

How to use the Achondroplasia module in the Core Registry



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How to create an account in the Core Registry

Use this link for self-registration

<https://eurreca.lumc.nl/EuRREBAuth/Registration/Create>



Fill in the form, choose the **Core Registry Clinical Contributor** role to have access to the Core Registry.

Choose your centre from the list or **add** your centre's details if not listed yet. We will approve the centre addition along with your registration.



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 would like to be the Centre Lead for this Centre ? Yes No

Filter Centres by Country (optional)

* Centre

Fill in the mandatory information.
Your request will be approved shortly.



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How to change your application role if you already use e-REC

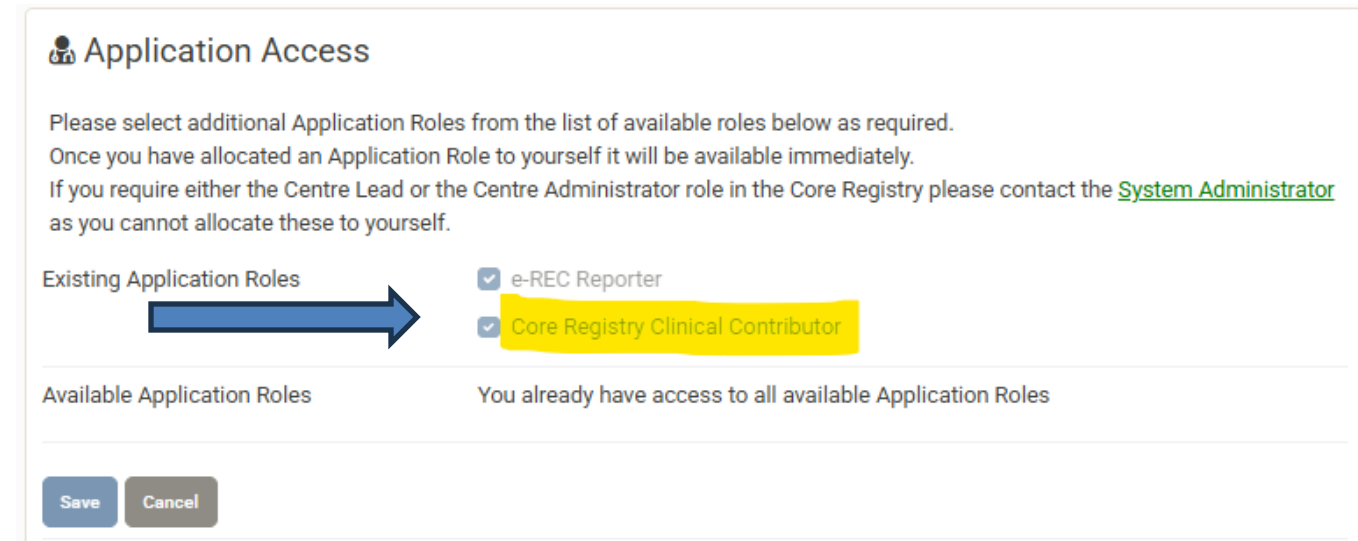
If you are already using e-REC, you can **allocate the Core Registry Clinical Contributor role to yourself.**

The Core Registry Clinical Contributor role will become available immediately.

Choose "Application access"
from the e-REC menu under
your name.



The screenshot shows the top navigation bar of the e-REC system. On the left is the EuRREB logo (European Registries for Rare Endocrine and Bone conditions). The main header is "e-Reporting of Rare Conditions (e-REC)". Below the header are navigation tabs: "Returns", "Reporting Setup", "Centre Reporters", and "Centre Users". On the right, the user's name "Dr. Mariya Cherenko" is displayed with a dropdown arrow. A menu is open under the user name, listing "Edit Account Details", "Change Password", "Application Access" (highlighted with a blue arrow), and "Log Out". On the left side of the page, there is a "Latest News" section with two links: "Join EuRREB Symposium 2025" and "Not sure about your ORPHAcode? Check this tool out!". A blue arrow points from the "Application Access" menu item to the right.

