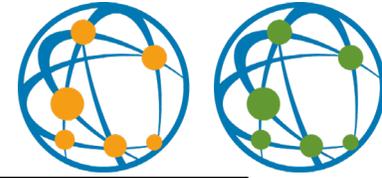


How to use the Core Registry?



You will need an invitation.
The invitation is sent by the responsible clinician to your email address.



Patient Access to Core Registry Inbox x

 **no-reply-eurecca@lumc.nl**
to me ▾

Dear Patient,

You can now have an access to the platform as you have previously asked. Best wishes, Mariya Cherenko

You have requested access to the Core Registry. To access the registry, please click on the following link and follow the instructions to create a user account.

[Create User Account](#)

If the link does not work, please copy the following link and paste it into your browser:

<http://eurreca.lumc.nl/EuRRECa/PatientAccount/Create?id=1225&token=3c3e3ba4-24f0-4349-be0e-edbe6ca7768c>

Yours sincerely

Natasha Appelman-Dijkstra
Centre Lead - Leiden University Medical Center

To activate your account, click the link

Core Registry Patient Account successfully created Inbox x

 **no-reply-eurecca@lumc.nl**
to me ▾

Dear Patient,

You have successfully created a user account for the Core Registry.

Your user name is: [REDACTED]

Click on the following link to go to the Core Registry Login Page: [Login](#)

Yours sincerely

Natasha Appelman-Dijkstra
Centre Lead - Leiden University Medical Center

A confirmation will be sent



You can login with your date of birth or another date if your physician entered this

Confirm your password

Logging in via the website: Go to <https://eurreb.eu/>



What are you looking for?

English ▼



Home

About ▼

News ▼

Registries ▼

Patients ▼

Contact ▼

Access →

e-REC

Core-Registry

Information

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

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

Press here to
Login to Core
registry



Core Registry

[Click here for Patient Login](#)

[Click here to login](#)



[Click here for Clinician Login](#)

For further information visit www.eurreb.eu



This website is part of the project '777215 / EuRRECa' and '946831 / Eurr-Bone' which have received funding from the European Commission, the European Consumers, Health, Agriculture and Food Executive Agency or any other body of the European Union. The European Commission

Patient Login

User Name

Password

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

6 digit PIN from your mobile device [?](#)

Click on the following link for further information about OTP authentication: [OTP Authentication](#)

Log in

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



European
Reference
Network



ERN BOND
EUROPEAN REFERENCE NETWORK
ON RARE BONE DISEASES



European Society for
Paediatric Endocrinology



European Society
of Endocrinology

For security reason, you will need to download OTP authenticator

On the opening screen you can find an overview
And below you can find 3 buttons



Core Registry

Patient Details

This is a copy of the data held in the Core Registry relating to your case. If you want to request changes or corrections to this data please contact the System Administrator: registries@lumc.nl

Patient Info	CALCIUM & PHOSPHATE	Outcomes - CALCIUM & PHOSPHATE	SEX DEVELOPMENT	BONE DYSPLASIA	Outcomes - BONE DYSPLASIA	Centre	Patient Reported Outcomes - EQ-5D	Patient Reported Outcomes - Generic	Settings
Patient Registry ID	4004								
Consent Type for Registry	Opt-in								
Date added to Registry	6/21/2022								
Date of Birth	12/8/1998								
Pseudonymised ID (e.g. SPIDER)									
Sex at Birth	Female								
Current Gender	Female								
Country of Birth	NETHERLANDS								
Country of Usual Residence	NETHERLANDS								
Patient Follow-up Status	Patient active								

Edit Account Details Change Password Request Deletion of Data

Via these buttons you can change your email address, password or your decision to share your data with the registry



Edit Account Details

Fields marked with * are required

* Email Address

Save

Cancel

Change Password

Fields marked with * are required

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: @ # ! ? € \$ £ % & _ + - ~

* New Password

* Confirm New Password

Save

Cancel



Request Deletion of Data

"I would like my data to be deleted from the Core Registry as well as any other registries that the data have been shared with."

You are about to submit this request. Are you sure?

Email Address

Yes

No

Patient Details

This is a copy of the data held in the Core Registry relating to your case. If you want to request changes or corrections to this data please contact the System Administrator: registries@lumc.nl

Patient Info	CALCIUM & PHOSPHATE	Outcomes - CALCIUM & PHOSPHATE	SEX DEVELOPMENT	BONE DYSPLASIA	Outcomes - BONE DYSPLASIA	
Centre	Patient Reported Outcomes - EQ-5D	Patient Reported Outcomes - Generic	Settings			
I can be contacted for research purposes by my responsible clinician at my local centre					Yes	Change
My data can be shared for research approved by the Data Access Committee					Yes	Change
I can be contacted by the registries on behalf of my local centre for the collection of Patient Reported Outcomes on an ongoing basis					Yes	Change
I would like to receive the EuRRECa/EuRR-Bone newsletters by email					Yes	Change
Preferred Language					English	Change



