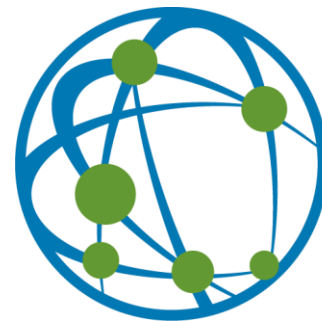


European Registries for Rare Endocrine and Bone conditions

ERN BOND Welcome Package



EuRRECa
European Registries for
Rare Endocrine Conditions



EuRR-Bone
European Registries for Rare
Bone and Mineral Conditions



Endo-ERN
European Reference Network
on Rare Endocrine Conditions

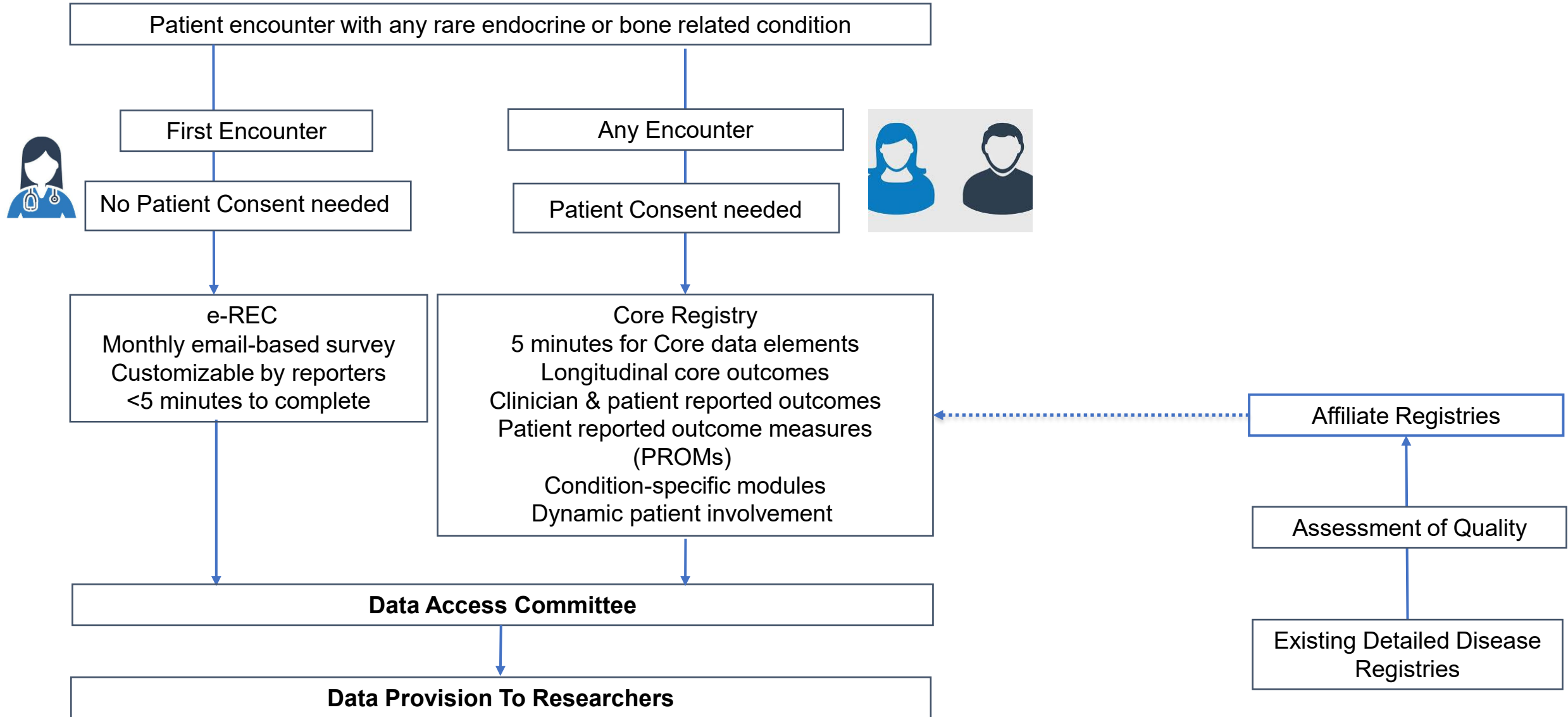
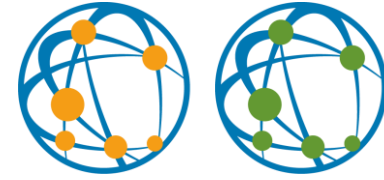