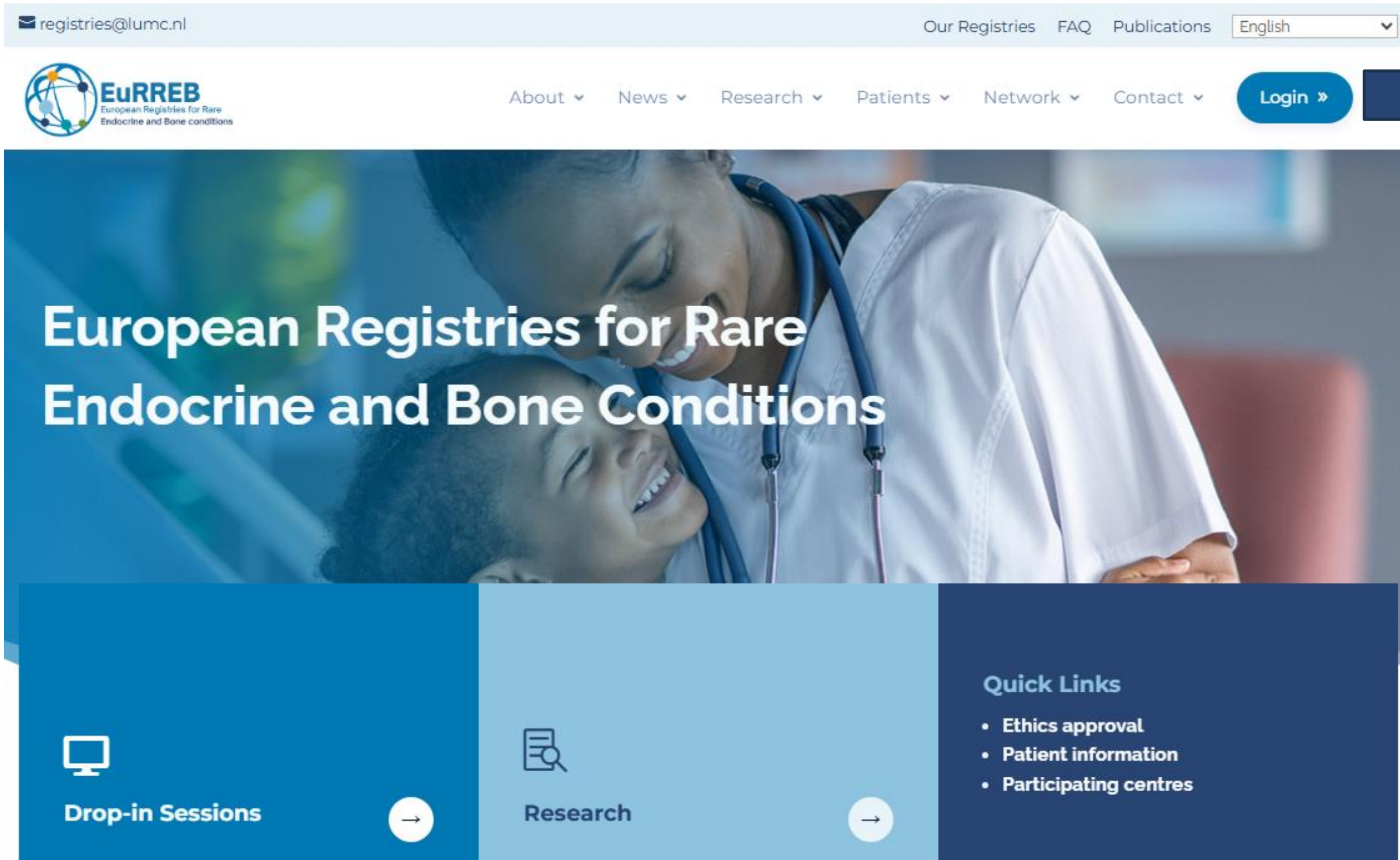


The screenshot shows the "Application Access" configuration page. The title is "Application Access" with a user icon. Below the title is a message: "Please select additional Application Roles from the list of available roles below as required. Once you have allocated an Application Role to yourself it will be available immediately. If you require either the Centre Lead or the Centre Administrator role in the Core Registry please contact the [System Administrator](#) as you cannot allocate these to yourself." Below this message is a section titled "Existing Application Roles" with a blue arrow pointing to a list of roles. The list contains two roles: "e-REC Reporter" (checked) and "Core Registry Clinical Contributor" (checked and highlighted in yellow). Below the list is a section titled "Available Application Roles" with the text "You already have access to all available Application Roles". At the bottom of the page are "Save" and "Cancel" buttons.

