# How to use e-REC User guide





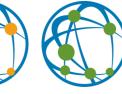






## e-REC





- 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.

## Go to <a href="https://eurreb.eu/">https://eurreb.eu/</a>









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.

Registries Symposium 2024 22 Monday 22 April 2024

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

MAY **ECE 2024 Annual Meeting** 11

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 cli	ick on the following Reset Password link
	◆) Log in
	+) Log in
	→D Log in
♣ New Users	+∂ Log in
New Users  To request access to the system please click on the following the system please click on the system please click on the following the system please click on the syste	
New Users  To request access to the system please click on the foll	









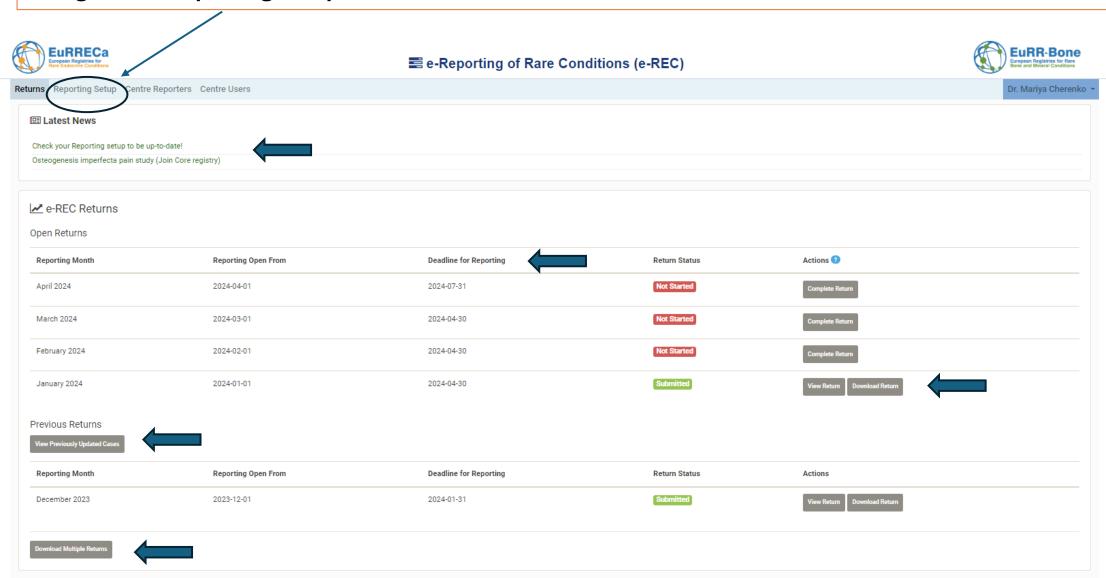






EuRR-Bone

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** 









#### **≡** e-Reporting of Rare Conditions (e-REC)



eturns Reporting Setup Centre Reporters Centre Users		
<b>♥</b> \$ 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	cific Age Group. To see the list of users at your cen	tre, click on Centre Users in the main
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] 2	<b>0 2</b>	
Acromegaly [ORPHA963]	Assigned to Dr. Ana Priego	☑
Cushing disease [ORPHA96253]	<b>2</b>	
Prolactinoma [ORPHA2965]	<b>2</b>	
Non-functioning pituitary adenoma [ORPHA91349]	<b>0</b>	
Combined pituitary hormone deficiencies, genetic forms [ORPHA95494] 2	<b>0</b>	<b>2</b>
Acquired Hypopituitarism [ORPHA95502]	<b>0</b>	
Craniopharyngioma [ORPHA54595]	<b>2</b>	

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

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.

## Complete your return









**EuRRECa** 

Download Multiple Return

### ■ e-Reporting of Rare Conditions (e-REC)

Dr. Mariya Cherenko Returns Reporting Setup Centre Reporters Centre Users ■ Latest News Check your Reporting setup to be up-to-date! Osteogenesis imperfecta pain study (Join Core registry) ✓ e-REC Returns Open Returns Actions 2 Reporting Month Reporting Open From Deadline for Reporting Return Status April 2024 2024-04-01 2024-07-31 Not Started March 2024 2024-03-01 2024-04-30 Not Started 2024-02-01 2024-04-30 February 2024 Not Started 2024-01-01 2024-04-30 January 2024 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





#### 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]		■ Va	lue must be less than or equ	ual to 99.
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

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**.

