

How to use the Core Registry: Patient's Guide

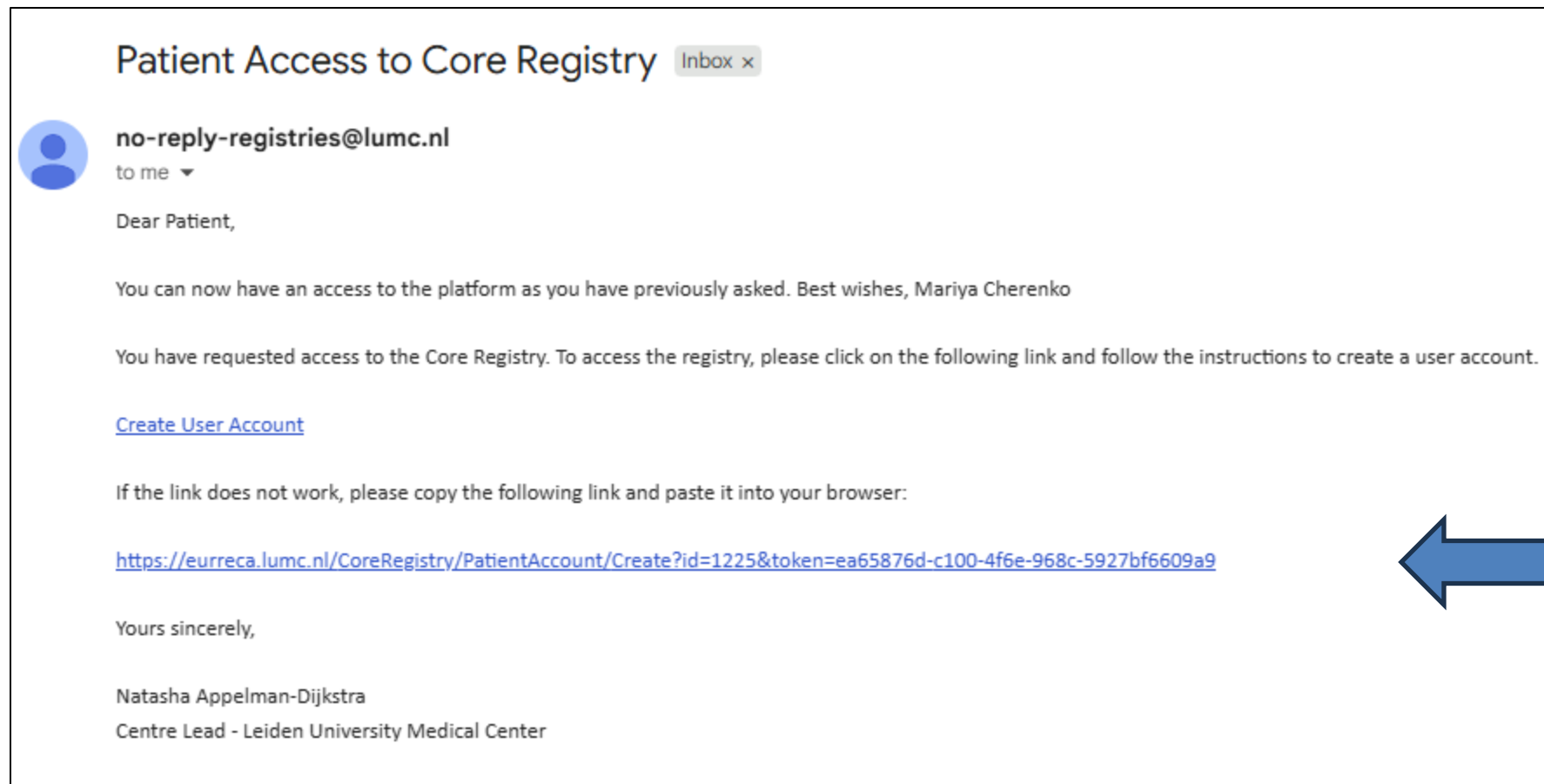


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How to get an account for the Core Registry?



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

To **activate** your account, click the link.
Afterwards, a **confirmation** will be sent.