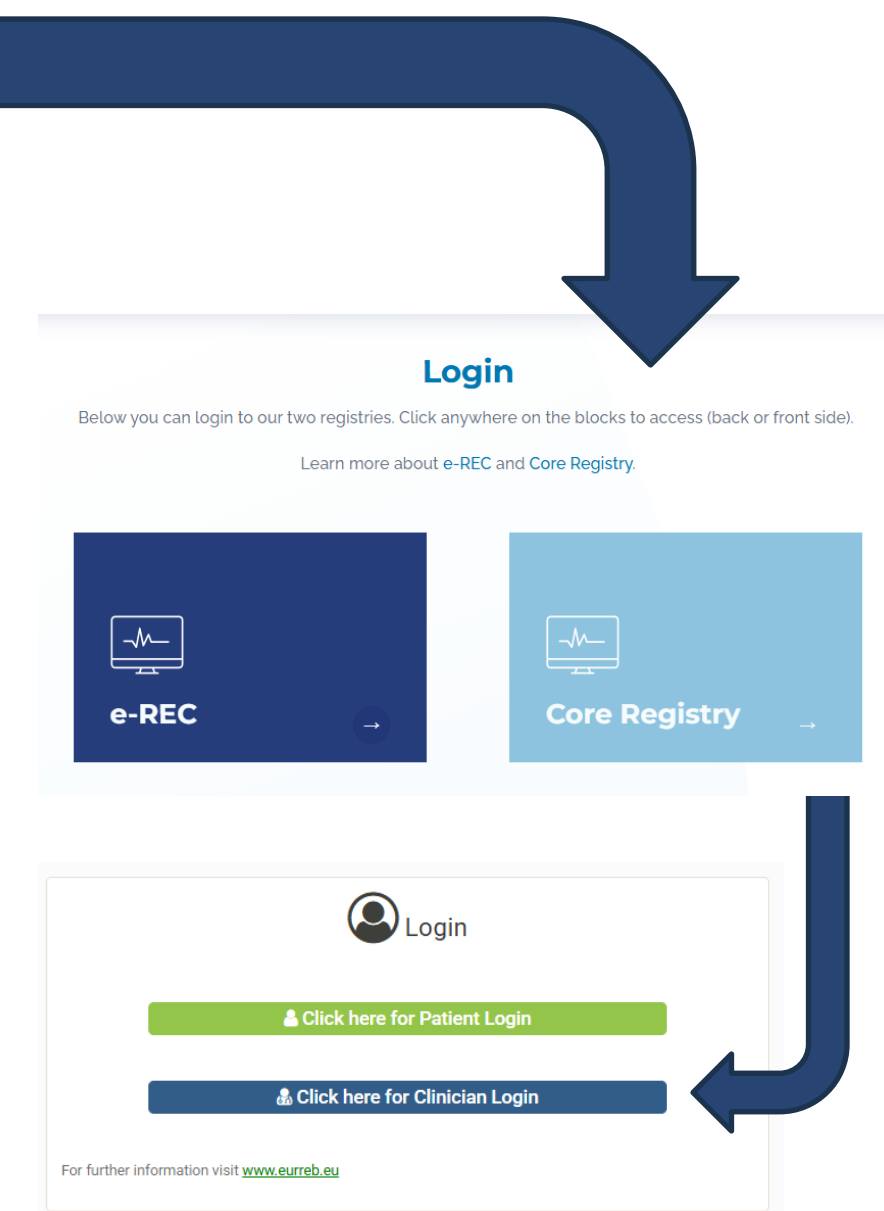


How to log in into the Core Registry

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



The screenshot shows the homepage of the European Registries for Rare Endocrine and Bone Conditions (EURREB). At the top left is the email address registries@lumc.nl. The top right navigation bar includes links for "Our Registries", "FAQ", "Publications", and a language dropdown menu set to "English". Below this is a main navigation menu with "About", "News", "Research", "Patients", "Network", and "Contact", followed by a prominent blue "Login" button. The main banner features a photograph of a doctor examining a child, with the text "European Registries for Rare Endocrine and Bone Conditions". At the bottom, there are three sections: "Drop-in Sessions" with a monitor icon, "Research" with a magnifying glass icon, and "Quick Links" which lists "Ethics approval", "Patient information", and "Participating centres".