- [Edit Account Details](#)
- [Change Password](#)
- [Request Deletion of Data](#)

You can change your preferred language and level of consent

Patient Details

This is a copy of the data held in the Core Registry relating to your case. If you want to request changes or corrections to this data please contact the System Administrator: registries@lumc.nl

Patient Info	CALCIUM & PHOSPHATE	Outcomes - CALCIUM & PHOSPHATE	SEX DEVELOPMENT	BONE DYSPLASIA	Outcomes - BONE DYSPLASIA	Centre	Patient Reported Outcomes - EQ-5D
Patient Reported Outcomes - Generic		Settings					
Centre Name	Leiden University Medical Center						
Address							
Centre Lead Name	Natasha Appelman-Dijkstra						
Centre Lead Email	bot@lumc.nl						

[Edit Account Details](#)[Change Password](#)[Request Deletion of Data](#)

You can find information here about your centre and the name of the person who functions as the centre lead for the registry. This can be a different person than your doctor.

[Patient Info](#)
[CALCIUM & PHOSPHATE](#)
[Outcomes - CALCIUM & PHOSPHATE](#)
[SEX DEVELOPMENT](#)
[BONE DYSPLASIA](#)
[Outcomes - BONE DYSPLASIA](#)

[Centre](#)
[Patient Reported Outcomes - EQ-5D](#)
[Patient Reported Outcomes - Generic](#)
[Settings](#)

Condition Group	Bone Dysplasia
e-REC ID	
First Contact with Centre	
Clinician Responsible for Case	Mariya Cherenko
Date of First Clinical Manifestations	
Primary Condition	Primary bone dysplasia with micromelia
Specific Diagnosis	Achondroplasia
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	

You will find information about your specific condition here. You can see what your doctor has added.

Patient Details

This is a copy of the data held in the Core Registry relating to your case. If you want to request changes or corrections to this data please contact the System Administrator: registries@lumc.nl

- Patient Info
- CALCIUM & PHOSPHATE
- Outcomes - CALCIUM & PHOSPHATE
- SEX DEVELOPMENT
- BONE DYSPLASIA
- Outcomes - BONE DYSPLASIA**

- Centre
- Patient Reported Outcomes - EQ-5D
- Patient Reported Outcomes - Generic
- Settings

Created Date	Completed By	Questionnaire	Current Specific Diagnosis	
2023-10-27	Patient	Achondroplasia PROs - Achondroplasia PROs	Achondroplasia	<div data-bbox="1974 711 2168 836">View Amend Delete</div> <div data-bbox="1974 891 2262 949">Previous 1 Next</div>

[New Outcome](#)

Press new outcome to see the questionnaire

Here you can see the list of previously completed outcomes. You can view them, amend or delete

- [Edit Account Details](#)
- [Change Password](#)
- [Request Deletion of Data](#)

Patient Details

This is a copy of the data held in the Core Registry relating to your case. If you want to request changes or corrections to this data please contact the System Administrator: registries@lumc.nl

Patient Info CALCIUM & PHOSPHATE Outcomes - CALCIUM & PHOSPHATE SEX DEVELOPMENT BONE DYSPLASIA Outcomes - BONE DYSPLASIA

Centre **Patient Reported Outcomes - EQ-5D** Patient Reported Outcomes - Generic Settings

Created Date	Completed By	Type	Mobility	Self Care	Activity	Pain	Anxiety	EQ VAS	
2023-11-03	Patient	EQ-5D-5L	3	3	2	3	4	53	Delete
2022-06-21	Mariya Cherenko	EQ-5D-5L	3	2	2	3	2	80	

[New Outcome](#)

Press here to fill in EQ-5D questionnaire on your quality of life.
This can also be filled in by your clinician if you already did the questionnaire at the clinic.
Your physician has set the amount of questionnaires to be filled.
You are able to see all the dates and the results in the list.

[Edit Account Details](#) [Change Password](#) [Request Deletion of Data](#)

Patient Details

This is a copy of the
Administrator: regi

Patient Info

Centre

Pati

Created Date

2023-11-03

2022-06-21

Mariya Cherenko

EQ-5D-5L

3

2

2

3

2

80

New Outcome

System

ASIA

Delete

Previous

1

Next

EQ-5D-5L



Please select the ONE box that best describes your health TODAY.

MOBILITY

I have no problems in walking about

I have slight problems in walking about

I have moderate problems in walking about

I have severe problems in walking about

I am unable to walk about

Next 

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EQ-5D-5L



Please select the ONE box that best describes your health TODAY.

