

**ERN coordinators and
project managers meeting**
9-10 October 2023



**European
Reference
Network**

for rare or low prevalence
complex diseases

**Venue: Assembly Hall “Salón de Actos”, Hospital de Cruces,
Bilbao**

Cruces Plaza, 48903 Barakaldo

Metro stop: Gurutzeta/Cruces

October 9th – Day 1

Zoom link → <https://med-uni-tuebingen-de.zoom-x.de/j/68512756997?pwd=ektBUUdiMm9OWTR6dHJUVzVrQkgyQT09>

Time	Topic
14:00 – 14:05	Welcome
14:05 – 16:15	Core activities in all ERNs – status and plan (5 min per ERN)
	<i>Coffee break (30 min)</i>
16:45 – 18:00	ERN performance indicators that are able to show added value of ERN core activities for RD patients and member states
	<i>Dinner at 20:00 in Restaurante Aizian</i>

October 10th – Day 2

Zoom link → <https://med-uni-tuebingen-de.zoom-x.de/j/64364425089?pwd=Nm1ZMldsVzNmMVV1VjJWemVWZk8wUT09>

Time	Topic
09:00 – 09:20	Inter-ERN activities
09:20 – 09:40	Network agreements
09:40 – 10:00	Cooperation with clinicians from European countries that are politically not eligible to participate in ERNs
10:00 – 10:30	Expansion of disease Collaboration with HaDEA General communication with DG SANTE
	<i>Coffee break (30 min)</i>
11:00 – 12:00	Database on ERN guidelines Guidelines for ultrarare diagnoses
	<i>End of the event</i>

How to get to the venue?

Hospital de Cruces, Cruces Plaza, 48903 Barakaldo

Metro stop: Gurutzeta/Cruces

Assembly Hall (“Salón de Actos/Cafeteria” big yellow arrow on the map below).



How to get to the restaurant?

Restaurante Aizian, Leizaola Lehendakariaren Kalea, 29, 48001 Bilbao

Metro stop: San Mamés



List of participants on site

	<i>Coordinator</i>	<i>Project managers</i>
ERN BOND	Luca Sangiorgi	Lorena Casareto
ERN CRANIO		Ikram L'khssim Inga Bos Jana Steernman
Endo-ERN		Charlotte van Beuzekom
ERN EpiCARE	Alexis Arzimanoglou	Anne Robert
ERKNet		Alicia Armbruster
ERN-RND	Holm Graessner	Carola Reinhard Sophie Ripp
ERNICA		Iris den Uijl Sara Roman Galdran Romee van Steekelenburg
ERN LUNG		Thazhone Stephy Varghese Lisa Gietz Elisabeth Humbert-Dorfmueller
ERN Skin		Marie Guillou
ERN EURACAN		Johanna Schell Muriel Rogasik
ERN EuroBloodNet		María del Mar Mañu Pereira Victoria Gutierrez Valle
ERN eUROGEN	Wout Feitz	Michelle Battye
ERN EURO-NMD		Heike Pascal
ERN EYE	Hélène Dollfus	Dorothee Leroux
ERN GENTURIS	Nicoline Hoogerbrugge	Katarzyna Urbanczyk
ERN GUARD-HEART		Nynke Hofman
ERN ITHACA	Alain Verloes	Klea Vyshka
MetabERN	Maurizio Scarpa	Cinzia Maria Bellettato
ERN PaedCan		Zoltán Dobai
ERN RARE-LIVER		Hendrik Matthies Juliane Gaenge
ERN ReCONNET	Marta Mosca	Diana Marinello Eleonora Passeri
ERN RITA		Bart Uitterhaegen Coline Guiol
ERN TRANSPLANT-CHILD	Paloma Jara	Yadira Bravo Jose Luis Narro
VASCERN		Julie Hallac