

EUROPE BIOBANK WEEK 2022

ROADSHOW

ESBB

European, Middle Eastern
& African Society
for Biopreservation
and Biobanking



BBMRI-ERIC®

PAEDIATRIC BIOBANKING AND MINOR ENGAGEMENT

AN INTERACTIVE WORKSHOP

13-14 OCTOBER, ROME, ITALY

UPDATED

PRELIMINARY

SCIENTIFIC PROGRAMME

EUROPE BIOBANK WEEK - ROADSHOW

ESBB and BBMRI-ERIC are delighted to announce a new, common community engagement activity, our **EUROPE BIOBANK WEEK ROADSHOW**. The **EBW ROADSHOW** consists of a series of smaller and regional face-to-face events covering a fine selection of hot topics in biobanking. We'll bring EBW on the road and invite you to join us for high-quality scientific programmes, opportunities to meet and discuss topics with your peers, and exchange information with companies at exhibitions. Our topic forecast covers Quality in Biobanking (Germany), Paediatrics (Italy), and Information Technology (Austria). While we focus on the **EBW ROADSHOW** this year, we are planning to relaunch our successful face-to-face **EBW CONGRESS** in spring 2023, hereby mitigating risks due to the continued COVID-19 pandemic.

PAEDIATRIC BIOBANKING AND MINOR ENGAGEMENT

We invite you to the 2nd Europe Biobank Week (EBW) Roadshow Meeting & Exhibition held at the Children's Bambino Gesù Hospital, in Rome, Italy, from 13–14 October 2022. This meeting has been organized by ESBB and BBMRI-ERIC in partnership with the BBMRI ERIC Stakeholder Forum Patient Pillar, the Children's Bambino Gesù Hospital, the IDEA Network, and the National Node BBMRI.it. The meeting will kick off with an overview of European commitment to paediatric research and healthcare, followed by an in-depth exchange on good practices, highlighting the priorities set by various actors to raise awareness and encourage citizen science, facilitate assent and consenting processes, and improve engagement. The first day will close with a keynote speech on the use of innovative genomic approaches with undiagnosed patients and precision medicine in children by Franco Locatelli and Marco Tartaglia. The second day features parallel breakout sessions to support the codesign of a shared recommendation on paediatric biobanking. We invite you to enjoy the amazing scientific programme, meet and discuss topics with your peers at the poster session and networking event, and exchange information with companies at the exhibition.

Dominik Lermen
President ESBB

Jens K. Habermann
Director General BBMRI-ERIC

Bruno Dallapiccola
Scientific Director
IRCCS Ospedale Pediatrico
Bambino Gesù

Marialuisa Lavitrano
National Node Director
BBMRI Italy

SCIENTIFIC PROGRAMME COMMITTEE

BRUNO DALLAPICCOLA, Scientific Director, IRCCS Children's Hospital Bambino Gesù, Rome (Italy)

DOMINIK LERMEN, President, ESBB

ELKE SMITS, Head of Science & Innovation Department, Antwerp University Hospital, ESBB

JENS HABERMANN, General Director, BBMRI-ERIC

MARIALUISA LAVITRANO, National Node Director, BBMRI.it

RICHARD STEPHENS, Patient advocate, chair of BBMRI-ERIC Stakeholder Forum Patient Pillar

SARA CASATI, Bioethicist, ELSI Services & Research Unit, BBMRI-ERIC

TIZIANA FRANCHIN, Head of Research Biobank, IRCCS Children's Hospital Bambino Gesù, Rome (Italy)

Thursday – 13 OCTOBER 2022

- 09.00 - 13:00 **REGISTRATION OPEN**
- 12.30 - 12:45 **WELCOME & OPENING CEREMONY**
General Director, BBMRI-ERIC, President, ESBB, Local Host, Director BBMRI.it
- 12:45 - 14:15 **A COMMON RESPONSIBLE HORIZON TO FOSTER PAEDIATRIC RESEARCH AND HEALTHCARE**
Co-Chairs: Jens Habermann, Dominik Lermen
SPEAKER
Christina Kyriakopoulou (DG Research, EU Commission: available only online)
A European priority: paediatric research and healthcare.
EFPIA Representative TBC
Industry as a partner to respond to the paediatric challenge
Tiziana Franchin (IRCCS Children's Hospital Bambino Gesù/ IDEA Network)
Lorenza Putignani (RCCS Children's Hospital Bambino Gesù)
The role of paediatric biobanking in translational medicine. A showcase from the IDEA network: system-medicine in microbiome - diagnostic & therapeutic approach
- 14.15 - 14:30 **POOLING GOOD PRACTICES, TACKLING CHALLENGES RELATED TO BIOBANKING WITH MINORS**
Sara Casati (BBMRI-ERIC ELSI Service & Research Unit)
Sharing the results from Paediatric biobanking and engagement call for participation.
- 14.30 - 15:15 **Good practice session BIOBANKING, RESEARCH IS ABOUT ME – RAISING AWARENESS & INVITING CITIZEN SCIENCE**
Biobanking in the modern world involves data and sample-based research. It presupposes the construction of an inclusive extended scientific community that works as a team between all the players. It asks for a new social pact for science. Without citizens' understanding and engagement, biobanking does not work. Patients, citizens, and families, new generations, are the heart of biobanking, making it possible for research to benefit all of us.
Chair: Richard Stephens
SPEAKER
Anna Codina (Paediatric Biobank for Research, Sant Joan de Déu, Spain)
Gillian Martin, (Malta University, MALTA)
Lorenzo Mellini (Italian Poland Syndrome Association, Italy)
- 15:15 - 15:45 **NETWORKING BREAK & EXHIBITION**