USUAL ACTIVITIES (e.g. work, study, housework, family or leisure activities)

I have no problems doing my usual activities

I have slight problems doing my usual activities

I have moderate problems doing my usual activities

I have severe problems doing my usual activities

I am unable to do my usual activities

 Previous

Next 

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EQ-5D-5L

- We would like to know how good or bad your health is TODAY.
- You will see a scale numbered from 0 to 100.
- 100 means the best health you can imagine. 0 means the worst health you can imagine.
- Please indicate on the scale how your health is TODAY.

**YOUR
HEALTH
TODAY**

The best health
you can imagine



The worst health
you can imagine

← Previous

Next →

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EQ-5D-5L

- We would like to know how good or bad your health is TODAY.
- You will see a scale numbered from 0 to 100.
- 100 means the best health you can imagine. 0 means the worst health you can imagine.
- Please indicate on the scale how your health is TODAY.

**YOUR
HEALTH
TODAY
77**

The best health
you can imagine



The worst health
you can imagine

← Previous

Next →

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Patient Details

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Patient Info CALCIUM & PHOSPHATE Outcomes - CALCIUM & PHOSPHATE SEX DEVELOPMENT BONE DYSPLASIA Outcomes - BONE DYSPLASIA

Centre Patient Reported Outcomes - EQ-5D Patient Reported Outcomes - Generic Settings

Created Date	Completed By	Type	Mobility	Self Care	Activity	Pain	Anxiety	EQ VAS	
2024-01-26	Patient	EQ-5D-5L	2	3	3	2	3	77	Delete
2023-11-03	Patient	EQ-5D-5L	3	3	2	3	4	53	Delete
2022-06-21	Mariya Cherenko	EQ-5D-5L	3	2	2	3	2	80	

[New Outcome](#)

Previous 1 Next

[Edit Account Details](#) [Change Password](#) [Request Deletion of Data](#)

New outcome will appear immediately on the top of the list and your doctor will receive a notification, that you have completed an outcome

Patient Details

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Patient Info CALCIUM & PHOSPHATE Outcomes - CALCIUM & PHOSPHATE SEX DEVELOPMENT BONE DYSPLASIA Outcomes - BONE DYSPLASIA

Centre Patient Reported Outcomes - EQ-5D **Patient Reported Outcomes - Generic** Settings

Created Date	Completed By	Questionnaire	
2023-10-31	Mariya Cherenko	BPI-SF - Brief Pain Inventory Short Form	View

[Previous](#) **1** [Next](#)

Show Requested Questionnaires Only Show All

Questionnaire - Select - 

[New Outcome](#)

- Select -
- Oral Health Impact Profile (OHIP-14)
- MSK-HQ - MUSCULOSKELETAL HEALTH QUESTIONNAIRE

[Edit Account Details](#) [Change Password](#) [Request Deletion of Data](#)

Here you will see other questionnaires requested by your responsible clinician

Patient Details

This is a copy of the data held in the Core Registry relating to your case. If you want to request changes or corrections to this data please contact the System Administrator: registries@lumc.nl

Patient Info CALCIUM & PHOSPHATE Outcomes - CALCIUM & PHOSPHATE SEX DEVELOPMENT BONE DYSPLASIA Outcomes - BONE DYSPLASIA

Centre Patient Reported Outcomes - EQ-5D Patient Reported Outcomes - Generic Settings

Created Date	Completed By	Questionnaire	
2023-10-31	Mariya Cherenko	BPI-SF - Brief Pain Inventory Short Form	View

[Previous](#) **1** [Next](#)

Show Requested Questionnaires Only Show All

Questionnaire

[New Outcome](#)

[Edit Account Details](#) [Change](#)

- Select -

- Select -

BPI-SF - Brief Pain Inventory Short Form

MSK-HQ - MUSCULOSKELETAL HEALTH QUESTIONNAIRE

Oral Health Impact Profile (OHIP-14)

Profile 25 (Child) - PROMIS Paediatric Profile v2.0

Profile 25 (Parent Proxy) - PROMIS Parent Proxy Profile v2.0

Profile 29 (Adult) - PROMIS Profile 29 v2.1

Profile 37 (Child) - PROMIS Paediatric Profile v2.0

Profile 37 (Parent Proxy) - PROMIS Parent Proxy Profile v2.0

Profile 49 (Child) - PROMIS Paediatric Profile v2.0

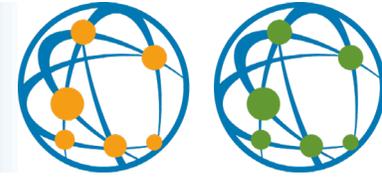
Profile 49 (Parent Proxy) - PROMIS Parent Proxy Profile v2.0

Profile 57 (Adult) - PROMIS Profile v2.1

WHO-ICF Mobility

You can also fill in other available questionnaires

Contact us!



Thank you for your participation!

Please don't hesitate to contact us by e-mail registries@lumc.nl in case of any questions.

Or join our regularly drop-in sessions <https://eurreb.eu/events/drop-in-sessions/>