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REPORT FROM MEETINGS OF THE COORDINATION ACTIVITY

Executive Summary

One of the tasks of ADOPT WP7 dealing with Rare Diseases (RD) is to coordinate the efforts and integrate existing biobanks and resources within the RD field towards sustainable biobanking. Important for achieving this task is the alignment of activities within RD projects and initiatives to ensure the sustainable base for the RD biobanks within BBMRI-ERIC.

In order to obtain this aim, several meetings and teleconferences have been attended by BBMRI-ERIC, LUMC/UMCG and IOR representatives under the coordination duties. During these gatherings a plan for the upcoming H2020 calls was drafted, the sustainability plan aimed at continuing the cataloguing efforts of RD-CONNECT within BBMRI-ERIC was elaborated and, with the help of National Node, the joint programme for RDs. Following these activities, BBMRI-ERIC has made the BBMRI-ERIC IT services interoperable and aligned with the services of the RD Communities. Furthermore, BBMRI-ERIC improved the sustainability of RD-CONNECT and facilitating access to RD biobanks by specific tools (BBMRI-ERIC Negotiator).

During this period, IOR in collaboration with ERN BOND has accomplished a collaboration with Osteogenesis Imperfecta Federation Europe (OIFE) and Brittle Bone Diseases Consortium (BBDC). This collaboration has achieved a survey on the state of the art of diagnosis and treatment of OI in Europe. The results of the survey have been reported in a White Paper (<http://brittlebone.org/oi-white-paper-ern-bond/>) that sheds light on the unmet needs of patients in this specific area and will serve as a basis for a dialogue with policy-makers on the challenges related to diagnosis of rare bone diseases.

IOR has led the BBMRI Rare Diseases Working Group (WG) in order to sustain the continuous work on activities related to rare diseases. The WG efforts aim to avoid any duplication of work on overlapping activities among other linked projects ERNs, ADOPT WGs, RD-CONNECT and ELIXIR. In order to obtain this result, IOR has developed and improved a Helpdesk model and has created a Pilot Study on OI in collaboration with the National Nodes of BBMRI, the RD-CONNECT project and ELIXIR infrastructure.



Finally, the networking has been realized particularly with BBMRI-ERIC and RD-CONNECT in order to provide sustainable cataloguing solutions for RD-CONNECT within BBMRI-ERIC.

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1. Background

RD research projects have developed many biobanks and registries in Europe as part of their efforts to allow access to samples and data for research and clinical trials. Several projects have also contributed to the RD area in providing shared tools and unified platforms for the benefit of the RD community. However, many initiatives suffer from unsustainable structures for governance and funding schemes. Part of the work on ADOPT WP7 is to coordinate and integrate the activities and efforts of different projects involving RD biobanks. For this purpose, BBMRI-ERIC, LUMC/UMCG and IOR together follow the developments within the RD community, participate in meetings and coordinate working group teleconferences for the advancement of a sustainable basis for biobanking activities within the RD community.

2. Approaches (Methods)

This report is an update to the reports provided at M12 and M24 including information on several meetings, teleconferences and a webinar relevant to the coordination activities of WP7 in the RD field.

3. Results

3.1 Coordination activities (M1; Oct 2015 - M12; Sept 2016)

Several meetings and teleconferences have been attended by BBMRI-ERIC, LUMC/UMCG and IOR representatives under the coordination duties (Table 1). The 1st Coordination meeting was held in October 2015 (Table 1). The focus of the meeting was to provide an update of any news relevant to the RD Community and to draft a plan for the upcoming H2020 calls (participants present from BBMRI-ERIC, LUMC/UMCG and IOR). An important collaborative meeting with RD-CONNECT representatives was held in March 2016 during the RD-CONNECT Annual meeting within a separate session on ‘sustainability of key RD-CONNECT assets’. This session determined the future collaboration steps and the sustainability plan aimed at continuing the cataloguing efforts of RD-CONNECT within BBMRI-ERIC (participants from BBMRI-ERIC and IOR). In May 2016, a coordination teleconference was organised with several research infrastructures (EATRIS, ECRIN, BBMRI-ERIC, ELIXIR) to discuss the joint programme for RDs and to discuss the national strategies towards the joint effort in the RD field. Table 1 addresses the other meetings in regards to the coordination efforts in RD field realised within the 1st year of ADOPT BBMRI-ERIC.