Co-funded by
the European Union



ERN BOND
EUROPEAN REFERENCE NETWORK
ON RARE BONE DISEASES

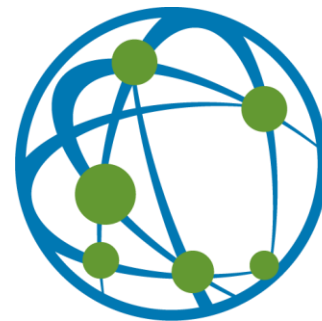
The Registries in a Nutshell



e-REC User guide



EuRRECa
European Registries for
Rare Endocrine Conditions

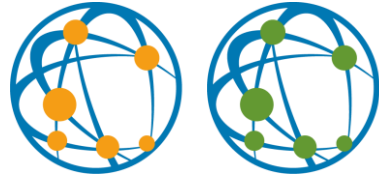


EuRR-Bone
European Registries for Rare
Bone and Mineral Conditions



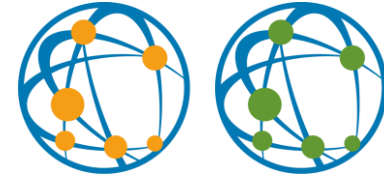
Endo-ERN
European Reference Network
on Rare Endocrine Conditions





- e-REC is an electronic reporting programme that only captures the number of **new** cases, suspected or confirmed, seen monthly at the participating centres.
- e-REC does not collect any personal data - no informed consent is needed.
- We expect you to report monthly. Reporting period for each quartal is open for one month after.
- You can report a new case as suspected. In this situation – save the report but do not submit it. Then you will be able to change the status to confirm or to exclude this case.
- **A new case can only be reported either as suspected or confirmed. The status of a suspected case can be changed later.**

How to Register as a User



1. Go to the [registration page](#)
2. Fill out all information
3. Select your Centre from the list

In case your centre is not in the list, add the following steps:

3. Select “ – My Centre is not listed – add Centre details –”
4. More questions will appear
5. Confirm with your colleagues who will be the Centre Lead. That person must register and select ‘I am the Centre Lead for this Centre’ *

New User Registration Request

Fields marked with * are mandatory

* Application Role Requested

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)

e-REC Reporter Core Registry Clinical Contributor

3

* Centre

4

* Centre

* Centre Name

* City

* Country

Address

- My Centre is not listed - add Centre details -

5

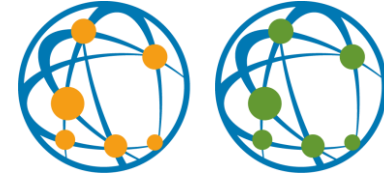
I am the Centre Lead for this Centre



Please provide details of at least one professional association, scientific society or network of clinical reference centres of which you are a current member

* If your Centre already exists, you cannot become a Centre Lead without consulting the current Centre Lead first

How to Use e-REC



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

 English 

- Home
- About
- News
- Registries
- Patients
- Contact

Access

- e-REC
- Core-Registry
- Information

Click here to log in

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

APR 22 **Registries Symposium 2024**
Monday 22 April 2024

APR 23 **SAVE THE DATE: Endo-ERN General Assembly 2024**
April 23rd - Wednesday 24 April 2024

MAY 11 **ECE 2024 Annual Meeting**
May 11th - Tuesday 14 May 2024

On the login page you will find a dashboard with a *live* case count by condition group and age

