



**EUROPEAN JOINT PROGRAMME  
RARE DISEASES**

**TRAINING WORKSHOP**

**ORGANIZING & MAXIMIZING RARE DISEASE  
BIOLOGICAL SAMPLE DATA IN BIOBANKS**

**29 – 30 October 2019, Vilnius**

## GENERAL INFORMATION

### INTRODUCTION AND OBJECTIVES

This training workshop is a part of a series of capacity building programs put forth by the [European Joint Programme on Rare Diseases](#) (EJPRD). EJPRD is a European Commission funded project (grant agreement No 825575, 2019 – 2023) with the goal “to create a comprehensive, sustainable ecosystem allowing a virtuous circle between research, care and medical innovation”.

The organisation of this workshop series on biobanks and biological samples is coordinated by Fondazione Telethon, Italy. Project partners in this training series are BBMRI-ERIC, Charité – Universitätsmedizin Berlin, Institute of Health Carlos III Spain, Hacettepe University Turkey, Medical University Gdansk Poland, University Medical Centre Groningen the Netherlands and Vilnius University Hospital Lithuania.

*Biological samples* from rare disease (RD) patients are precious resources for research. Due to their intrinsic rarity, these samples are often dispersed in multiple biobanks and are difficult to locate. The accessibility of these biological samples underpins the development of new diagnostic techniques, biomarker development, identification of potential therapeutic targets and testing therapeutic response.

*Biobanks* are key research infrastructures that offer professional services to the research community for sample sourcing and management. They play an important role in maintaining the quality of the biological samples from time-of-collection to distribution, as well as conserving the privacy and wishes of the patients. Biobanks have begun to share RD sample datasets to centralised sample catalogues (eg. [RD-Connect](#), [EuroBioBank](#)) to facilitate sample access and support the change towards best practice with their special position interfacing patients, clinicians and researchers. However, RD samples and associated data pose particular management challenges for their high variety of data types (e.g. disease names, genetic variants, phenotypes, clinical data), as well as balancing the need to share while preserving privacy and rights of RD patients.

The goal of this training series is to develop the capacity on data management of biobanks, allowing them to optimise operations to support the need of RD research community. Through the workshops, we aim to promote FAIR of resources and research reproducibility. The training workshops will offer biobanks to learn how to harmonise and share their rare disease biological sample data and encourage direct interactions between RD clinicians/researchers and biobanks, where researchers can exchange on how to leverage biobanks in their RD research.

### 2019 WORKSHOPS & THEME

Several training workshops on rare disease sample management will be organised during the EJPRD run time.

In 2019, the theme is “**Organizing & maximizing rare disease biological sample data in biobanks**“. Two workshops are available in 2019 and will have similar contents. The two workshops may vary only slightly to tailor the local organisers logistical or needs. Workshop themes may vary from year to year, based on feedback from participants and EJPRD project outputs.

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|-------------------|--|
| <b>Workshop 1</b> | <b>1-2 April 2019, Milan, Italy</b>      |
| <b>Workshop 2</b> | <b>29-30 October, Vilnius, Lithuania</b> |

### LEARNING METHOD

The training workshop will consist of plenary lectures and interactive small-group exercises, based to the *Problem-Based Learning* (PBL) method. PBL is a highly interactive and learner-centred approach where the learning occurs by working in a small group assisted by a facilitator to develop a solution of a problem. Practical demonstration of biobank or sample catalogue related tools are also included. Participants are asked to bring their **laptops** in order to participate in the PBL and the practical demonstrations.

## **PARTICIPANTS AND REGISTRATION**

The training workshop is open to healthcare professionals, researchers, clinicians, biobank managers, database managers and rare disease patient advocates. In particular, we welcome participants from all types of biobanks (academic, hospital, private) with focuses on rare diseases. To ensure active participation and exchange with teaching staff and participants, a maximum of **30 attendees** will be admitted. A selection process will be applied based on the participants' background, role with reference to biobanking activities, and involvement in ERNs.

## **FEES AND COSTS**

The workshop and registration is free of charge. Coffee refreshments and lunches will be offered during the workshop. Participants must arrange their own travel, accommodation and other expenses to attend the workshop. The workshop organisers will not cover expenses incurred by the participants.

**Travel Fellowships - application deadline 15 September 2019:** two travel fellowships are available to cover one round trip flights and up to two nights of hotel accommodation, for a total of up to 470 euros. We especially encourage participants from EU-13 countries, if you wish to apply for a travel fellowship please submit the completed registration with the fellowship section by 1 September 2019.

## **ATTENDANCE CERTIFICATES**

At the end of the workshop a certificate of attendance will be handed to the participants who attended the entire workshop. No credits of Continuing Education in Medicine will be issued.

## **LANGUAGE**

Workshops will run in English

## **CONTACT**

If you have questions please write to the workshop organiser Dr. Mary Wang [mwang@telethon.it](mailto:mwang@telethon.it) or local organisers Danute Vanseviute [Danute.Vanseviute@santa.lt](mailto:Danute.Vanseviute@santa.lt), Dr. Birute Tumiene [tumbir@gmail.com](mailto:tumbir@gmail.com).

