



European Joint Program on Rare Diseases

Training Workshop

Rare Disease Biobanks: Roles in Research Networks and International Collaborations

10-11 May 2021

Online

As a part of the work in EJP RD Pillar 3: Capacity Building & Empowerment
Organised by project partners Hacettepe University (Ankara, Turkey) and
Fondazione Telethon (Milan, Italy)

www.ejprarediseases.org

ABOUT THE TRAINING WORKSHOP

This training is a beginner level course.

The workshop is aimed at biomedical researchers, medical professionals and biobank managers who want to organise biomedical research projects on human biological samples. We welcome the participation of representatives from patient organisations as well.

The aim is to emphasize the need for rare disease biobank networks to overcome sample scarcity and to draw attention to some of the challenges for collaborative research but at the same time also give examples of platforms, infrastructures and national activities that are catalysing national and international collaborations. It is hoped that at the end of this training course, lectures will highlight a checklist for the attendants as a guideline for biobank networks and research.

This training has two modules:

The **first module** will assess the important contribution of collaborations at national and international level for research on rare diseases and the pivotal role biobanks play. Local experiences and RD Biobanks in national plans will be described. To be able to harmonize networking activities main challenges that need to be overcome will be taken up. Lectures will take up subjects involving ELSI topics such as informed consent types, quality assurance programs and the new ISO standards, FAIR data principles for data sharing and GDPR and its role in the context of biobank samples and data usage.

In the **second module**, lectures are organized to give an overview of already functioning networks in research demonstrating some solutions to the challenges taken up in the first module. Presentations will provide examples of cross-border collaborations, biobanks in European Reference Networks (ERNs), virtual resources created for biobank research through EJP RD. Finally, a case report of a transnational collaboration in research will be given by a project approved through Pillar 1 of EJP-RD.

List of speakers and chairs:

Ece Akhan, Hacettepe University, **EJP RD**, Turkey
Neşe Atabey, BBMRI National Node Turkey
Eva Bermejo-Sanchez, Instituto de Salud Carlos III, **EJP RD**, Spain
Ronny Baber, Leipzig Medical Biobank, ESBB, Germany
Monica Cano Abadia, BBMRI-ERIC, **EJP RD**, Austria
Lorena Casareto, Telethon Network of Genetic Biobanks, Italy
Esther van Enckevort, University Medical Center Groningen, **EJP RD**, Netherlands
Pierre-Emmanuel Gleizes, Université Toulouse III - Paul Sabatier, France
Daphne Jaoui, Rare Disease Cohorts Programme (RaDiCo), INSERM, **EJP RD**, France
Annalisa Landi, Benzi Foundation, **EJP RD**, Italy
Michaela Th. Mayrhofer, BBMRI-ERIC, **EJP RD**, Austria
Uğur Özbek, Acibadem University, **EJP RD**, Turkey
Meral Özgüç, Hacettepe University, Turkey
Köksal Özgül, Hacettepe University, Turkey
Manuel Posada de la Paz, Instituto de Salud Carlos III, **EJP RD**, Spain
Ulrike Rohrer, BBMRI-ERIC, **EJP RD**, Austria
Luca Sangiorgi, Istituto Ortopedico Rizzoli, ERN BOND, **EJP RD**, Italy
Mary Wang, Fondazione Telethon, **EJP RD**, Italy
Andrea Wutte, BBMRI-ERIC, **EJP RD**, Austria
(TBC) Andreas Kurtz, Fraunhofer-Institut für Biomedizinische Technik (IBMT), hPSCreg, **EJP RD**, Germany
(TBC) Patient Organization Network Turkey



Rare Disease Biobanks: Roles in Research Networks and International Collaborations

10-11 May 2021, online training workshop (times in CET)

Preliminary Program

10 May 2021 DAY 1

12:30 - 13:00	Online system, connection and sound testing for participants	
	Opening Session: Biobanks in National Plans for RD Chair: Ece Akhan, Hacettepe University, Turkey	
13:00 - 13:15	Welcome address - Introduction to the aim and context of the training course - What is a biobank	Meral Özgüç Hacettepe University, Turkey
13:15 - 13:25	Introduction - Presentation of the EJP RD Project - IRDiRC vision & goals	Mary Wang Fondazione Telethon, Italy
13:25 - 13:35	Patient perspective of biobanks	(TBC) Patient Organization Network Turkey
13:35 - 13:55	- National networking activities of biobanks - ADOPT BBMRI Project	Neşe Atabey BBMRI National Node Turkey
13:55 - 14:10	<i>Discussion, Q&A</i>	
14:10 - 14:20	Break	
	Session 2: "Challenges for Networking" Chair: Mary Wang, Fondazione Telethon, Italy	
14:20 – 14:40	Quality Assurance Schemes in biobanks and ISO standards.	Andrea Wutte / Ulrike Rohrer BBMRI-ERIC, Austria
14:40 – 15:00	Biobank ELSI concerns; sample sharing for research, ELSI helpdesk service	Michaela Th. Mayrhofer / Monica Cano Abadia BBMRI-ERIC, Austria
15:00 – 15:20	Informed consent for RD research and GDPR: Practical lessons from ERNs	Annalisa Landi Benzi Foundation, Italy
15:20 – 15:40	FAIR DATA principles for biobanks	Esther van Enckevort University Medical Center Groningen, Netherlands
15:40 – 16:00	<i>Discussion, Q&A and End of the Day</i>	



11 May 2021 DAY 2

Session 3: Networking among Biobanks – Their Vision and Goals Chair: Eva Bermejo-Sanchez, Instituto de Salud Carlos III, Spain		
09:00 – 09:10	Opening day 2, recap	
09:10 – 09:30	Perspectives for successful collaborations for networking	Ronny Baber ESBB & Leipzig Medical Biobank. Germany
09:30 – 09:50	Evolution of a collaborative platform: EuroBiobank	Manuel Posado de la Paz Instituto de Salud Carlos III, Spain
09:50 – 10:10	National network of rare genetic biobanks	Lorena Casareto Telethon Network of Genetic Biobanks, Italy
10:10 – 10:30	Pluripotent stem cells as biological twins and models: Banking, data and sharing by EBiSc and hPSCreg	(TBC) Andreas Kurtz Fraunhofer-Institut für Biomedizinische Technik (IBMT), Germany
10:30 – 11:00	<i>Discussion and Q&A</i>	
11:00 – 13:00	Break	
Session 4: Biobanks in Research Networks Chair: Uğur Özbek, Acibadem University , Turkey		
13:00 – 13:20	Resources for biological samples in the EJP RD Virtual Platform. How the VP can support researchers and biobanks.	Daphne Jaoui Rare Disease Cohorts Programme (RaDiCo), France
13:20 – 13:40	Role of biobanks in European Reference Networks (ERN)	Luca Sangiorgi ERN BOND, Italy
13:40 – 14:00	Example of a collaborative research activity/ Ways to improve collaboration of biobanks	Köksal Özgül Hacettepe University, Turkey
14:00 – 14:20	Case report from the RiboEurope consortium	Pierre-Emmanuel Gleizes Université Toulouse III - Paul Sabatier, France
14:20 – 14:55	<i>Discussion and Q&A</i>	
14:55 – 15:00	Closing Remarks	