Use your e-mail address and password to log in, or reset the password if needed



e-Reporting of Rare Conditions (e-REC)



Total number of cases in e-REC by condition group

Condition group	Children(<18)	Adults(≥ 18)	Total
ADRENAL	330	1865	2195
BONE DYSPLASIA	469	515	984
CALCIUM & PHOSPHATE	276	543	819
GENETIC ENDOCRINE TUMOURS (incl. NETs)	130	600	730
GLUCOSE & INSULIN	330	146	476
GROWTH & OBESITY	521	42	563
HYPOTHAL & PITUITARY	624	5256	5880
SEX DEVELOPMENT	2932	1510	4442
THYROID	700	2327	3027
TOTAL	6312	12804	19116

Login

e-REC User Name

Password

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

[Log in](#)

New Users

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

For further information visit www.eurreb.eu or contact us at registries@lumc.nl



On the home page you will find the latest news and a list of your returns (submitted, open and in progress) With a deadline for reporting. You can view and/or download the returns if needed. **To start reporting – first go to the reporting setup section**



Latest News

Check your Reporting setup to be up-to-date!
Osteogenesis imperfecta pain study (Join Core registry)

e-REC Returns

Open Returns

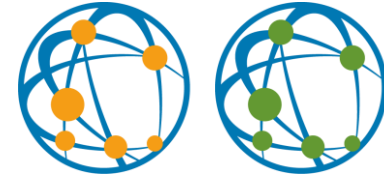
Reporting Month	Reporting Open From	Deadline for Reporting	Return Status	Actions
April 2024	2024-04-01	2024-07-31	Not Started	Complete Return
March 2024	2024-03-01	2024-04-30	Not Started	Complete Return
February 2024	2024-02-01	2024-04-30	Not Started	Complete Return
January 2024	2024-01-01	2024-04-30	Submitted	View Return Download Return

Previous Returns

View Previously Updated Cases

Reporting Month	Reporting Open From	Deadline for Reporting	Return Status	Actions
December 2023	2023-12-01	2024-01-31	Submitted	View Return Download Return

Download Multiple Returns



Reporting Setup

Please select the Age Group(s) and Conditions you intend to report on. Please note that some options may be unavailable as only one Reporter per Centre can report on a specific Condition for a specific Age Group. To see the list of users at your centre, click on Centre Users in the main menu.

Condition Groups

Thematic Groups

ADRENAL

GLUCOSE & INSULIN

GENETIC ENDOCRINE TUMOURS (incl. NETs)

GROWTH & OBESITY

HYPOTHAL & PITUITARY Adult (≥ 18): 7 Conditions selected

Condition	Child (< 18) +/-	Adult (≥ 18) +/-
Pituitary Adenoma [ORPHA99408] ?	<input type="checkbox"/> ?	<input checked="" type="checkbox"/>
Acromegaly [ORPHA963]	<input type="checkbox"/> ? Assigned to Dr. Ana Priego	<input checked="" type="checkbox"/>
Cushing disease [ORPHA96253]	<input type="checkbox"/> ?	<input checked="" type="checkbox"/>
Prolactinoma [ORPHA2965]	<input type="checkbox"/> ?	<input checked="" type="checkbox"/>
Non-functioning pituitary adenoma [ORPHA91349]	<input type="checkbox"/> ?	<input checked="" type="checkbox"/>
Combined pituitary hormone deficiencies, genetic forms [ORPHA95494] ?	<input type="checkbox"/> ?	<input type="checkbox"/> ?
Acquired Hypopituitarism [ORPHA95502]	<input type="checkbox"/> ?	<input checked="" type="checkbox"/>
Craniopharyngioma [ORPHA54595]	<input type="checkbox"/> ?	<input checked="" type="checkbox"/>

Scroll through the different Condition Groups by clicking on them and choose all the conditions you intend to report on. There is no limit of MTGs and conditions to be reported on.

Note: only one reporter per centre can report on a specific condition for a specific age group. You can also see to whom this condition is assigned to within your centre.