Thursday – 13 OCTOBER 2022

15:45 - 16:30

Good practice Session FROM ASSENT TO CONSENT: COMMON ISSUES AND DIFFERENT APPROACHES

Biobanking with children challenges our practice. It requires us to recognize the child as an active participant, with all the rights that we confer on adults. We need to rethink the issues of assent and consent, and to move towards dynamic and participatory models of regulation and interpretation. It's a huge change of pace and represents a significant challenge in terms of engagement of a participant, the minor, who progressively but often separately acquires decision-making competence and legal capacity. So, who is primarily responsible for proposing to the minor that they might participate in research biobanking? What tools are available to inform and increase the child's understanding? By whom is the child's capacity assessed to understand and assent?

Co-Chairs: Stella Antoniou, Valentina Colcelli

SPEAKER

Liselot Mus (UZGent/UGent, Belgium)

Anwar Baban (IRCCS Children's Hospital Bambino Gesù, Italy)

Deborah Mascalconi (EURAC, Italy & CRB- Center for Ethics and Bioethics Uppsala University, Sweden)

Sara Frygner-Holm (Uppsala University, Sweden)

16:30 - 17:15

Good practice Session MULTI-ACTOR ENGAGEMENT TO BIOBANK TOGETHER (EARLIER, OVER TIME, FOLLOWING U

Biobanking can be compared to a team-game, to the multidimensional action of a system based on transparency, inclusion, participation, and reciprocal engagement. Each actor, from the family to the clinicians, to the Research Ethics Committees, the researchers, etc., is necessary for the development, sustainability, and fairness both of biobanking and of data-based science. This is critical with children, they are individuals in evolution, with a situated vulnerability: paediatric (research) biobanking practices need to collect samples before diseases develop and maintain a prospective follow-up. Such a process would entail the involvement and the conscious commitment of all the players along time. This implies a training shift based on innovative empowerment models that engage all the actors.

Chair: Akylina Despoti

SPEAKER:

Roseline Favresse (EURORDIS, France)

Domenico Coviello (Paediatric Hospital "Gaslini Foundation", Italy)

Elke Smits (Antwerp University Hospital, ESBB ambassador, Belgium)

Thursday – 13 OCTOBER 2022

17:15 - 17:30 **First day insights in view of the final statement**

Sara Casati & Elke Smits

18:00 - 19:00 **PAEDIATRIC BIOBANKING AND INNOVATION IN CHILDREN**

From innovative genomic approaches with undiagnosed patients to paediatric precision medicine

Co-Chairs: Tommasina Iorno, Patient Advocate, Fondazione Giambrone, member of the REC National Commission (TBC) and **ESBB representative** (TBC)

SPEAKER:

Franco Locatelli (*Children's Hospital Bambino Gesù, Italy*)

Marco Tartaglia (*Children's Hospital Bambino Gesù, Italy*)

19:00 - 21:00 **NETWORKING EVENT**

Friday – 14 OCTOBER 2022

- 9:00 - 9:15 **Work Summary and Introduction to Day 2 - Interactive Training for a Community of Practice**
Richard Stephens & Sara Casati
 Two sessions where small groups will work in parallel to recognise and map good practice, training and learning from each other to build a paediatric (research) biobanking community based on shared knowledge and strengthened skills.
- 9:15 - 10:15 **Interactive Training for a Community of Practice – Part 1**
Biobanking Together: Raising Awareness and Delivering Citizen Science with the new Generations of Citizens and Researchers
Facilitators:
Gillian Martin (Malta University, Malta)
Richard Stephens (Chair, BBMRI-ERIC Stakeholder Forum Patient Pillar)
Valentina Colcelli (Institute CNR-IFAC, National Research Council, Italy)
- 10:15 - 10:30 **Sharing outputs**
- 10:30 - 11:30 **Interactive Training for a Community of Practice – Part 2**
Facilitators: Georgia Charalambidou (University of Cyprus)
Akylina Despoti (BBMRI-ERIC Stakeholder Forum Patient Pillar, EPIONI-Greek Carers Network, Greece)
Olga Tzortzatou (Attorney at law, Athens, Greece)
- 11:30 - 12:00 **BREAK & SPONSOR EXHIBITION**
- 12:00 - 12:30 **Shared statement and next steps**
- 12:30 - 12:45 **Take-home message**

