

EPAG MEETING 2024

Meeting minutes

Location: Oslo, TSR-Sunnaas Hospital

Date: 5-7 June 2024

Participants:

	NAME	ROLE	PRESENCE
Liana	la Forgia	ePAG advocates, chair	Yes
Rebecca Tvedt	Skarberg	ePAG advocates, chair	Yes
Inês	Alves	ePAG advocates	Yes
Claudia	Finis	ePAG advocates	Yes
Susana	Noval Iruretagoyena	ePAG advocates	Online
Claudio	Pirola	ePAG advocates	Apology
Marco	Sessa	ePAG advocates	Apology
Tenna Toft	Sylvest	ePAG advocates	Yes
Nadine	Großmann	ePAG advocates	Yes
Luca	Sangiorgi	Coordinator, WP1-2-3-6-8 leader	Yes
Lorena	Casareto	Coordination Team	Online
Giusi	Giordano	Coordination Team	Online
Karen	Heath	WP4 leader - Grant beneficiary	Online
Natasha M.	Appelman-Dijkstra	WP5 leader - Grant beneficiary	Online
Joachim	Horn	WP7 leader - Grant beneficiary	Yes
Lena Lande	Wekre	WP7 leader - Grant beneficiary	Yes
Ines	Hernando	Eurordis - Invited speaker	Yes
Ole Rasmus	Theisen	TAKO Centre - Invited speaker	Yes

1. AGENDA ITEMS

Wednesday, 5th June 2024 (Times in CEST)

16:00-18:00	Arrival of participants at TRS Centre	
	Welcome and venue tour	Rebecca Tvedt Skarberg, Lena Lande Wekre
18:00-20:00	Networking dinner @ the meeting venue	

Thursday, 6th June 2024 (Times in CEST)

8:00-9:00	Breakfast	
9:00-9:15	Welcome and overview of meeting	Rebecca Tvedt Skarberg, Liana la Forgia
9:15-11:15	Review of all working groups	Luca Sangiorgi
	WP5 Registry, data management & analysis (9:15 - 9:30)	Natasha Appelman-Dijkstra
	WP1 Coordination and WP3 Monitoring (9:30-9:45)	Luca Sangiorgi, Lorena Casareto
	WP4 Healthcare and CPMS (9:45 - 10:00)	Karen E. Heath
	WP2 Dissemination (10:00 - 10:15)	Luca Sangiorgi, Lorena Casareto
	WP6 Training and Education (10:15 - 10:30)	Luca Sangiorgi, Lorena Casareto
	WP8 Capacity building for Ukraine (10:30 - 10:45)	Luca Sangiorgi, Lorena Casareto
	WP7 Clinical Practice Guidelines and Decision Support Tools (10:45 - 11:15)	Lena Lande Wekre, Joachim Horn
11:15-11:30	Coffee break	
11:30-12:30	Follow up on patient priorities	Inês Alves, Claudia Finis, Rebecca Tvedt Skarberg and Liana la Forgia
12:30-14:00	Lunch	
14:00-15:00	How Eurordis can help support ePAG groups	Ines Hernando (Eurordis)
15:00-15:45	Patient Journeys	Tenna Toft Sylvest
15:45-16:15	Coffee break	
16:15-17:00	Planning of ERN BOND plenary meeting 2024	Rebecca Tvedt Skarberg, Liana la Forgia, Luca Sangiorgi
17:00-17:30	Wrap up of the day	Plenary discussion. Chairs: Rebecca Tvedt Skarberg, Liana la Forgia, Luca Sangiorgi
19:00	Networking dinner @ The View Restaurant	

Friday, 7th June 2024 (Times in CEST)

8:00-9:00	Breakfast	
8:00-9:00	Breakfast Morning Meeting: discussion on future ePAG meetings over next 5-year period	Plenary discussion. Chairs: Rebecca Tvedt Skarberg, Liana la Forgia, Luca Sangiorgi
9:00-9:30	Wrap up of the meeting	Plenary discussion
9:30-11:30	Break	
11:30-12:30	Oral issues in rare bone conditions	TAKO Centre for oral health in rare medical conditions
12:30-14:00	Lunch	