## Organizing & maximizing rare disease biological sample data in biobanks Preliminary Program of the Workshop

**29 October 2019**      **“What do I need to consider”**

08:30 - 09:00	Participants registration	
09:00 - 09:10	Welcome address	Prof. Algirdas Utkus (the Dean of the Faculty of Medicine, Vilnius University) Prof. Feliksas Jankevičius (General Director of the Vilnius University Hospital Santaros Klinikos)
09:10 - 09:30	Presentation of the European Joint Program on Rare Diseases	Dr. Birutė Tumienė (Vilnius University, Faculty of Medicine, Vilnius, Lithuania)
09:30 - 10:00	Introduction <ul style="list-style-type: none"> <li>• Biobanks and the training workshop</li> <li>• Problem Based Learning</li> </ul>	Dr. Mary Wang (Fondazione Telethon, Milan, Italy)
10:00 - 11:15	<i>PROBLEM ANALYSIS</i> Reading and analysis of the problem	Discussion in 4 groups with facilitators: Dr. Birutė Tumienė, Dr. Laima Ambrozaitytė (Vilnius university, Faculty of Medicine, Vilnius, Lithuania) Dr. Živilė Gudlevičienė (National Cancer Institute, Vilnius, Lithuania) PhD student Mindaugas Morkūnas (National Center of Pathology, Affiliate of Vilnius University Hospital Santaros Klinikos, Vilnius, Lithuania)
11:15 - 11:40	Coffee break	
11:40 - 12:10	<i>LECTURE 1</i> Rare disease biobanking and network state-of-art	Dr. Manuel Posada (Institute of Health Carlos III, Madrid, Spain)
12:10 - 12:40	<i>LECTURE 2</i> Principles of sample data sharing and MIABIS	Dr. David van Enckevort (University Medical Center Groningen, Groningen, Netherlands)
12:40 - 13:30	Lunch	
13:30 - 14:00	<i>LECTURE 3</i> Privacy management & case study	Dr. Michaela Th. Mayrhofer (BBMRI-ERIC, Graz, Austria)
14:00 - 16:00	<i>PROBLEM SOLUTION</i>	Discussion in 4 groups with facilitators Dr. Birutė Tumienė, Dr. Laima Ambrozaitytė (Vilnius university, Faculty of Medicine, Vilnius, Lithuania) Dr. Živilė Gudlevičienė (National Cancer Institute, Vilnius, Lithuania) PhD student Mindaugas Morkūnas (National Center of Pathology, Affiliate of Vilnius University Hospital Santaros Klinikos, Vilnius, Lithuania)
16:00 - 16:15	Coffee break	
16:15 - 17:30	Group presentations with feedback from the trainers Chair: Dr. Mary Wang (Fondazione Telethon, Milan, Italy)	
17:30	End of day 1	

30 October 2019 “Getting Practical on Data Management”

08:30 - 09:00	Arrival/set up	
09:00 - 09:10	Aims of the day	Dr. Mary Wang (Fondazione Telethon, Milan, Italy)
09:10 - 09:45	<i>LECTURE 4</i> Overview of Lithuanian biobanking: state-of-art	Prof. Algirdas Utkus (Vilnius University, Faculty of Medicine, Vilnius, Lithuania) Prof. Arvydas Laurinavičius (National Center of Pathology, Affiliate of Vilnius University Hospital Santaros Klinikos, Vilnius, Lithuania) Dr. Živilė Gudlevičienė (National Cancer Institute, Vilnius, Lithuania)
09:45 - 10:45	<i>LECTURE 5</i> Orphanet Nomenclature and Orphanet Rare Disease ontology (ORDO)	Dr. Emmanuel Maxime (Orphanet, Paris, France)
10:45 - 11:15	Coffee break	
11:15 - 12:15	<i>TOOL DEMOS</i> RD-Connect Sample Catalogue BBMRI-ERIC Negotiator (researcher) BBMRI-ERIC Negotiator (biobank) Human pluripotent stem cell registry	Dr. Mary Wang (Fondazione Telethon, Milan, Italy) Dr. David van Enckevort (University Medical Center Groningen, Groningen, Netherlands) Dr. Andreas Kurtz (Charité – Universitätsmedizin, Berlin, Germany)
12:15 - 13:15	Lunch	
13:15 - 15:15	<i>PRACTICAL SESSION</i> Hands-on exercise on data harmonization	Dr. David van Enckevort and Aneas Hodselmans (University Medical Center Groningen, Groningen, Netherlands)
15:15 - 15:30	Concluding remarks, gathering of feedbacks	
15:30	End of workshop	

## LOGISTICAL INFORMATION 2019 WORKSHOP 2

### VENUE

Vilnius University Hospital Santaros Klinikos  
Santariskiu st. 2, Vilnius, Lithuania

Airports: Vilnius Airport

Link to GoogleMaps: <https://goo.gl/maps/744rBVTQzPFjQLhL8>