REGISTRATION FEES

CATEGORY	FEE [€]
ESBB/BBMRI-ERIC MEMBER	85
NON-ESBB/BBMRI-ERIC MEMBER	160

SPONSORSHIP OPPORTUNITIES

Want to become an EBW 22 Roadshow Sponsor? Find out more about our Sponsorship Opportunities for this event [here!](#)

ACCOMMODATION

Hotel reservations need to be individually handled and are not part of the registration process of the EBW22 Roadshow Rome. Please find below accommodation suggestions near metro stop.

Hotel/B&B	Address	Phone	E-mail	Web	Single*	Double*
B&B Easy	Via Ostiense 73, 00154 Rome	+39 331 2149481	info@bnbeasy.it	https://bnbeasy.it/	80 €	90 €
St. Paul Palace Relais	Viale Giustiniano Imperatore, 16 00145 Rome	+39 346 0811759	Angelor.airbnb@gmail.com	https://st-paul-palace-relais.business.site/?utm_source=gmb&utm_medium=referral	80 €	90 €
RE Monti Guest House	Via Cavour, 184, 00184 Rome	+39 06 69481985	info@remontiroma.com	https://www.remontiroma.com/en/index	82 €	89 €
Aelius Guest House	Via Volturno 7, 00187 Rome	+39 06 48907251	info@roma-inn.com	https://www.roma-inn.com/	90 €	100 €
Lungotevere Suite	Lungotevere degli Artigiani 20, 00153 Rome	+39 06 94518330	info@lungoteveresuite.com	https://www.lungoteveresuite.com/	90 €	100 €
Hotel Santa Prisca	Largo Manlio Gelsomini, 25 Rome	+39 06 5741917	hsprisca@hotelsantaprisca.it	https://www.hotelsantaprisca.it/en/	90 €	100 €
Hotel Aberdeen	Via Firenze 48, 00184 Rome	+39 06 4823920	info@hotelaberdeem.it	https://www.hotelaberdeem.it/en/	90 €	100 €
Hotel Parker	Via Giovanni Giolitti 431, 00185 Rome	+39 06 770005	info@hotelparkerroma.it	http://www.hotelparkerroma.it/en/home/	90 €	100 €

*min price – price depends on travel time.
Most of the prices include breakfast.

ACCOMMODATION

Hotel	Address	Phone	E-mail	Web	Single*	Double*
Hotel San Silvestro Roma***	Via del Gambero, 3 00187 Rome	+39 06 6796494	hsansilvestro@gmail.com	https://www.hotelsansilvestroroma.com/index.php	179 €	238 €
Hotel Scalinata di Spagna***	Piazza Trinità dei Monti 17, Rome	+39 06 45686150	info@hotelscalinata.com	https://www.hotelscalinata.com/en/	191 €	242 €
Hotel The Code****	Via Sistina, 79, 00187 Rome	+39 06 81157521	info@thecodehotelrome.com	https://www.thecodehotelrome.com/	222 €	237 €
Hotel Mozart****	Via dei Greci 23 B, 00187 Rome	+39 06 36001915	info@hotelmozart.com	https://www.hotelmozart.com/en/	230 €	300 €
Hotel Accademia Rome***	Piazza Accademia di San Luca 74/75, Rome	+39 06 6991242	accademia@travelroma.com	https://www.accademiahotel.com/en/rome-hotel-trevi-fountain/	262 €	268 €
Hotel Valadier****	Via della Fontanella, 15 00187 Rome	+39 063611998	info@hotelvaladier.com	https://www.hotelvaladier.com/en/	276 €	282 €
Hotel Manfredi Suite Luxury Hotel	Via Margutta 61, 00187 Rome	+39 06 3207676	info@hotelmanfredi.it	https://www.hotelmanfredi.com/en/boutique-hotel-via-margutta-roma	289 €	321 €
Hotel Stendhal****	Via Sistina 4, 00187 Rome	+39 06 422921	info@hotelstendhalrome.com	https://www.hotelstendhalrome.com/	290 €	344 €
Hotel Tritone***	Via del Tritone 210, 00187 Rome	+39 06 69922575	tritone@travelroma.com	https://www.tritonehotel.com/	347 €	347 €

*min price – price depends on travel time.
Most of the prices include breakfast.

ORGANIZED BY

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