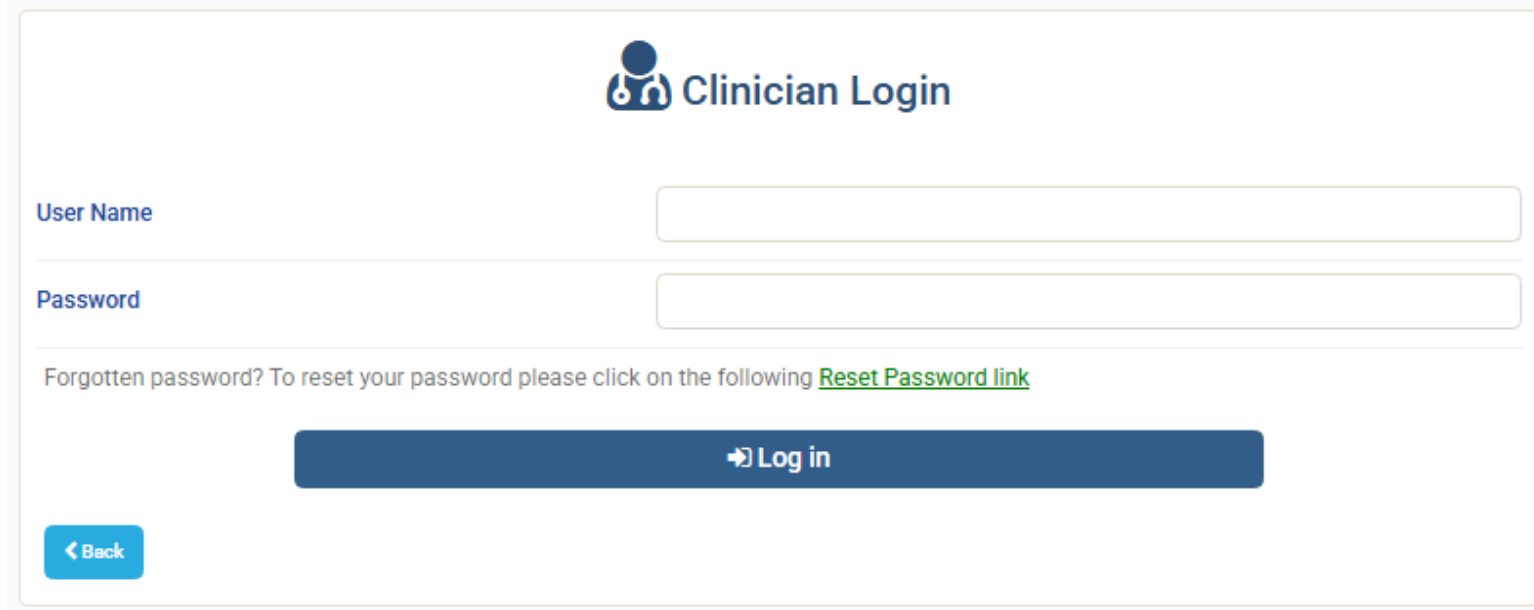


This flowchart illustrates the login process. It starts with a large blue arrow pointing from the "Login" button on the homepage to a "Login" page. The "Login" page contains the text "Below you can login to our two registries. Click anywhere on the blocks to access (back or front side). Learn more about e-REC and Core Registry." Below this text are two buttons: "e-REC" and "Core Registry". A second blue arrow points from the "Core Registry" button to a "Login" page. This page has a "Login" header and two buttons: "Click here for Patient Login" (highlighted in green) and "Click here for Clinician Login". A final blue arrow points from the "Click here for Clinician Login" button to the right side of the slide.