Table 1: Coordination efforts in the RD field within the first year of ADOPT BBMRI-ERIC

Meeting no.	Name of the meeting	Participants	Locations and dates	Meeting
1	Kick off Meeting ADOPT BBMRI-ERIC	L. Sangiorgi, GJv Ommen, O. Törnwall, JE. Litton	Vienna, 20-21/10/2015	Kick off Meeting
2	RD-CONNECT Annual Meeting	L. Sangiorgi, M. Mordenti, GJv Ommen, O. Törnwall	Barcelona, 8-10/03/2016	Annual meeting
3	EUROBIOBANK Assembly meeting	L. Sangiorgi	Barcelona, 9/03/2016	Assembly meeting



4	ADOPT BBMRI-ERIC Meeting	L. Sangiorgi GJv Ommen, O. Törnwall, JE. Litton	La Valletta, Malta, 16-18/03/2016	Project meeting
5	ADOPT BBMRI-ERIC AoM #6	L. Sangiorgi	Vienna, 27-28/04/2016	Meeting
6	ECRD 2016: The European Conference on Rare Diseases & Orphan Products	L. Sangiorgi	Edinburgh 26-28/05/2016	Meeting-Poster
7	RD-ACTION Workshop: 'Exchanging data for virtual care within the ERN Framework	L. Sangiorgi	Brussels, 28-29/09/2016	Workshop
8	Europe Biobank Week, Patient and ELSI sessions	L. Sangiorgi	Vienna, 13-16/09/2016	Meeting



3.2 Coordination activities (M13; Oct 2016 - M24; Sept 2017)

During this period, BBMRI-ERIC participated in several meetings to make the BBMRI-ERIC IT services interoperable and aligned with the services of the RD Communities, namely represented by RD-CONNECT (Table 2). BBMRI-ERIC also works towards the sustainability of RD-CONNECT (e.g. integrating the ID cards within the BBMRI-ERIC Directory) and facilitating access to RD biobanks by specific tools (e.g. BBMRI-ERIC Negotiator).

IOR has also been leading the coordination efforts on their behalf by partaking and presenting ADOPT project activities in several meetings relevant to the RD field (Table 2). During this period, IOR in collaboration with ERN BOND (ERN on bone disorders) mainly focused on setting up a collaboration for future joint activities with Osteogenesis Imperfecta Federation Europe (OIFE) and Brittle Bone Diseases Consortium (BBDC). As reported at M12, ERN BOND has settled the collaboration with OIFE for the conduction of a survey on the state of the art of diagnosis and treatment of OI in Europe.

The Objective of the Survey

The aim of this questionnaire was to provide a picture of the situation in the 10 Member States represented within ERN-BOND (Belgium, Czech Republic, Estonia, France, Germany, Italy, The Netherlands, Portugal, Sweden, United Kingdom) in regard to diagnosis and to identify the main challenges and potential solutions that could help reduce diagnosis delays. This activity served to identify existing care gaps within and among ERN BOND full members and to collect patient information on their experience leading to the disease diagnosis. The results of the survey have been reported in a White Paper (<http://brittlebone.org/oi-white-paper-ern-bond/>) that sheds light on the unmet needs of patients in this specific area and will serve as a basis for a dialogue with policy-makers on the challenges related to diagnosis of rare bone diseases.

This questionnaire, focusing on Osteogenesis Imperfecta (OI), one of the disease areas covered by ERN BOND, was used as a prototype taking into consideration that OI represents a heterogeneous group of generic disorders that affect the bones.

OIFE facilitated the capillary dissemination of the questionnaire among patients, utilizing the OIFE Network in Europe.

Lastly, a member of OIFE is an ePAG (patient representative) in ERN BOND and is member of the BOND Steering Committee, the most important organ in the governance of the Network.

