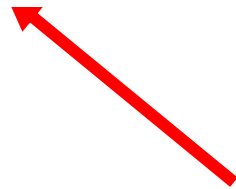
No Outcomes found

New Outcome Language

English

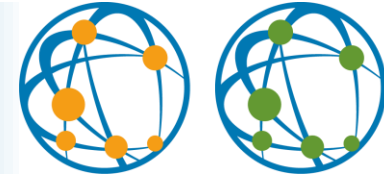
Edit Section Options

New Outcome



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

Fill in the data into the module and save



Add Diagnosis-specific Outcome

Patient ID - Date of Birth - Condition Group - Pituitary

Questionnaire: Pituitary tumour module - Pituitary tumour

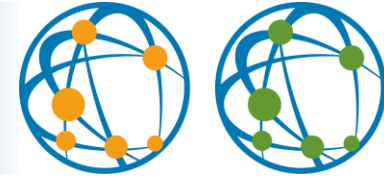
New Outcome

- Basic disease module
- Auxology parameters
- Endocrine manifestations
- Secreted hormones
- Visual impairment
- Imaging
- Genetics
- Histopathology
- Radiation
- Medical therapy
- Surgical outcomes

Assessment Date	?	<input type="text" value="dd-mm-yyyy"/>
What is the level of genetic disruption?		<input type="text" value="- Select -"/>
Isolated and familial pituitary tumours	?	<input type="text" value="- Select -"/>
Paragangliomas, pheochromocytomas and pituitary tumours	?	<input type="text" value="- Select -"/>
Other genes associated with pituitary tumours		<input type="text" value="- Select -"/>
Other (freetext)	?	<input type="text"/>

[Save](#) [Back](#)

Give the Patient access to the Core Registry



Core Registry

Dashboard Patients Centres Users Centre Users Patient Users Reference Data

HYPOTHAL & PITUITARY

Patient Access

Generic Outcomes

Diagnosis-specific Outcomes

Audit

Patient List

Edit Patient

Patient ID -

1

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

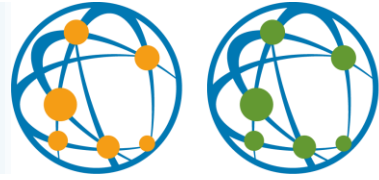
mm/dd/yyyy

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/>