

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

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 second 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
Past 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

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SCIENTIFIC PROGRAMME COMMITTEE



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Scientific Director
IRCCS Children's Hospital Bambino Gesù
Rome, Italy



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National Node Director
BBMRI.it



Dominik Lermen

Past President
ESBB



Richard Stephens

Patient advocate
Chair of BBMRI-ERIC Stakeholder Forum Patient Pillar



Elke Smits

Chief Science and Innovation Officer
Antwerp University Hospital
Belgium
ESBB



Sara Casati

Bioethicist
ELSI Services & Research Unit
BBMRI-ERIC



Jens Habermann

General Director
BBMRI-ERIC



Tiziana Franchin

Head of Research Biobank
IRCCS Children's Hospital Bambino Gesù
Rome, Italy

THE VENUE – Ospedale Pediatrico Bambino Gesù Auditorium

Auditorium Valerio Nobili
Ospedale Pediatrico
Bambino Gesù
Viale Ferdinando Baldelli, 38-40
00146 Rome, Italy

[Google Map Link](#)



How to reach the venue

By car/taxi: from Grande Raccordo Anulare, exit no. 28, via Ostiense to Roma Center

By bus (ATAC): no. 23, 128, 670, 702, 707, 715, 761, 766, 791

By subway (ATAC): B Line (from “Termini Station” stop, direction “Laurentina”), get off at the stop “Basilica di San Paolo” and walk for about 5 minutes

By Fiumicino airport: take the train with stop at Ostiense Station, walk for 3 minutes to subway stop “Piramide” (B Line, direction “Laurentina”), get off at the stop “Basilica di San Paolo” and walk for about 5 minutes

PROGRAMME AT A GLANCE

Thursday 13.10.2022	Friday 14.10.2022
09.00 - 13.00 Registration is open	9.00 - 9.15 Work Summary and Introduction to Day 2
12.30 - 12.45 Welcome & Opening Ceremony	9.15 - 10.15 Interactive Training for a Community of Practice - Part I
12.45 - 14.15 Overview Session	10.15 - 10.30 Sharing Outputs
14.00 - 14.15 Q & A	10.30 - 11.00 Break and Sponsor Exhibition
14.15 - 14.30 Pooling Good Practices, Tackling Challenges for Biobanking with Minors	11.00 - 12.00 Interactive Training for a Community of Practice - Part II
14.30 - 15.15 1st Good Practice Session	12.00 - 12.30 Shared statement and next steps
15.15 - 15.45 Break & Sponsor Exhibition	12.30 - 12.45 Concluding address
15.45 - 16.30 2nd Good Practice Session	
16.30 - 17.15 3rd Good Practice Session	
17.15 - 17.30 1st day Insights in view of final statement	
18.00 - 19.00 Success Stories Session - Paediatric Biobanking and Innovation in Children	
19.00 - 21.00 Networking Evening	

SUCCESS STORIES – SPEAKER



Prof. Dr. Franco Locatelli

Director of Experimental and Precision Medicine Board, IRCCS Children's Hospital Bambino Gesù, Rome, Italy

President of the "Consiglio Superiore di Sanità", Rome, Italy

Franco Locatelli is the Head of the Department of Paediatric Haematology and Oncology, IRCCS Bambino Gesù Children's Hospital, Rome and Full Professor of Pediatrics at the Catholic University of the Sacred Heart of Rome, Italy. He leads the largest programme of childhood allogeneic haematopoietic stem cell transplantation (HSCT) in Italy.

In 2019 Prof. Locatelli was appointed President of the Italian Higher Council of Health, the technical scientific advisory body to the Ministry of Health.

Professor Locatelli is an expert in haematological and oncological malignancies of childhood. He has been the President of the Italian Association for Pediatric Hematology-Oncology AIEOP from 2004 to 2006 and served as chairman of the European EWOG-MDS consortium from 2005 to 2011.

Currently, he coordinates the national protocols for children with newly diagnosed acute myeloid leukaemia and relapsed acute lymphoblastic leukaemia (ALL). He has implemented in Italy the first-in-human academic studies on children with CD19+ lymphoid malignancies using 2nd-generation retroviral and lentiviral chimeric antigen receptor (CAR) T cells and on children with neuroblastoma and other solid tumors expressing GD2 molecule using 3rd-generation retroviral CAR T cells.

Professor Locatelli is also involved in the development and validation of gene therapy and genome editing approaches in patients with thalassaemia and sickle cell disease and he has extensive experience in running Phase I/II clinical trials.

He is the author or co-author of more than 1.249 peer-reviewed articles published in international journals and he has an overall impact factor above 7000 and an H-index of 112 (Scopus source).

SUCCESS STORIES – SPEAKER



Dr. Marco Tartaglia
Head of Genetics and Rare Diseases Research Division
IRCCS Children's Hospital Bambino Gesù
Rome, Italy

Dr. Tartaglia is a human molecular geneticist serving as Head of the Genetics and Rare Diseases Research Division at the Ospedale Pediatrico Bambino Gesù, Rome, Italy. He previously directed the Molecular and Cellular Endocrinology and Physiopathology of Genetic Diseases Sections at the Istituto Superiore di Sanità, Rome.