Table 2: Coordination efforts in the RD field within the second year of ADOPT BBMRI-ERIC

Meeting no.	Name of the meeting	Participants	Locations and dates	Meeting
9	RD-CONNECT Hackathon	P Holub, D.J. van Enckevort	Milan, 22/11/2016	Sustainability and synergies
10	RD-CONNECT & BBMRI-ERIC sustainability meeting	P Holub, D.J. van Enckevort	Milan, 20/02/2017	Sustainability and synergies
11	BBMRI & European Commission's Joint Research Centre (JRC) meeting	P Holub	Ispra, 13-14/06/2017	Collaboration with BBMRI and JRC
12	Kick off meeting ERN BOND	L. Sangiorgi	Rome, 22-24/05/2017	Kick off Meeting



13	Meeting with OIFE	L. Sangiorgi, I Westerheim, R Tvedt	Oslo, 26/08/2017	Future collaboration with OIFE and ERN BOND
14	OIOslo2017, 13th International Conference on Osteogenesis Imperfecta	L Sangiorgi, I Westerheim, R Twedt, L W Valerie, C Daire, K Javaid	Oslo, 27-30/08/2017	Collaboration meeting with OIFE and ERN BOND
15	MonitoRaRe - Report 2017	L Sangiorgi	Italian Parliament Rome, 27/07/2017	An update on the Italian national and European situation on RDs
16	Brittle Bone diseases Consortium (BBDC)	L. Sangiorgi, C V R Sutton	Oslo, 27/07/2017	Towards structured collaboration of ERN BOND and BBDC
17	13th meeting of the International Skeletal Dysplasia Society	L. Sangiorgi, C V R Sutton	Bruges, 20-23/09/2017	Structured collaboration with BBDC, follow up meeting from BBDC (nr 13)
18	Meeting with CHAFAEA	L. Sangiorgi, M de la Calle, P D'acapito	Luxemburg, 06/09/2017	Future activities discussions with ERN BOND and CHAFAEA Project
19	Meeting with Lauro Panella and Antonio Tajani	L. Sangiorgi	Rome, 07/09/2017	Presentation of the OIFE Survey White Book
20	EURORDIS	L. Sangiorgi	Brussels 07/09/2017	Preparation for presenting ERN BOND to during an upcoming Parliament audition in 2018
21	13th International Skeletal Dysplasia Society (ISDS) Meeting	L. Sangiorgi	Bruges 20-23/09/2017	Presenting ERN BOND to ISDS
22	Second RD-Action Workshop "Using Standards and Embedding Good Practices to Enable Interoperable Data-Sharing in ERNs"	D.J. van Enckevort	Brussels, 27/04/2017	Recommended Practices for Data Standardisation in the Context of the operation of European Reference Networks
23	ADOPT midterm review	L. Sangiorgi	Brussels, 27-28/06/2017	Project meeting
24	BBMRI-ERIC Assembly of Members	L. Sangiorgi	Losanna, 19/05/2017	Meeting



IOR has led and organised 4 teleconferences (15/11/2017, 06/02/2017, 10/05/2017, 05/07/2017) for the BBMRI Rare Diseases Working Group (WG) in order to sustain the continuous work on activities related to rare diseases. The WG teleconferences have involved representatives from BBMRI-ERIC, BBMRI.fi, BBMRI.pl, BBMRI.mt, BBMRI.be, BBMRI.ee, BBMRI.tr, BBMRI.nl, BBMRI.it, BBMRI.at and representatives from the RD-CONNECT project. The WG efforts aim to avoid any duplication of work on overlapping activities among other linked projects ERNs, ADOPT WGs, RD-CONNECT and ELIXIR. The WG also enabled the involvement of the BBMRI National Nodes within the RD activities.

The main topics and achievements are as follows:

- Improvements and further development of the Helpdesk model
- Pilot Study on OI: collaboration with the National Nodes of BBMRI, the RD-CONNECT project and ELIXIR infrastructure towards:
 - o FAIR (findable, accessible, interoperable, reusable) data within the biobanks and RD registries
 - o ERN BOND involvement
 - o Mapping of data and samples for OI (what is available and where) based on the data model of IOR has been initiated. Support for this work will be provided by ELIXIR and BBMRI-ERIC Common Service IT.
 - o Current involvement of 250 patients for OI with further cases in the pipeline
- Steps taken towards assessing the sustainability of RD biobanks, how to move forward e.g. collaboration with Pharma and ERNs -> small working group to be established for this
- Upgrading the concept of RD Common Service by considering the existence of ERNs in EU – future users of BBMRI-ERIC and National Node services
- Focus to invest in the quality of the sample-related data
- The outputs of the Quality groups of BBMRI-ERIC and EuroBioBank will follow in regards to the sample quality
- The BBMRI-ERIC Directory of RD Biobanks, developed under BBMRI-ERIC by UMCG/LUMC will be tested also in the Telethon Network of Genetic Biobanks (TNGB)

RD Helpdesk Webinar

BBMRI-ERIC organised a Webinar on the RD-Helpdesk on 16/06/2017 providing a hands-on tutorial showing how to use Request Tracking (RT) system¹, which is the basis for the Rare Diseases Helpdesk. The tutorial focused on how to submit a request (thus how to create a "ticket"), how to manage the ticket and also how to manage queues of tickets within the whole RT. The webinar was well received by the participants.