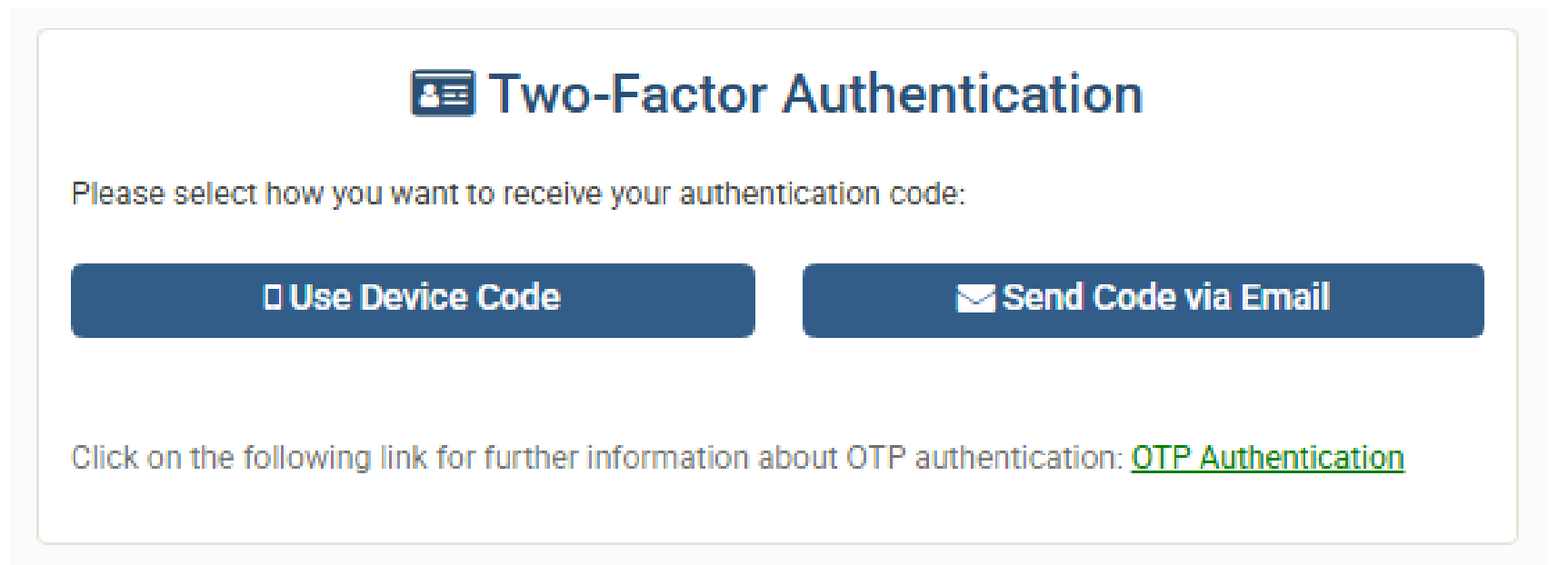
Login to the Core Registry

Via this [page](#) or by following the previous steps fill in your credentials (username is your e-mail). You can reset password anytime.



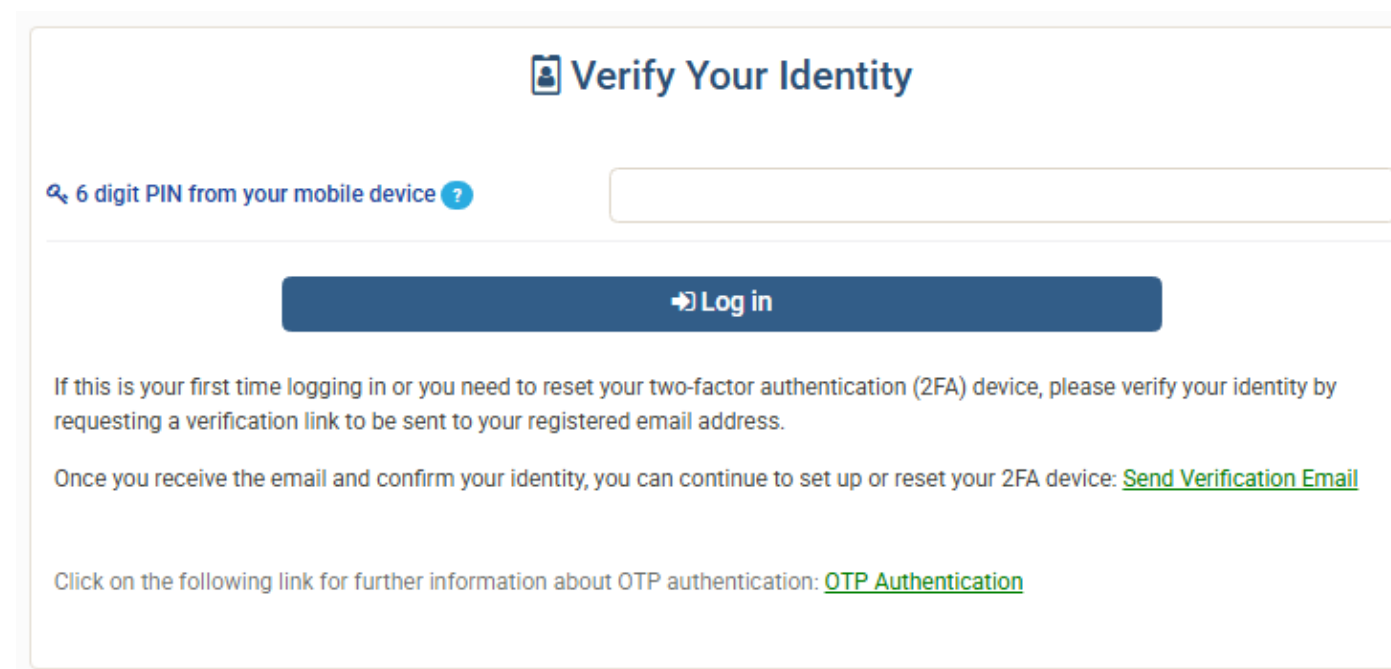
The screenshot shows the 'Clinician Login' page. At the top, there is a header with a person icon and the text 'Clinician Login'. Below this, there are two input fields: 'User Name' and 'Password'. Under the password field, there is a link for 'Reset Password link'. A large blue button with a right-pointing arrow and the text 'Log in' is centered below the fields. In the bottom left corner, there is a smaller blue button with a left-pointing arrow and the text 'Back'.