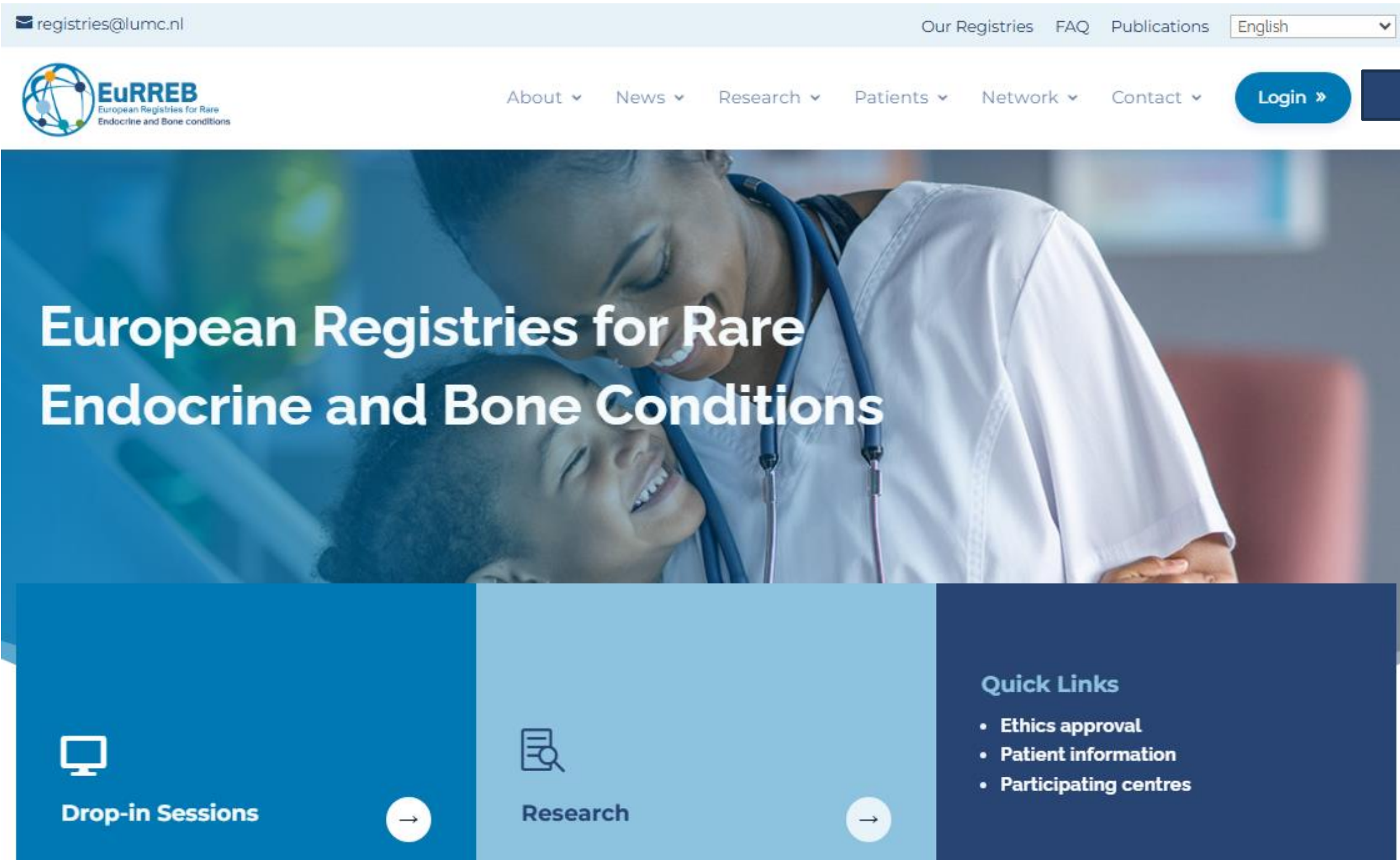
You can **login** with your date of birth or another date if your physician entered this.

Confirm your password.



How to log in into the Core Registry

Go to <https://eurreb.eu/> , click on [Login](#) , then on Core Registry and choose [Patient Login](#).



The screenshot shows the EURREB website homepage. At the top left is the email address registries@lumc.nl. To the right are links for "Our Registries", "FAQ", and "Publications", along with a language dropdown menu set to "English". The EURREB logo is on the left, and a navigation menu with "About", "News", "Research", "Patients", "Network", and "Contact" is in the center. A blue "Login »" button is on the right. The main banner features a photo of a doctor with a stethoscope and a child, with the text "European Registries for Rare Endocrine and Bone Conditions". Below the banner are three sections: "Drop-in Sessions" with a monitor icon, "Research" with a magnifying glass icon, and "Quick Links" with a list: "Ethics approval", "Patient information", and "Participating centres".



The screenshot shows the login page. At the top is the "Login" heading. Below it is the text: "Below you can login to our two registries. Click anywhere on the blocks to access (back or front side). Learn more about e-REC and Core Registry." There are two buttons: "e-REC" (dark blue) and "Core Registry" (light blue). Below these is a "Login" section with a user icon and the text "Login". There are two buttons: "Click here for Patient Login" (green) and "Click here for Clinician Login" (dark blue). At the bottom, it says "For further information visit www.eurreb.eu".