Patient involvement

BBMRI-ERIC has established a patient chapter as part of its Stakeholder Forum involving various patient advocacy groups (Genetic Alliance UK, Alzheimer Europe and Dutch VSOP) including an RD representation (EURORDIS). The aim of the Stakeholder Forum is to know and address the concerns of its stakeholders and to provide a platform for discussions for the various groups.

3.3 Coordination activities (M25; Oct 2017 - M36; Sept 2018)

Several meetings and teleconferences were attended during last year of project (Table 3).

¹ <https://bestpractical.com/request-tracker>



BBMRI-ERIC works towards RD-CONNECT, and regarding the RD-CONNECT tool sustainability beyond the end of the project, a joint meeting with all entities involved (i.e., BBMRI-ERIC, RD-CONNECT, EuroBioBank) was held in September 2018 on the IOR premises. Activities for the integration of RD-CONNECT tools into the BBMRI-ERIC platform are still ongoing.

Furthermore, in order to sustain the continuous work on the activities related to rare diseases, IOR has continued to lead and organize teleconferences (27/09/2017, 01/02/2018, 23/04/2018) for the BBMRI Rare Diseases Working Group (RDWG). The RDWG teleconferences have involved regular BBMRI-ERIC and RD-CONNECT representatives. The WG also enables the involvement of the BBMRI National Nodes within the RD activities: representatives/contact persons for National Nodes Members (Austria, Belgium, Estonia, Finland, Germany, Italy, Malta, The Netherlands, Poland, United Kingdom, Czech Republic, France, Greece, Norway, Sweden, Switzerland, Latvia) and observers (Switzerland, Turkey, Cyprus). Moreover, representatives/contact persons of Spain Biobanks and of Telethon Network of Genetic Biobanks have been involved.

The main topics and achievements are as follows:

- OI Pilot study: to make data of biobanks and registries Findable, Accessible, Interoperable and Reusable (FAIR) – a system developed at Leiden University, LUMC – a pilot study to demonstrate that it is possible to integrate data and make it interoperable:
 - selected ontologies: Orphanet (diseases), HPO (signs and symptoms) and HGNC (gene)
 - OI elements file (.xls) individuated from the data collection formats of OI registry, shared also with the RD WG
 - few driving questions for OI Pilot study, as example
 - updating of the work progress by LUMC
- Helpdesk: preparation and discussion of the Frequently Asked Questions (FAQs) and Wikis, related to RD Biobanks and Registries

The Survey

The White Paper was presented on Rare Disease Day 2018 at the European Parliament. In the future, this questionnaire could be replicated in other disease areas.

Table 3: Coordination efforts in the RD field within the third year of ADOPT BBMRI-ERIC

Meeting no.	Name of the meeting	Participants	Locations and dates
25	<i>ERN coordinators meeting</i>	Coordinator	Brussels, 10-12/10/2017
26	<i>FOP (Fibrodysplasia Ossificans Progressiva) Drug Development Forum</i>	BOND member	Alghero, 13-14/10/17
27	<i>ERN Info Day, Ministry of Health</i>	Coordinator	Rome, 16/10/17
28	<i>WORKSHOP ON HOSPITAL MANAGERS AND EUROPEAN REFERENCE NETWORKS IMPLEMENTATION</i>	L: Sangiorgi	Rotterdam, 16-17 /11/17
29	<i>GIORNATA INTERNAZIONALE BBMRI.IT</i>	L. Sangiorgi, M. Locatelli	Milan, 15/11/2017
30	<i>BBMRI ERIC ASSEMBLY OF MEMBERS 10^o SESSION</i>	L: Sangiorgi	Vienna, 8/11/2017
31	<i>Residential course "Congenital malformations: from prenatal diagnosis to postnatal therapy"</i>	L: Sangiorgi	Rome, 30/10/2017