Note: you can change your reporting setup if needed, but only if there are no **open returns**. Otherwise, submit or delete your report and then change reporting setup

Complete your return



e-Reporting of Rare Conditions (e-REC)



Returns Reporting Setup Centre Reporters Centre Users

Dr. Mariya Cherenko ▾

Latest News

Check your Reporting setup to be up-to-date!

Osteogenesis imperfecta pain study (Join Core registry)

e-REC Returns

Open Returns

Reporting Month	Reporting Open From	Deadline for Reporting	Return Status	Actions ?
April 2024	2024-04-01	2024-07-31	Not Started	Complete Return
March 2024	2024-03-01	2024-04-30	Not Started	Complete Return
February 2024	2024-02-01	2024-04-30	Not Started	Complete Return
January 2024	2024-01-01	2024-04-30	Submitted	View Return Download Return

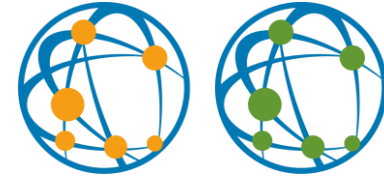
Previous Returns

[View Previously Updated Cases](#)

Reporting Month	Reporting Open From	Deadline for Reporting	Return Status	Actions
December 2023	2023-12-01	2024-01-31	Submitted	View Return Download Return

[Download Multiple Returns](#)





Return for December 2023

For suspected cases, save the Return as In Progress, then if the case is confirmed the return can be updated before submission

HYPOTHAL & PITUITARY

Condition	Suspected Cases - Child (< 18)	Confirmed Cases - Child (< 18)	Suspected Cases - Adult (≥ 18)	Confirmed Cases - Adult (≥ 18)
Pituitary Adenoma [ORPHA99408] ?			123	0
Acromegaly [ORPHA963]				
Cushing disease [ORPHA96253]			0	0
Prolactinoma [ORPHA2965]			0	0
Non-functioning pituitary adenoma [ORPHA91349]			0	0
Acquired Hypopituitarism [ORPHA95502]			0	0
Craniopharyngioma [ORPHA54595]			0	0

! Value must be less than or equal to 99.

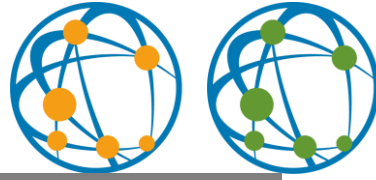
Enter the number of new cases seen during the month of interest at your centre by Condition/ORPHACODE. You cannot report more than 99 cases per condition.

When you report a case as suspected, you should confirm or exclude it later. **Do not report the same case twice.**

CALCIUM & PHOSPHATE

Condition	Suspected Cases - Child (< 18)	Confirmed Cases - Child (< 18)	Suspected Cases - Adult (≥ 18)	Confirmed Cases - Adult (≥ 18)
Hypocalcaemic vitamin D dependent rickets [ORPHA289157]	0	0		
Autosomal recessive hypophosphataemic rickets [ORPHA289176]			0	0

Submit your report



Returns Reporting Setup Centre Reporters Centre Users

Return for January 2024

For suspected cases, save the Return as In Progress, then if the case is confirmed the return can be updated before submission

HYPOTHAL & PITUITARY

Condition	Suspected Cases - Child (< 18)	Confirmed Cases - Child (< 18)	Suspected Cases - Adult (≥ 18)	Confirmed Cases - Adult (≥ 18)	Condition	Suspected Cases - Child (< 18)	Confirmed Cases - Child (< 18)	Suspected Cases - Adult (≥ 18)	Confirmed Cases - Adult (≥ 18)
Pituitary Adenoma [ORPHA99408] ?			0	0	Thyroid hormone signaling disorders				0
Acromegaly [ORPHA963]									0
Cushing disease [ORPHA96253]			1	0	Congenital Hyperthyroidism [ORPHA424]				0
Prolactinoma [ORPHA2965]			0	0	Non-metastatic thyroid carcinoma [ORPHA100088]				0
Non-functioning pituitary adenoma [ORPHA91349]			0	0					
Acquired Hypopituitarism [ORPHA95502]			2	0					
Craniopharyngioma [ORPHA54595]			0	0					

Note: once the report is submitted it cannot be edited anymore

Submit

When this Return is Submitted it will be locked and will no longer be editable. e-REC IDs will be generated and issued for the cases in the Return. Please confirm that you wish to Proceed.