Choose how you want to receive your authentication code: mobile device or email .



The screenshot shows the 'Two-Factor Authentication' page. At the top, there is a header with a person and a list icon and the text 'Two-Factor Authentication'. Below this, there is a text prompt: 'Please select how you want to receive your authentication code:'. There are two large blue buttons: 'Use Device Code' and 'Send Code via Email'. Below the buttons, there is a text prompt: 'Click on the following link for further information about OTP authentication: [OTP Authentication](#)'.

Enter the 6-digit PIN you received by either method. If using your mobile device, you will need to request a verification email before logging in for the first time or for resetting your 2FA.



The screenshot shows the 'Verify Your Identity' page. At the top, there is a header with a person icon and the text 'Verify Your Identity'. Below this, there is a text prompt: '6 digit PIN from your mobile device ?' followed by an input field. A large blue button with a right-pointing arrow and the text 'Log in' is centered below the field. Below the button, there is a text prompt: 'If this is your first time logging in or you need to reset your two-factor authentication (2FA) device, please verify your identity by requesting a verification link to be sent to your registered email address.' Below this, there is a text prompt: 'Once you receive the email and confirm your identity, you can continue to set up or reset your 2FA device: [Send Verification Email](#)'. At the bottom, there is a text prompt: 'Click on the following link for further information about OTP authentication: [OTP Authentication](#)'.



The Core Registry



Dashboard



You can explore the different features of the dashboard:

- you have access to all patients registered in your centre
- you can see the latest news
- you can see the distribution of cases by MTG and age groups
- you can check patient access status and patient and clinician outcomes status