32	<i>workshop on General Data Protection Regulation (GDPR)</i>	BOND member	Brussels, 20/10/17
33	<i>Hyperkalcemia and hypokalcemia in neonates, 19th Days of Pediatric Endocrinology</i>	BOND member	Pisek, 10/11/17
34	<i>Conference German Society of pediatric endocrinologists</i>	BOND member	Freiburg, 17/11/17
35	<i>Italian Society of Human Genetics Conference, XX Ed.</i>	project manager	Naples, 15-18/11/2017
36	<i>Workshop Role of Hospital Managers in Shaping the Future of the European Reference Networks.</i>	Coordinator, BOND member, HCP representatives	Rotterdam, 17/11/17
37	<i>Conference on Undiagnosed Rare Diseases, National Center for Rare Diseases</i>	project manager	Rome, 20/11/2017
38	<i>OSR meeting</i>	Coordinator	Milan, 01/12/17
39	<i>A girl with fracture of clavicle and lower limb, 18th Days of Pediatric Endocrinology</i>	BOND member	Pardubice, 01/12/17
40	<i>workshop on clinical practice guidelines, RD-ACTION.</i>	BOND member	Rome, 07/12/17
41	<i>ERN BOND Info Day</i>	Coordinator, project manager	Bologna, 18/12/17
42	<i>Workshop on the Preparation of Final Report</i>	project manager, financial manager	Rome, 22/01/18
43	<i>ERN Symposium – LUMC</i>	BOND member	Leiden, 24/01/18
44	<i>1st Meeting on Rare Bone Diseases</i>	BOND member	Coimbra, 16-17/02/18
45	<i>ERN BOND – First Technical meeting</i>	All BOND Members	Brussels, 26-28/02/2018
46	<i>ERN-BOND White Paper on Diagnosis, European Parliament</i>	All BOND Members	Brussels, 28/02/2018
47	<i>RE(ACT) CONGRESS 2018:</i>	Coordinator	Bologna, 07/03/18
48	<i>EPTRI Kick off Meeting</i>	L: Sangiorgi	Rome, 15-16/01/2018
49	<i>Meeting European Society on rare bone diseases</i>	L: Sangiorgi	Brussels, 16-17/1/2018
50	<i>EPJ RD MEETING</i>	L: Sangiorgi	Paris, 5-6/2/2018
51	<i>RD-ACTION, EMA AND DG SANTE WORKSHOP: HOW ERNs CAN PROVIDE ADDED-VALUE IN THE AREA OF CLINICAL RESEARCH</i>	L: Sangiorgi	London, 28-30/5/2018
52	<i>SYMPOSIUM IN CLINICAL GENETICS & GENOMICS</i>	L: Sangiorgi	Athens, 1-2/6/2018
53	<i>X TRUST-4RD Methodology for use of RWE for Rare Diseases Stakeholder Roundtable</i>	L: Sangiorgi	Brussels, 21/6/2018
54	<i>RD ACTION FINAL EVENT</i>	L: Sangiorgi	Paris, 28/6/2018
55	<i>EURO BIO BANK WHORKSHOP</i>	L. Sangiorgi, M. Locatelli	Rome, 18/10/2018
56	<i>9th WORLD ORPHAN DRUG CONGRESS</i>	L: Sangiorgi	Barcelona, 6-8/11/2018
57	<i>BBMRI AoM #12</i>	L: Sangiorgi	Breukelen, 12-13/11/2018



3.4 Networking and Synergies

ERN on Rare Bone Diseases (ERN BOND)

The ERN proposal on Rare Bone Diseases comprising 38 healthcare providers from 10 EU countries was approved in December 2016 by the European Reference Network Board of Member States. BOND combines skeletal dysplasia and metabolic bone diseases, and the application has been coordinated by the ISDS, ESPE, ICCBH, ESE and ECTS. The Network Coordinator is Dr Luca Sangiorgi (IOR).

European Reference Networks (ERNs) create a clear governance structure for knowledge sharing and care coordination across the EU. They are networks of centres of expertise, healthcare providers and laboratories that are organized across borders. A centre of expertise could be a clinical team, a medical centre or a hospital and must be formally accredited by its Member State.

4. Discussion and conclusions

Through coordination of activities within the RD field, the WP7 is able to set out the platform for RD Common Service. Collaboration with various European projects and initiatives also enables planning and execution of the OI pilot study with maximum capacity and expertise. With coordinated actions, the tools developed in WP7 (e.g. Helpdesk, ID Cards for the RD biobanks) can be tested, validated and improved. Furthermore, transnational efforts executed in a coordinated manner are essential to optimally use the existing resources and avoid duplication of work.