Login Page



Core Registry

Patient Login

User Name

Password

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

→ Log in

← Back

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

← Use your email and password

← If you have forgotten your password, please reset it here



Login Page

Two-Factor Authentication

Please select how you want to receive your authentication code:

Use Device Code

Send Code via Email

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

For security reasons **two-factor authentication** is needed.
Choose any option which you prefer.



Verify Your Identity

 Enter the 6-digit code you received by email

 Log in

Didn't receive the email? [Resend Code](#)

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



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Home Page

Patient Details

Latest News

[Survey Psychosocial consequences of living with a pituitary tumour](#)

[Read our latest news](#)

This is a copy of the data held in the Care 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 | 12/8/1990 | | | | | | | | |
| 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.



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Settings

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.



Centre Information

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](#)

Here you can find **information** about your **centre** and the name of the person who functions as the **centre lead** for the registry.

Attention: This can be a different person then your doctor.



Specific Condition Information

| | | | | | |
|--|--|-------------------------------------|-----------------|----------------|---------------------------|
| 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.



Outcomes

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 | View Amend Delete |

[New Outcome](#) **Press new outcome to see the questionnaire**

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

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



Patient Reported Outcomes: EQ-5D

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 | |

Previous | 1 | Next

[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 number of questionnaires to be filled. You are able to see all the dates and the results in the list.



Patient Reported Outcomes: EQ-5D

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 | |
|--------------|-----------------|----------|----------|-----------|----------|------|---------|--------|--------|
| 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 | |

Previous 1 Next

New Outcome

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

Edit Account Details

Change Password

Request Deletion of Data



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Patient Reported Outcomes: Generic

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 |

Show Requested Questionnaires Only Show All

Questionnaire: [New Outcome](#)

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

Here you will see other **questionnaires requested** by your responsible clinician.

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



Patient Reported Outcomes: Generic

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 |

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.



Reminders

EuRREB Patient Reported Outcome Reminder Inbox x



no-reply-registries@lumc.nl

to me ▾

Dear Patient,

I would be very grateful if you could complete a special questionnaire which enquires about your health condition.

To complete the PRO, please click on the following link : [New Outcome](#).

Thank you for your help.

Yours sincerely,

Mariya Cherenko

Leiden University Medical Center

← Reply

→ Forward



Sometimes you will receive a **reminders to fill in questionnaires**.
Follow the link in your e-mail or click on the items highlighted in red on the homepage



* Some of your requested questionnaires are now due, please fill them in by following the highlighted tabs.

| | | | | |
|---------------------------|---|----------------------------------|-----------------------------------|---------------------------------------|
| Patient Info | CALCIUM & PHOSPHATE | * Outcomes - CALCIUM & PHOSPHATE | GENETIC ENDOCRINE TUMOURS | Outcomes - GENETIC ENDOCRINE TUMOURS |
| Outcomes - BONE DYSPLASIA | Patient Reported Outcomes - Life-course | Centre | Patient Reported Outcomes - EQ-5D | * Patient Reported Outcomes - Generic |



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Your participation

The screenshot shows the top navigation bar with the email 'registries@lumc.nl', 'Our Registries', 'FAQ', 'Publications', and a language dropdown set to 'English'. The main navigation includes 'About', 'News', 'Research', 'Patients', 'Network', and 'Contact', along with a 'Login' button and a search icon. The 'Patients overview' section features a central paragraph and six interactive cards: 'General Registries Information', 'Patient Information', 'Contribute as a Patient', 'Tools and Outcomes', and 'Patients FAQ'. Each card includes a descriptive paragraph and a 'Learn More' button.

registries@lumc.nl Our Registries FAQ Publications English

EuRREB
European Registries for Rare
Endocrine and Bone conditions

About News Research Patients Network Contact Login

Patients overview

Patients are at the heart of our registries. They are not only the focus of our work but also active participants in it. By logging in and answering surveys, they contribute directly to research. Additionally, patient representatives play a key role in all our studies and committees.

- General Registries Information**
More information about what we do
[Learn More](#)
- Patient Information**
More information on what it means to be a patient participating in the registries
[Learn More](#)
- Contribute as a Patient**
Patients can contribute to the registries in different ways
[Learn More](#)
- Tools and Outcomes**
Learn more about the surveys that you can fill out on the platform and what their results mean
[Learn More](#)
- Patients FAQ**
Find here the answers to frequently asked questions by patients
[Learn More](#)

Thank you for your participation! This helps to improve the healthcare system for rare conditions.

If you want to find more information – please go to our website to [patients' section](#)

There you can also find more information about [all the questionnaires](#) we are working with.





Funded by
the European Union



Ways to contact us:



eurreb.eu



registries@lumc.nl



[drop-in sessions via Zoom](#)



[European Registries for Rare
Endocrine and Bone Conditions](#)



EuRRREB

European Registries for Rare
Endocrine and Bone conditions



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