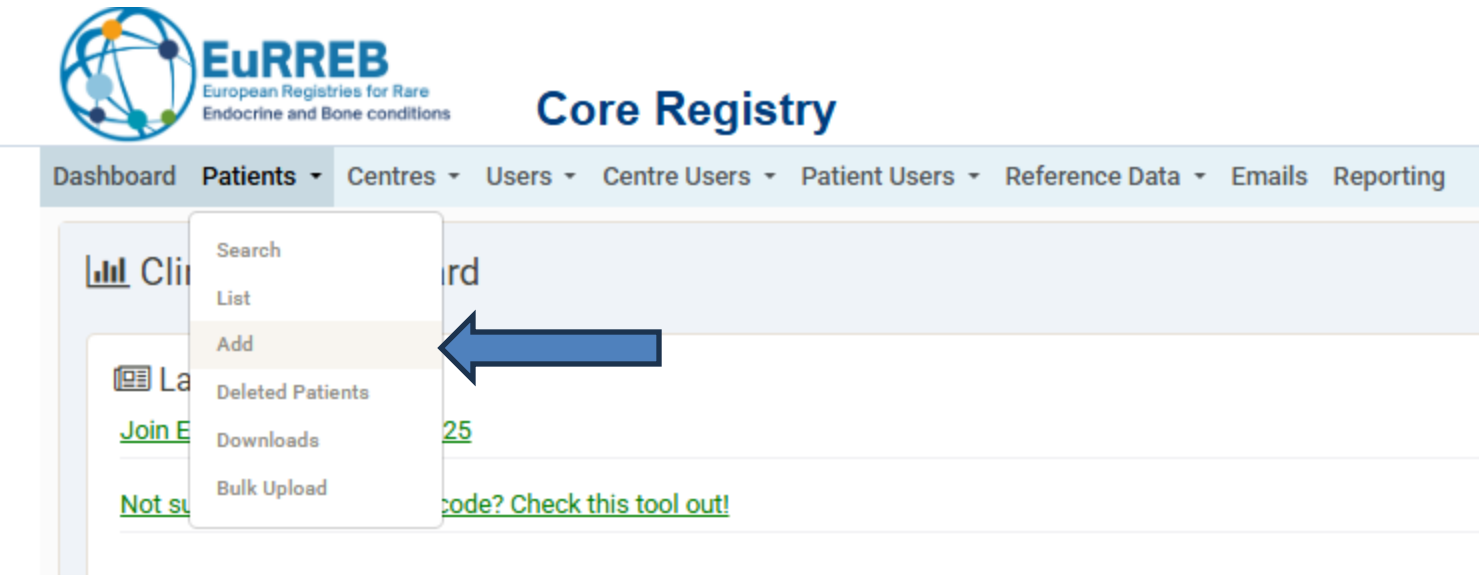


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How to add a new patient

Click on "Add" from the menu tab "Patients"



Fill in the Common Data Elements

Mandatory fields



If applicable



Add Patient

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

Choose "Bone dysplasia"



Opt-in Opt-out

ADRENAL CALCIUM & PHOSPHATE GLUCOSE & IN:

BONE DYSPLASIA

Male Female Other Unknown

Male Female Non-binary Other Asked but unkno

NETHERLANDS

NETHERLANDS

Patient active Patient inactive Patient care suspended

mm/dd/yyyy

- Select -

Yes No Not Known

Yes No Not Known

Yes No Not Known

Yes No Not Known

Yes No Not Known



Access the patient condition section

Edit Patient

Patient ID - [redacted] [Edit To Do](#)

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

BONE DYSPLASIA Generic Outcomes Audit Patient List

Opt-in [?](#) Opt-out [?](#)

[redacted]

- ADRENAL [?](#) CALCIUM & PHOSPHATE [?](#) GLUCOSE & INSULIN [?](#)
 GENETIC ENDOCRINE TUMOURS [?](#) GROWTH & OBESITY [?](#) HYPOTHAL & PITUITARY [?](#)
 SEX DEVELOPMENT [?](#) THYROID [?](#) BONE DYSPLASIA [?](#)

test Cher

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

mm/dd/yyyy

- Select -

Yes No Not Known

Yes No Not Known

Yes No Not Known



Click here to fill in the bone dysplasia tab



Fill in Bone Dysplasia tab

Core Data Generic Outcomes Diagnosis-specific Outcomes Audit

Edit Patient Condition

Patient ID - [redacted] Date of Birth - [redacted] Edit To Do

Bone Dysplasia

Senior Clinician < 18 - N/A

Senior Clinician ≥ 18 - N/A

If applicable →

e-REC ID

First Contact with Centre

Clinician Responsible for Patient

Date of Condition Onset

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 Kn

Date of Diagnosis

Participation in Detailed Disease Registry Yes No Not Known

Detailed Disease Registry

Detailed Disease Registry Patient ID

Biobank Sample Available for Research Yes No Not Known

Biobank Details

Fill in all mandatory fields

Select the Primary Condition - "PBD with micromelia", for specific diagnosis – choose "Achondroplasia" from the list.

Save Cancel



Giving patients access to the Core Registry

If your patient consented for access to the Core Registry:

Edit Patient Condition

Patient ID - [redacted] Date of Birth - [redacted] - [redacted] Edit To Do

Bone Dysplasia

Senior Clinician < 18 - N/A

Senior Clinician ≥ 18 - N/A

e-REC ID

First Contact with Centre

Clinician Responsible for Patient

Date of Condition Onset

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

Detailed Disease Registry

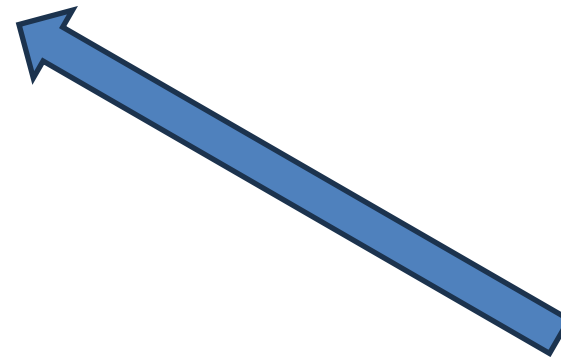
Detailed Disease Registry Patient ID

Biobank Sample Available for Research

Yes No Not Known

Biobank Details

- Core Data
- BONE DYSPLASIA
- Patient Access**
- Generic Outcomes
- Diagnosis-specific Outcomes



Give access to your patient.