Specifically, the WP7 main goal is to establish a Common Service for Rare Diseases, including a registry and biobank service with helpdesk function and translational tools, as well as standards and templates for data harmonization. The challenge is to maintain, on one hand, the well-established infrastructures, tools and procedures developed by the RD community (e.g., patient registries, research- and clinician-driven biobanks, platforms, etc.) and on the other hand, to integrate and harmonize them with BBMRI-ERIC standards and procedures.

In order to pursue these objectives, we also set up a working group on rare diseases to reduce fragmentation and work jointly to optimize the results of various infrastructures and projects which are currently working on rare diseases. In line with these activities, one of the main initiatives for the implementation of an RD common service is to establish a Help-desk facility to provide real-time support to RD biobanks and/or registries. Registry/biobank Help-desk facility (RD-HD) has been developing, using as a model the Tiered Structure-Generalist Model: it provides for a layered structure with requests to three possible levels, and three possible levels of assistance.

Moreover, BBMRI-ERIC started in 2018 with a new vision towards a more service orientated organization and after the official Common Service ELSI review, work has been conducted to incorporate the Rare Diseases common service and help-desk to the existing Common Services.

Lastly to deploy the visibility and accessibility of Rare Disease Biobanks in the BBMRI-ERIC portal, the Directory 3.0 software has been extended to create a separate section in the Directory that highlights Rare Disease biobanks, and synergized with efforts in the RD-connect project, the MIABIS standardization effort for minimum information about biobanks and the MOLGENIS open source project.



As part of the sustainability plan of RD-Connect we will import the entire RD-Connect ID-Card catalogue into the Directory and make RD-Connect and make use of the concept of networks in the Directory to make the participating biobanks visible as an interconnected resource.

With the update of the BBMRI-ERIC Directory to version 3, the existing collections were reviewed and compared with the listing of Rare Disease biobanks that is publicly available on the RD-Connect ID-Card system. Further, the collections of these biobanks have been classified as 'rare disease collection' to make them visible in the dedicated rare disease section that we created as outlined above.

5. Next Steps

Though the ADOPT project has come to an end, BBMRI Rare Diseases Working Group will continue to strengthen the established collaboration with other RD realities, i.e. BBMRI National Nodes, and ERN BOND. Several efforts will be put in place to continue towards harmonizing initiatives within the RD field, achieving sustainability and providing services for the RD community. ERNs are a pivotal collaborator and a high impact player in the RD field, particularly as primary user of the services of BBMRI-ERIC and/or National Nodes, especially the requests of samples and data access.



Appendix I: ERN BOND Newsletter N.2



ERN BOND Newsletter N.2

- ❖ **21st-22nd November 2018** – 4th Conference on European Reference Networks was held in Brussels. All presentations and streaming videos are available at the following link: https://ec.europa.eu/health/ern/events/ev_20181121_en
 - To see the promotional video animation on ERNs: https://ec.europa.eu/health/ern/videos_en
 - For those of whom participated to the Conference, you can give your feedback on the conference via this short survey: <https://ec.europa.eu/eusurvey/runner/ERNConferenceSatisfactionSurvey>. It will take only a few minutes and will be helpful for us to improve future events. The conference satisfaction survey will be available until 03/12.
 - A flash report on the Conference was published in the Commission webpage https://ec.europa.eu/health/sites/health/files/ern/docs/ev_20181121_sr_en.pdf
- ❖ **13th and 14th November** - Luca visited the Leiden University Medical Center to see the training and education platform in use at Leiden University and to new technology solutions that can be used within ERN BOND WG8 training plan.
- ❖ **c4c application** - BOND WG4 Clinical Trial is coordinating the application to c4c from ECRIN for funding from to undertake a study of repurposing losartan in osteogenesis imperfecta. <https://www.ecrin.org/news/c4c-call-proposals>
- ❖ **2019 Call for proposals on Registries** – European Commission confirmed a new call for registries will be come out in 2019 dedicated to ERNs. ERN BOND Coordinator will keep you updated.
- ❖ **15th December** – ERN BOND public website will be launched: <http://ernbond.eu/>
- ❖ **13th - 14 February** – the ERN BOND Annual Technical Meeting will be held, at Regione Emilia-Romagna Rue Montoyer 21 - 1000 Bruxelles. All ERN BOND Members are invited to participate.

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