His research has been directed to advance our knowledge on the molecular bases of human disorders affecting development. A major longstanding interest deals with Noonan syndrome and a family of clinically related diseases collectively known as “RASopathies”, with efforts that have mainly been directed to the identification of the genes implicated in these disorders, elucidation of the mechanisms underlying pathogenesis, and characterization of clinically relevant information for a more effective patient care. His work has led to recognize novel mechanisms by which intracellular signalling dysregulation through RAS proteins and their effectors perturbs development. Closely linked to his major interest on signal transduction and RAS signalling, Dr. Tartaglia has characterized novel molecular mechanisms contributing to leukemogenesis, and particularly on events perturbing signal transduction networks controlling cell proliferation and survival.

Since the introduction of second-generation sequencing technologies, Dr. Tartaglia has successfully used exome/genome sequencing and functional genomics to gain insights into the molecular causes of rare diseases and unclassified conditions affecting development, and understanding the molecular and cellular processes altered in these disorders by using complementary in vitro and in vivo (*C. elegans* and *D. rerio*) experimental approaches. His research has allowed to identify more than 40 new disease genes and a similar number of previously unrecognized genetic disorders. Linked to this topic, Dr. Tartaglia is exploring the use of genome-wide DNA methylation profiling in the clinical setting. His team has identified several disease-specific epigenatures and is applying this new diagnostic approach to classify the clinical/functional relevance of variants of uncertain significance emerged from genomic sequencing.

Prof. Dr. Franco Locatelli and Dr. Marco Tartaglia

Rare diseases represent a public health priority. It is estimated that >8,500 different rare diseases with proven/suspected Mendelian basis exist. While individually rare, they affect 3-6% of the population (>30 million people in Europe), the majority having childhood onset. Subjects affected by rare diseases share similar needs, suffer diagnostic delay, uncertainty in genetic counselling, and lack of a proper clinical management. Often, these diseases are not straightforwardly recognized even by experienced clinicians, and many of them lack key diagnostic handles. Moreover, complex phenotypes might not be classified possibly due to blended signs/features (i.e., co-occurring diseases). The average diagnostic delay has been estimated >5 years, with a significant proportion of individuals remaining without diagnosis lifetime, and half of them receiving an initial misdiagnosis.

During the last decade, the progressive decrease of DNA sequencing costs and the implementation of dedicated bioinformatics pipelines have resulted in a wide application of genomic sequencing as a “hypothesis-free”, highly informative tool in exploring the molecular causes of Mendelian disorders. The application of this technology and other omics in the clinical practice represents a diagnostic milestone and is considerably influencing medical decision-making. Nevertheless, establishing the clinical relevance of genomic variants remains a major diagnostic challenge, often requiring dedicated functional validation efforts.

Here an overview of the *Ospedale Pediatrico Bambino Gesù's* "Undiagnosed Patient Program" (UPP), which started in 2015 and has been focused on the genomics of rare/undiagnosed diseases, is provided. In the frame of this program a multidisciplinary workflow fully integrating a tele-health approach and the application of complementary -OMICS technologies has been developed and validated both in healthcare and research contexts, allowing an increase in diagnostic yield and the discovery of several novel disease genes and previously unrecognized disorders. Since 2019, this model has been implemented in the frame of Italian networks for undiagnosed patients (i.e., Italian UPP Network and Rete IDEA), favouring the access of patients on the entire national territory with significant results in terms of diagnostic yield and discoveries. The success of the present workflow is strengthened by the opportunity to couple the diagnostic path with complementary *in silico*, *in vitro* and *in vivo* experimental approaches for the functional validation of the genomic findings. The project has been also directed to generate patient-derived iPSC lines that are banked to make available disease-specific tools for disease modelling, functional genomics, and drug screening and validation.

Thursday – 13 OCTOBER 2022

- 09.00 - 13:00 **REGISTRATION OPEN**
- 12.30 - 12:45 **WELCOME & OPENING CEREMONY**
 General Director (BBMRI-ERIC) President (ESBB), Bruno Dallapiccola (Scientific Director, IRCCS Children’s Hospital Bambino Gesù) and Marialuisa Lavitrano (National Node Director, BBMRI.it)
- 12:45 - 14:15 **A COMMON RESPONSIBLE HORIZON TO FOSTER PAEDIATRIC RESEARCH AND HEALTHCARE**
Co-Chairs: General Director (BBMRI-ERIC) and President (ESBB)
SPEAKERS
Christina Kriakopoulou (DG Research, EU Commission: available only online)
Andreas Holtel (REA, EU Commission: available only online)
 A European priority: paediatric research and healthcare
Tiziana Franchin (IRCCS Children’s Hospital Bambino Gesù/ IDEA Network)
Lorenza Putignani (IRCCS 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
Liselot Mus (UZ Gent and UGent)
 Innovative framing paediatric biobanking for early drug development in paediatric oncology
- 14.00 - 14.15 **Q & A Session**
- 14.15 - 14.30 **POOLING GOOD PRACTICES, TACKLING CHALLENGES FOR BIOBANKING WITH MINORS**
Sara Casati (BBMRI-ERIC ELSI Service & Research Unit)
 Sharing the results from paediatric biobanking and an engagement call for participation. Introduction to the proactive good practice sessions.