Note: You must know the patient's e-mail for this.



The ACHON Module



Go to diagnosis-specific outcome

Edit Patient Condition

Patient ID - [redacted] Date of Birth - [redacted] Edit To Do

Bone Dysplasia

Senior Clinician < 18 - N/A
Senior Clinician ≥ 18 - N/A

e-REC ID: [text input]

First Contact with Centre: mm/dd/yyyy [calendar icon]

Clinician Responsible for Patient: Mariya Cherenko [dropdown arrow]

Date of Condition Onset: mm/dd/yyyy [calendar icon]

Primary Condition: Primary bone dysplasia with micromelia [dropdown arrow]

Specific Diagnosis: Achondroplasia [dropdown arrow]

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: mm/dd/yyyy [calendar icon]

Participation in Detailed Disease Registry: Yes No Not Known

Detailed Disease Registry: [text input]

Detailed Disease Registry Patient ID: [text input]

↑ Use this button to put notes/reminders if needed

↖ Click here to fill in the disease-specific module.



Fill in the new outcome

Diagnosis-specific Outcomes

Core Data BONE DYSPLASIA Patient Access Generic Outcomes Audit Patient List

Patient ID - Date of Birth -

Bone Dysplasia

Supplemental material to complete this module

No Outcomes found

[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 - [redacted] Date of Birth - [redacted] Condition Group - Bone Dysplasia

Questionnaire: Achondroplasia - Child

New Outcome

Date of Birth	[redacted]	e-REC ID		Primary Condition	Primary bone dysplasia with micromelia
Current Gender	Male	Clinician Responsible for Patient	Mariya Cherenko	Specific Diagnosis	Achondroplasia
				Date of Diagnosis	

Family history | Anthropometry | Developmental score | Monitoring | Medical therapy | Surgery and other therapies

Genetics

Paternal height

Maternal height

Paternal age at conception

Maternal age at conception

- Select -

?

?

?

?

Fill in all the tabs which are applicable

Save Back



Fill in the generic outcomes

Generic Outcomes

Patient ID Date of Birth -

Core Data BONE DYSPLASIA Patient Access Diagnosis-specific Outcomes Audit Patient List

EQ-5D BPI-SF PROMIS Profile WHO ICF Patient Reported Outcome Request Settings

Show 10 entries Search:

Created Date	Completed By	Type	Mobility	Self Care	Activity	Pain	Anxiety	EQ VAS	Actions
2022-11-02	Dr. Ana Priego	EQ-5D-5L	2	2	2	2	1	71	
2021-03-24	Dr. Ana Priego	EQ-5D-Y	1	1	1	2	2	74	
2021-03-24	Dr. Ana Priego	EQ-5D-5L	1	2	2	1	1	80	

Previous 1 Next

Current Patient EQ-5D Request Settings: EQ-5D-5L every 3 months, starting on 2022-06-30

Patient EQ-5D Request Settings Create EQ-5D

Click here to fill in the new generic outcome for your patient: mobility, FQ-5D or other



PROMs



Choose the frequency for PROMs

Generic Outcomes Core Data BONE DYSPLASIA Patient Access Diagnosis-specific Outcomes Audit

Patient ID Date of Birth -

EQ-5D BPI-SF PROMIS Profile WHO ICF Patient Reported Outcome Request Settings

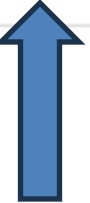
Create or edit requests for the Patient to complete generic questionnaires

Show entries

Generic Outcome Questionnaire	Request Frequency (months)	Request Start Date	Actions
WHO-ICF Mobility	9	2022-11-01	Edit Delete

Previous 1

Add Outcome Request



Click here to choose and add the frequency of email requests to the Patient to self-complete a Patient Generic Outcome Questionnaire.



Choose the frequency for PROMs

Core Registry Dashboard Patients Centres

Generic Patient Reported Outcome Request Settings

These settings control the frequency of email requests to the Patient to self-complete a Patient Generic Outcome Questionnaire

Outcome Questionnaire: WHO-ICF Mobility

Request Frequency: 6 months

Date of Next Request: mm/dd/yyyy

Save Cancel

Click here to choose the frequency of email requests to the Patient to self-complete a Patient Generic Outcome Questionnaire.





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Ways to contact us:



eurreb.eu



registries@lumc.nl



[drop-in sessions via Zoom](#)



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