Close Confirm

CALCIUM & PHOSPHATE

Condition	Suspected Cases - Child (< 18)	Confirmed Cases - Child (< 18)	Suspected Cases - Adult (≥ 18)	Confirmed Cases - Adult (≥ 18)
Hypocalcaemic vitamin D dependent rickets [ORPHA289157]	0	0		
Autosomal recessive hypophosphataemic rickets [ORPHA289176]			0	0

Save Submit and generate e-REC IDs Back

Return for February 2024

For suspected cases, save the Return as In Progress, then if the case is confirmed the return

HYPOTHAL & PITUITARY

Condition	Suspected Cases - Child (< 18)	Confirmed Cases - Child (< 18)	Suspected Cases - Adult (≥ 18)	Confirmed Cases - Adult (≥ 18)
Pituitary Adenoma [ORPHA99408] ?				
Acromegaly [ORPHA963]				
Cushing disease [ORPHA96253]				
Prolactinoma [ORPHA2965]				
Non-functioning pituitary adenoma				
Non-metastatic thyroid carcinoma [ORPHA100088]				

Return Submitted

Return submitted.

The following e-REC IDs have been generated for this Return. They will be emailed to you and can also be accessed by viewing the Submitted Return from the Returns screen.

Acromegaly [ORPHA963] - Adult (≥ 18) - Suspected Cases

202402-0912

202402-0913

Congenital Hyperthyroidism [ORPHA424] - Child (< 18) - Confirmed Cases

202402-0914

202402-0915

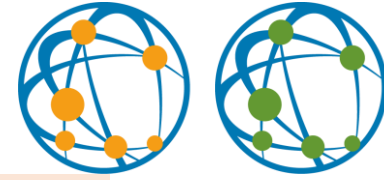
Close

Once you have submitted your report a list of e-REC IDs will be generated automatically. We kindly ask you to store it locally and link the IDs your patients. This way we can refer to them in the future if needed (e.g. for a secondary survey)

CALCIUM & PHOSPHATE

Condition	Suspected Cases - Child (< 18)	Confirmed Cases - Child (< 18)	Suspected Cases - Adult (≥ 18)	Confirmed Cases - Adult (≥ 18)
Hypocalcaemic vitamin D dependent rickets [ORPHA289157]	0	0		
Autosomal recessive hypophosphataemic				

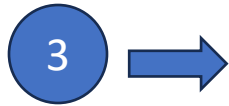
Updating suspected cases



You can update a suspected case at any moment (exclude or confirm), but if the report is already submitted you won't see changes in your report.

Previous Returns

To confirm or exclude suspected cases in a submitted return, please click on the Update Suspected Cases button next to the return



View Previously Updated Cases

Reporting Month	Reporting Open From	Deadline for Reporting	Return Status	Actions
April 2023	2023-04-01	2023-07-31	Submitted	View Return Download Return Update Suspected Cases



Click here to see your updated cases

Update Unconfirmed Suspected Cases for April 2023

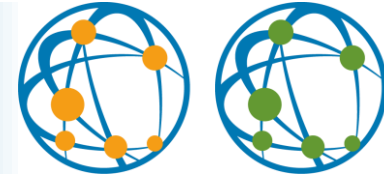
BONE DYSPLASIA

Condition	e-REC IDs - Child (< 18)
McCune-Albright syndrome [ORPHA562]	202304-0002

- Select -
- Select -
Confirmed
Excluded

Save Back





<https://www.eurreb.eu/>



Online Drop-in sessions

<https://eurreb.eu/events/drop-in-sessions/>

- Every second Friday 14:00-15:00 CEST
- Every fourth Wednesday 16:00-17:00 CEST



registries@lumc.nl