2. MINUTES

WEDNESDAY, 5TH JUNE 2024

WELCOME AND VENUE TOUR

- 🌀 Round table of introduction of participants.
- 🌀 Venue tour and accommodation

THURSDAY, 6TH JUNE 2024

WELCOME AND OVERVIEW OF MEETING

- Welcome from Norwegian partners, Rebecca and Lena
- Welcome from ERN BOND Coordinator
- Welcome from the TRS Center for rare disease representative, presenting TRS organisation
- Round table of introduction of all attendants, in-person and online

WP5 REGISTRIES

- Overview of the registries their evolution since creation and their process of access
- Indices and geographical coverage of the centres reporting in e-REC and in the Core Registry
- Condition specific modules developed and their outcomes
- Procedure for opening new specific modules is explained: set up of a devoted module development group with action plan and timeline to have effective participation of the study group

⇒ ACTIONS/PLANS

- WP5 meeting calendar under definition
- Collaboration with WP4 to develop a rare skeletal dysplasia module
- Continuous monitoring via e-REC for facilitating the data retrieve (already in place with Endo-ERN)
- Inactive study groups will be dismissed in order to open to other studies
- Proposal to prepare a publication per study group: some of them are under preparation and will be shortly to the co-authors. Study groups leaders should coordinate the drafting.

WP1 - WP3 COORDINATION AND EVALUATION

- WP1 and WP3 activities are jointly presented and conducted as they have synergistic and complementary activities
- Overview of the leaders and beneficiaries: 8 WPs, each WP leader is now also a beneficiary of the EU Grant. All WPs have at least an ePAG advocate in the composition
- 2024 ERN BOND meeting on 15-16 October in Milan. ePAG participation in the meeting is discussed in the specific agenda item.
- ERN monitoring exercise: 18 core indicators. Reported on annual basis.
- 2024 monitoring exercise (related to 2023 data) had very positive results in the member response rate: 100% for ePAG and 94% for HCPs
- ePAG advocates are also involved in some indicators: they need to track throughout the year their activities in the ERN for the monitoring report.
- Importance to acknowledge the network for having the activities recognised and counted in the monitoring exercise (and the project reporting)

⇒ ACTIONS/PLANS

- WPs meetings are proposed on the third Monday of March, June, September, December of each year at 2.30 PM.
- 2024-2025 Calendar is shared. First meeting (an exception to the series) is on 24 June. Link and calendar invitations will be shared.

WP4 HEALTHCARE AND CPMS

- Overview of the WP4 leaders and beneficiaries
- Objective to maximise the CPMS use: BOND has not used it too much so far. New CPMS 2.0 to be released in the 2024 last quarter (more user friendly, mobile and desktop versions will be available). Supposed to implement a pilot reimbursement scheme for HCPs.
- Actions for increasing the number of CPMS patient discussions: since April regular CPMS monthly meetings (Tuesdays at 5pm -> Next meeting June 18th), permanent section in the BOND newsletter and devoted e-mail announcements.
- Call for collaborations via the ERN BOND website for stimulating CPMS use and collaborative studies

- ePAG representative presence in CPMS discussions could be relevant in some specific aspects (eg treatment): to be brought to the ERN IT support's attention
- ePAGs express concern that patients do not receive specific feedback after a CPMS review. How is CPMS of use to the patients if they do not receive feedback and second opinion? ePAGs ask WP4 to look into this to find a solution and how to Inform patients/patient organizations of this service.

⇒ ACTIONS/PLANS

- Focus group on improving genetic testing in RBDs (lead: Hospital La Paz) and on improving healthcare in pregnancies (lead: Necker Hospital), both will be supported by the CPMS 2.0 platform and will have an in-person meeting and a review paper as outcome; subsequently these data will be used to develop in collaboration with WP5 the EuRR-Bone data collection on both topics and explore the possibility of designing specific module(s).

