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
Nese 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
Aniko Gal, Semmelweis University, Hungary
Pierre-Emmanuel Gleizes, Université Toulouse III - Paul Sabatier, France
Daphne Jaoua, 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 Özgül, Hacettepe University, Turkey
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

<table>
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<tr>
<th>Time</th>
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<tr>
<td>12:30 - 13:00</td>
<td>Online system, connection and sound testing for participants</td>
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| 13:00 - 13:15 | Opening Session: Biobanks in National Plans for RD  
Chair: Ece Akhan, Hacettepe University, Turkey  
Welcome address  
- Introduction to the aim and context of the training course  
- What is a biobank | Meral Önzüç  
Hacettepe University, Turkey |
| 13:15 - 13:25 | Introduction  
- Presentation of the EJP RD Project  
- IRDiRC vision & goals | Mary Wang  
Fondazione Telethon, Italy |
(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 | Discussion, Q&A |
| 14:10 - 14:20 | Break |

**Session 2: “Challenges for Networking”**  
Chair: Mary Wang, Fondazione Telethon, Italy

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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 | Discussion, Q&A and End of the Day |

This workshop has received funding from the European Union’s Horizon 2020 research and innovation programme under grant agreement No 825575 European Joint Programme for Rare Diseases.
### Session 3: Networking among Biobanks – Their Vision and Goals
**Chair:** Eva Bermejo-Sanchez, Instituto de Salud Carlos III, Spain

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<tr>
<td>09:00 – 09:10</td>
<td>Opening day 2, recap</td>
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<tr>
<td>09:10 – 09:30</td>
<td>Perspectives for successful collaborations for networking</td>
<td>Ronny Baber&lt;br&gt;ESBB &amp; Leipzig Medical Biobank, Germany</td>
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<tr>
<td>09:30 – 09:50</td>
<td>Personalised Medicine outlook on Biobanks as research supporting structures</td>
<td>Aniko Gal&lt;br&gt;Semmelweis University, Hungary</td>
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<tr>
<td>09:50 – 10:10</td>
<td>National network of rare genetic biobanks</td>
<td>Lorena Casareto&lt;br&gt;Telethon Network of Genetic Biobanks, Italy</td>
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<tr>
<td>10:10 – 10:30</td>
<td>Pluripotent stem cells as biological twins and models: Banking, data and sharing by EBiSc and hPSCreg</td>
<td>(TBC) Andreas Kurtz&lt;br&gt;Fraunhofer-Institut für Biomedizinische Technik (IBMT), Germany</td>
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<tr>
<td>10:30 – 11:00</td>
<td>Discussion and Q&amp;A</td>
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<td>11:00 – 13:00</td>
<td>Break</td>
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### Session 4: Biobanks in Research Networks
**Chair:** Uğur Özbek, Acibadem University, Turkey

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<tr>
<td>13:00 – 13:20</td>
<td>Resources for biological samples in the EJP RD Virtual Platform. How the VP can support researchers and biobanks.</td>
<td>Daphne Jaoui&lt;br&gt;Rare Disease Cohorts Programme (RaDiCo), France</td>
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<td>13:20 – 13:40</td>
<td>Role of biobanks in European Reference Networks (ERN)</td>
<td>Luca Sangiorgi&lt;br&gt;ERN BOND, Italy</td>
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<td>13:40 – 14:00</td>
<td>Example of a collaborative research activity/ Ways to improve collaboration of biobanks</td>
<td>Köksal Özgül&lt;br&gt;Hacettepe University, Turkey</td>
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<td>14:00 – 14:20</td>
<td>Case report from the RiboEurope consortium</td>
<td>Pierre-Emmanuel Gleizes&lt;br&gt;Université Toulouse III - Paul Sabatier, France</td>
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<td>14:20 – 14:55</td>
<td>Discussion and Q&amp;A</td>
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<td>14:55 – 15:00</td>
<td>Closing Remarks</td>
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