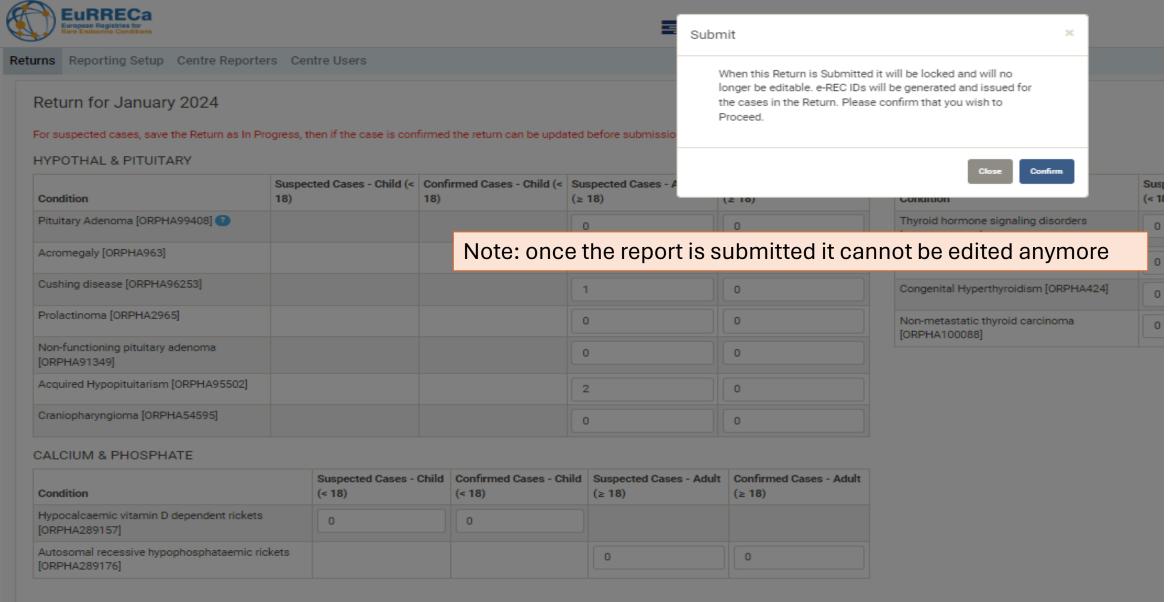
#### **CALCIUM & PHOSPHATE**

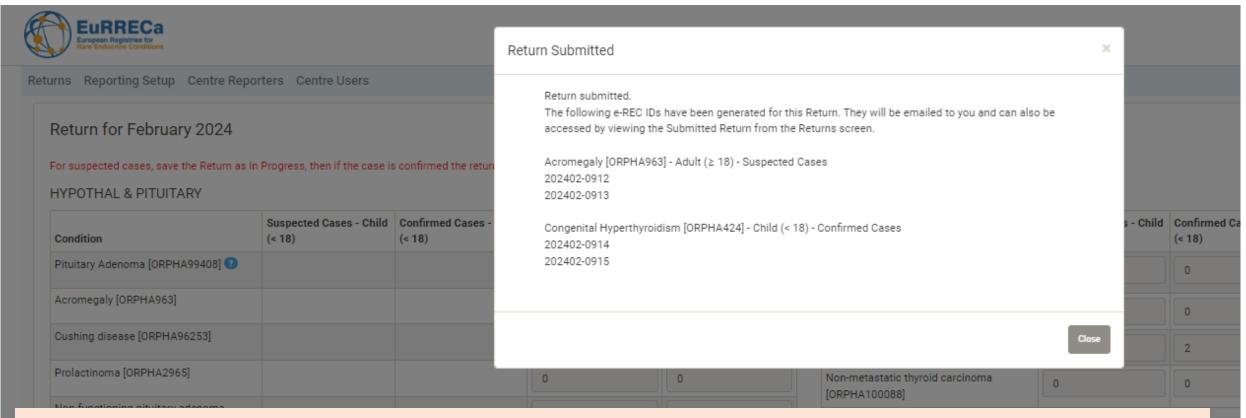
Condition	Suspected Cases - Child (< 18)	Confirmed Cases - Child (< 18)	Suspected Cases - Adult (≥ 18)	Confirmed Cases - Adult (≥ 18)
Hypocalcaemic vitamin D dependent rickets [ORPHA289157]	0	0		
Autosomal recessive hypophosphataemic rickets [ORPHA289176]			0	0

# Submit your report









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)

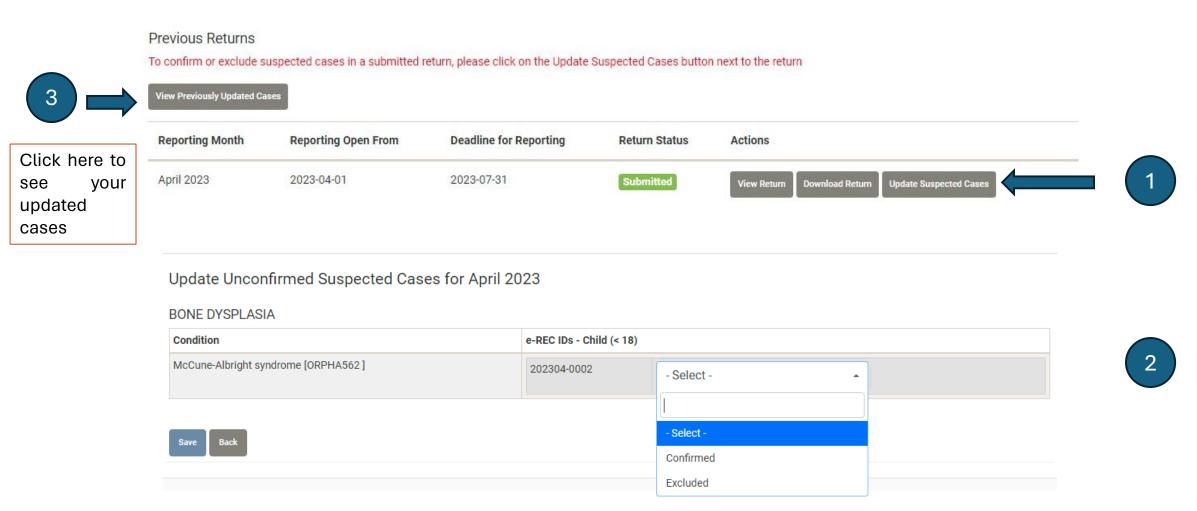
Condition	Suspected Cases -	Confirmed Cases -	Suspected Cases -	Confirmed Cases -
	Child (< 18)	Child (< 18)	Adult (≥ 18)	Adult (≥ 18)
Hypocalcaemic vitamin D dependent rickets [ORPHA289157]	0	0		

# 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.



## For further information







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



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