WP2-WP6-WP8 DISSEMINATION, EDUCATION AND TRAINING, CAPACITY BUILDING FOR UKRAINE

- These WP activities are jointly presented and conducted as they have synergistic and complementary activities
- Communication and dissemination actions occur mainly via the social media, newsletters and website but also through meetings/events and publications. Participants are encouraged to follow these channels and to support dissemination activities of the network.
- ERN BOND communication strategy is conducted at an internal and at an external level and tailored to all the stakeholders (Patients/Patient organisations, HCPs/experts, Authorities/Policy makers, Researchers both academic and from industry and scientific societies).
- ePAG webpage: it is updated in the team composition, however some changes in the content are needed.
- Publications/Special issues: opportunity to coordinate a themed article collection on Frontiers; Coordination suggest to focus on transition from childhood to adolescent together with WP7. Agreed to share with WP7 leaders/group for organising the group
- ERN BOND integration in the national RD context: ERN BOND Italia (BOND network of Italian HCPs) is already established and had two plenary meetings at the Italian Ministry of Health premises
- Education and Training activities: webinars (also in collaboration with other RD projects/societies) and thematic workshops
- ERN BOND for Ukraine: dissemination activities and translation of the dissemination material

⇒ ACTIONS/PLANS

- ePAG webpage: by mid-July it is agreed ePAG to send to coordination the updated content of the webpage
- Suggested to have separate devoted meetings in addition to the proposed WP2-WP6-WP8 calendar. ePAG request get involved in the communication strategy as well as the website content
- How to contribute? Propose your topic, proposal for the webinar series "talking about" or proposing other things – they could propose a series of webinars., joint webinars with experts... etc
- How to contribute to ERN BOND dissemination? Acknowledging the network, including the logo, disseminating information about ERN BOND and promptly communicating them to Coordination
- ERN BOND education programme: ePAG to propose topics (they could be ePAG driven only or jointly presented with the experts). During the meeting these topics were suggested: presentation of ePAGs - why, what and how?, presentation of patient priorities, dental issues and rare bone diseases, presentation of patient journeys.
- Plan to develop the RBD education programme (WP6-WP2) in Poland/Romania for favouring the participation of Ukrainian doctors. This needs to be explored with Hadea.

WP7 CLINICAL PRACTICE GUIDELINES AND CLINICAL DECISION SUPPORT TOOLS

- Overview of the WP: aims, tasks and deliverables
- Role of gait analysis in RBDs: scoping review of the literature concluded; outcome will be in a paper due by Sep 2025. Draft will be shared among the group and ePAGs
- ACAR "open dialogues" project is presented by Liana: results were published in the BOND EJMG special issue (Scognamiglio et al, 2024)

⇒ ACTIONS/PLANS

- Functions and challenges in adults with RBD: scoping review is planned. To select some pilot conditions to start with. Outcome could be as support to Patients' Journey

- ☼ Transition to adulthood: to constitute a multidisciplinary focus group, including patients, to review current knowledge and mapping existing tools with the final aim to produce a Clinical Practice Guideline.

FOLLOW UP ON PATIENT PRIORITIES

- ☼ Summary of the 2023 ePAG workshop “Patient priorities in ERN BOND beyond Quality of Life”. The workshop focused on 4 identified priorities: pain, pregnancy, movement and transition.
- ☼ Mentimeter results are summarised. They need to be addressed in the next workshop edition
- ☼ Commentary paper draft on the workshop outcomes, prepared by Ines who is in charge of coordinating the activity, is ready. Inputs from the group are now needed (see Actions/plans)

⇒ ACTIONS/PLANS

- ☼ Commentary paper:
 - to identify the journal which accepts commentary papers (EJMG-European Journal of Medical Genetics could be the best choice as we already published the [ERN BOND Special Issue](#); Coordination to contact the chief editor)
 - to clearly highlight the paper is from the ERN BOND ePAGs
 - Coordination to share the document on Drive, to provide number and type of participants
 - Deadline for sending comments: end of June for comments; early July for submission allowing to present it at the 2024 October network meeting
- ☼ Publishing a second paper(s) showing how workshop results have driven the ERN BOND action plan to be advertised in the October meeting for inviting experts to contribute