Thursday – 13 OCTOBER 2022

14.30 - 15.15

1st GOOD PRACTICE SESSION: BIOBANKING, RESEARCH IS ABOUT ME – RAISING AWARENESS AND CITIZEN SCIENCE

Co-chairs: Richard Stephens and Annagrazia Altavilla

Biobanking in the modern world involves data and sample-based research. It presupposes the construction of an inclusive extended scientific community to work 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.

SPEAKERS

Anna Codina (Paediatric Biobank for Research, Sant Joan de Déu, Barcelona, Spain)

Begonya Nafra Escalera (YPAG of Hospital Sant Joan de Déu, Spain)

Framing scientific citizenship, sharing biobanking practices with adolescents

Gillian Martin, (Malta University, Malta)

Introducing biobanking having fun: how puppets make the difference with young children

Lorenzo Mellini (Italian Poland Syndrome Association, Italy)

The Patient Association, a driving force to build an integrated biobanking community between clinicians, patients-families and biobanks

15:15 - 15:45

BREAK & SPONSOR EXHIBITION

15:45 - 16:30

2nd GOOD PRACTICE SESSION: FROM ASSENT TO CONSENT (AT THE LEGAL AGE) - COMMON ISSUES AND DIFFERENT APPROACHES

Co-Chairs: Stella Antoniou and Valentina Colcelli

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 how to engage 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 he or she might participate in research biobanking? What tools are available to inform and increase the child's understanding? Who assesses the child's capacity to understand and to assent?

SPEAKERS

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

Assent in clinical practice: a family empowerment process. The example from cardiogenetic centre.

Annagrazia Altavilla (Lawyer in Health Law and Bioethics, Chair of Teddy Network)

Framing the assenting to research processes together with children: the Teddy Kids experiences

Deborah Mascolzoni (CRB - Center for Ethics and Bioethics, Uppsala University, Sweden)

Sara Frygner-Holm (CRB - Center for Ethics and Bioethics, Uppsala University, Sweden)

Assenting and consenting with children in longitudinal studies in the rare disease field: pretend play as a way of informing and getting consent

Thursday – 13 OCTOBER 2022

16:30 - 17:15

3rd GOOD PRACTICE SESSION: MULTI-ACTOR ENGAGEMENT TO BIOBANK TOGETHER (EARLIER, OVER TIME, FOLLOWING UP)

Co-Chairs: Olga Tzortzatou and Laura Milita

Biobanking requires the multidimensional action of a system based on transparency, inclusion, participation, and reciprocal engagement. Each actor, from the clinicians to the Research Ethics Committee members and the researchers, is mutually necessary for the development, sustainability, and fairness of both biobanking and data-based science. This is a critical consideration with children, as they are individuals in evolution with a situated vulnerability in transition: Paediatric (research) biobanking practices need to collect samples before diseases develop and ensure that a prospective follow-up is maintained. Such a process would entail the involvement and the conscious commitment of all the players over time. This implies a training shift based on innovative empowerment models that engage all the actors.

SPEAKERS

Roseline Favresse (EURORDIS, France)

Innovative online training from the EJP RD - EU Joint Programme on Rare Diseases

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

Together with the patient organizations, clinical teams and genetic biobanks: an ecosystem engagement model

Elke Smits (Antwerp University Hospital, Belgium)

Community engagement as a backbone to strengthen paediatric biobanking.

17:15 - 17:30

First day insights in view of the final statement

Sara Casati (BBMRI-ERIC ELSI Service & Research Unit) and Elke Smits (Antwerp University Hospital, bbmri.be President, ESBB Ambassador)

18:00 - 19:00

SUCCESS STORIES: PAEDIATRIC BIOBANKING AND INNOVATION IN CHILDREN

Chairs: Tommasina Iorno and Roseline Favresse

SPEAKERS

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

Marco Tartaglio (Children's Hospital Bambino Gesù, Italy)

From innovative genomic approaches with undiagnosed patients to paediatric precision medicine

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 (BBMRI-ERIC Stakeholder Forum Patient Pillar) and Sara Casati (BBMRI-ERIC ELSI Service & Research Unit)
 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 - 11:00 **BREAK & SPONSOR EXHIBITION**
- 11:00 - 12:00 **INTERACTIVE TRAINING FOR A COMMUNITY OF PRACTICE – PART 2**
Minor Assent and Participation in Research as a Multi-Actor Dynamic Process
FACILITATORS
Georgia Charalambidou (ELSI Specialist Scientist, University of Cyprus, Cyprus)
Olga Tzortzatou (Attorney at law, Athens, Greece)
Sabrina Gainotti (Sociologist/Bioethicist, Ethics Unit, ISS, Italy)
- 12:00 - 12:30 **SHARED STATEMENT AND NEXT STEPS**
- 12:30 - 12:50 **CONCLUDING ADDRESS**
Giovanni Leonardi (Secretary General, Italian Ministry of Health)

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.

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