

May 2023

Welcome to the new EuRR-Bone newsletter!

EuRR-Bone in brief

The European Registries for Rare Bone and Mineral Conditions are funded by the European Union's Health Programme. EuRR-Bone, working closely with ERN BOND and Endo-ERN, aims to create a high-quality, patient-centred pan-European registry for rare bone and mineral conditions in collaboration with the EuRECa project (European Registries for Rare Endocrine Conditions). EuRR-Bone, with the support of the scientific societies and patient organizations, will be of service to all patients, health care professionals and researchers involved in the care of people with rare bone and mineral conditions. EuRR-Bone is also strictly connected with patients and their caregivers, to collect data that really matter.

Twitter
Get regular updates about EuRR-Bone activities following EuRR-Bone twitter profile @EuRRBone

New website for registries!

euREB, the European Registries for Rare Endocrine and Bone Conditions consists of the EuRECa and EuRR-Bone projects.

The registries are aimed at maximizing the opportunity for all patients, health care professionals, and researchers to participate and use high quality, patient-centred registries. We are supported by both Endo-ERN and ERN BOND European Reference Networks, scientific and patient societies. Our goal is to be Europe's most comprehensive and accessible resource for researchers studying rare endocrine and bone/mineral conditions.

With the collected data in our registries we are able to do research and improve the healthcare for our patients.

We are excited to announce our new website: euREB.eu

There could not have been a more perfect time to launch it than on 3 April 2023 during our first EuRECa / EuRR-Bone joint Symposium.



A fresh look with new features tailored to our patients, clinicians and researchers.

- 🌐 A direct access button on our homepage to easily log in on e-REC and Core-Registry database to enter patient data
- 🌐 A Patient page with FAQs and answers to provide all the necessary information to our patients
- 🌐 A Condition Specific Modules page to showcase our current 9 modules we collect datasets on

Registries Annual Activity Reports

e-REC and the Core Registry are now available. Take a look at the reports and learn more about the data collected in the registries and the participating centres.

Please be sure to not only visit these pages, but also have a look at our teasers of upcoming events, news and so much more. Share this great new resource for Rare Endocrine and Bone conditions!

Whilst it may not be perfect, we're still working on it. The site will be under construction over the next few weeks.

If you have any questions or remarks, please reach out to our team at registries@lumc.nl and make sure you share our website on socials!

Successful first joint EuRECa & EuRR-Bone Symposium!

On Monday April 3rd 2023, the first joint EuRECa/EuRR-Bone symposium took place in Leiden, the Netherlands. With participants representing 11 countries we celebrated five years of the registries, took a look at our future plans, and exchanged knowledge.

We got to listen to different perspectives on the registries; from the ERNs, clinicians, researchers and patients. Registries activities have been discussed, such as our Condition Specific Modules, and we closed off the symposium with a nice lunch and poster exhibition.

The Registries Team is looking back at a great symposium, thanks to everyone joining us, either online or in-person! If you were not able to join us, please [watch the recording!](#)



Registry Drop-in sessions

A series of sessions, scheduled on every second Friday of the month at 2pm (CET) and the fourth Wednesday in every month at 4pm CET via ZOOM, have been arranged to demonstrate the registries (e-REC and Core Registry). You don't need to register, just drop in. Click on the following link to join: <https://us02web.zoom.us/j/86149844975>



Final EuRR-Bone meeting

We would like to thank everyone online and in person for their contribution to a successful final meeting on Monday 13 February in Leiden!

We had fruitful discussions and it was nice looking back at all the work we have done of the past three years. Please find the [presentations and minutes](#) of the meeting, and the presentation of the [Melorheostosis module](#).

Conferences & Meetings

EuRR-Bone has been present at various conferences and meetings:

- OIFE virtual Investigator meeting took place on 18 November 2022. The registries virtually presented data regarding Osteogenesis Imperfecta
- QualityofLife4OI Third online Conference 10 - 11 February 2023
- Endo-ERN General Assembly (GA) on 4-5 April 2023 in Amsterdam, The Netherlands. The registries had an exhibition booth with information materials and one-on-one sessions to help attendees create an account and a demonstration on how to enter patient data in the registries
- European Calcified Tissue Society (ECTS) Annual Meeting from 15-18 April 2023, Liverpool, UK. The registries had an exhibition booth with information materials and interactive demos
- ERN BOND General Assembly, 4 May 2023 in Bologna, Italy. The registries will have an exhibition booth with information materials and interactive demos.

Upcoming Events

- 🌐 [European Congress of Endocrinology \(ECE 2023\)](#) from 13-16 May 2023 in Istanbul, Turkey. The registries will be present virtually
- 🌐 [Italian Association on Achondroplasia Congress \(AISAC\)](#), 13-14 May 2023 in Rimini, Italy. The Registries have been invited to present the project to experts in the field of achondroplasia.
- 🌐 [OIFE Balancing Life with OI](#), 9-10 June 2023 in Stockholm, Sweden. The registries will have an exhibition booth and a presentation.
- 🌐 [Annual ESPE Meeting 2023](#), 21-23 September 2023 in the Hague, The Netherlands. The registries will have an exhibition booth with information materials and interactive demos
- 🌐 [ASBMR 2023 Annual Meeting](#), 13-16 October 2023 in Vancouver, Canada
- 🌐 [The Dutch Society for Calcium and Bone Metabolism](#) will hold its annual meeting on 8 and 9 November 2023 in Zeist, The Netherlands.

Bone2Gene: Artificial Intelligence for the diagnosis of genetic skeletal diseases

There are currently more than 400 known different rare bone diseases with very heterogeneous phenotypic features that make their accurate diagnosis a very challenging task. The Bone2Gene project aims at training an artificial intelligence that would be able to detect and recognize various and subtle dysmorphisms and patterns caused by different bone diseases. To accomplish this, a large number of training data is required. To learn more about this project and ways to contribute contact Dr. B. Javanmardi (e-mail: bjav@uni-bonn.de) or watch this presentation https://www.youtube.com/watch?v=Mypx_cCoQkU