EURORDIS ROLE TO SUPPORT PATIENT PARTNERSHIP IN THE ERNs BY INES HERNANDO

- ☼ EURORDIS role to support ERNs: 3 main areas
- ☼ EURORDIS supporting ePAG advocates by facilitating peer learning in different areas (Q3-Q4 Calendar of meetings is shared), developing tools supporting the ePAG's role in the ERNs, providing tailored support to BOND ePAGs
- ☼ Patient Partnership Framework
- ☼ Patient Partnership Resources: online repository for easy access to resources & tools facilitating patient partnership in the ERNs

PATIENT JOURNEY

- ☼ Tenna presents a mapping exercise on the topic and the ePAGs discussions so far
- ☼ ERN BOND ePAGs have discussed two options for releasing Patient Journeys: endorsing existing journeys and/or producing the first ERN BOND patient journey ("transition" is the selected topic)
- ☼ Endorsement:
 - Defining the endorsing criteria in line with EURORDIS checklist
 - Policy on patient journey initiated from pharma companies
 - Develop an example and publish it on the website
 - Define the dissemination procedure to patient organizations and health care providers

⇒ ACTIONS/PLANS

- ☼ Agreed to proceed both in endorsing the existing journey endorsement and producing our new patient journeys in ultra rare bone diseases
- ☼ Define the added value and the implementation process
- ☼ Endorsement of existing Patient Journeys as presented and explore adding extra stages or content.
- ☼ Coordination will support ePAG in the process.
- ☼ Potential work with WP7: suggestion to produce guidelines and patient journeys on the same topic, highlighting the topic is addressed from different perspective
- ☼ Creating a working group -> to communicate to Tenna the willingness to take part

PLANNING OF ERN BOND PLENARY MEETING 2024 (EPAG CONTRIBUTION)

- ☼ The meeting will be on 15 October afternoon and the 16 Oct morning
- ☼ Open discussion for the ePAG role. Decisions in actions

⇒ ACTIONS/PLANS

- ePAG slot of one hour will be at the beginning of the meeting focusing on the patient priorities (presenting the commentary paper) and patient journeys, including the ePAG team introduction
- Devoted slot for the activities on Guidelines on pregnancy (ERN Guidelines Programme) for Claudia and Neveen
- Request from WP7 to have a WP meeting in the 15th morning
- To have a Mentimeter session
- ePAG would like to have a closed meeting however ePAG agree to prioritise to attend the WP meetings. A closed meeting to be planned outside of WP meetings.
- Proposal to have an ERN BOND patient summit: as this was not originally planned within the current 4-year project budget and eligibility needs to be checked. This is a proposal for future activities and could be held at the end of the current project period giving more time for organisation and administrative checks (see plenary discussion on 7th June).

FRIDAY, 7TH JUNE 2024

PLENARY DISCUSSION ON FUTURE ePAG MEETINGS

- A dedicated ePAG slot in the plenary meetings -> next one in Milan in Oct 2024
- Joint workshop with other patient associations in future (not decided yet if integrated in the ERN BOND plenary meeting)
- ePAG internal meeting in 2025 as the present in Oslo with WP leaders invited to participate in-person (proposal in Spring 2025). For the location it is important to have direct flights and accessibility. Time and place to be decided on as soon as possible.
- ePAG webinars and workshops to engage more RBD patient associations. Suggestions: ePAG presentation - how we are and what we do, ERN BOND's patient priorities, Patient Journey project, Dental issues in rare bone disease
- ERN BOND summit for dissemination of the ePAG actions and activities gathering all stakeholders:
 - to identify the added value of this summit
 - to be proposed to the Steering Committee
 - to check financial and administrative aspects
 - to explore possibility of external contributions
- Round table for the take home messages and final considerations
- Keywords from the meeting: **energising stimulating, challenging, promising and ambitious**

ORAL ISSUES IN RBDs PRESENTED BY DR. OLE RASMUS THEISEN

- Overview on the clinical aspects in the diagnosis of RBDs: dental issues and management (OI, XLH, FOP, MO, ACH)
- Norwegian health system is explained
- Dental experts are lacking in the BOND community
- The issue could be included in the patient journey
- The topic will be proposed in the webinar programme

Speakers' presentations are enclosed and are an integral part of the document.

3. NEXT STEPS

As described and listed throughout the document.

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