TEDDY General Assembly and Scientific Meeting

18-20 September 2026

University of Bari Aldo Moro

Piazza Cesare Battisti, 1, 70121 Bari, Italy

Friday 18 September - Afternoon		
17:00 - 17:30	Registration	
17:30 - 18:00	**Opening Remarks** – Twenty years of the Paediatric Regulation: the paediatric research needs in the European evolving scenario	Donato Bonifazi
18:00 - 19:30	The GAPP Study: Applying Innovative Methodologies in Paediatric Clinical Research – Roundtable with members from the Study Steering Committee, the Data Safety Monitoring Board and the Patient Advisory Board ***-Panellists:*** Eleonora Di Campi, Giorgio Reggiardo, Anna Szumowska, Paola Baiardi, Evelyne Jacqz-Aigrain ***-Young representatives:*** Muminah Aaisha-Seddika, Eirini Daskalopoulou, Francesco Meloni, Nepheli Mimi, Martina Leandro, Thuraya Layla Pearl Derby, Valeria Gatti, Valentina Jalby	*Moderator*: Oscar Della Pasqua
19:30 - 20:30	**Welcome Dinner**	

Saturday 19 September - Morning		
INNOVATION, EVIDENCE GAPS AND SOLUTIONS FOR CHILDREN		
09:00 - 09:15	***Keynote Lecture:*** From Science to Medicines: Bridging Translational and Regulatory Gaps in Paediatric Development	Giovanni Migliaccio
09:15 - 09:30	Early Regulatory approach to advance paediatric medicines access	Gianluca Sferrazza

09:30 - 09:45	DARWIN EU project - from real-world evidence to better medicines in Europe	Marek Migdal
09:45 - 10:00	AI-Based Drug Repurposing in Paediatric Rare Diseases: The ARPKD Use Case	Grazia Tamma
10:00 - 10:15	From Off-Label Use to Evidence Generation: Turning Paediatric Practice into Actionable Evidence	Madlen Gazarian
10:15 - 10:30	TEDDY involvement in the European Network of Centres for Pharmacoepidemiology and Pharmacovigilance (ENCePP)	Annalisa Landi
10:30 - 10:50	Q&A Session	
10:50 - 11:20	**Coffee Break**	
11:20 - 11:35	Biomarkers and Diagnostics in Paediatric Research: Patient Stratification and Therapeutic Development	Giuseppe Pontrelli
11:35 –12:00	Integrating Preclinical, Clinical and Real-World Data through PBPK Modelling for Neonatal Precision Dosing	Anne Smits & Pieter Annaert
12:00 - 13:00	From Small Populations to Robust Evidence: European Methodologies for Paediatric and Rare Disease Drug Development – Panel Discussion ***Panellists:*** Flora Musuamba Tshinanu, Sarah Zohar, Solange Corriol-Rohou	*Moderator*: Viviana Giannuzzi
OrphaDev4Kids Patient Expert Committee (PEC) Parallel Session - *BALAB Room*		
11:30 –13:00	Evaluation of paediatric and orphan Medical Devices innovative projects with Experts and PEC Members ***-Facilitators****:* Franco Bartoloni, Ana Muke, Francesco La Penna - ***Young Representatives:*** Alberto Giandomenico, Eirini Daskalopoulou, Karol Słowik, Leonardo Fiore	*Moderators:* Emanuela Crea
13:00 - 14:00	**Light Lunch**	

Saturday 19 September - Afternoon

FROM INNOVATIVE CONCEPTS TO TRIAL READINESS - ADVANCING CLINICAL RESEARCH IN RARE DISEASES

14:00 – 14.15	***Keynote Lecture*****:** Rare Diseases priority actions from local to global ecosystem - Illustrating Pathways towards Trial Readiness	Maurizio Scarpa
14:15 – 14.30	The Rare Epilepsy Model: Challenges and Opportunities for Clinical Development	Valentina de Giorgis
14:30 – 14.45	EU-PEARL NF1: A Platform Trial to Advance New Treatments for Neurofibromatosis Type 1	Dariusz Damczewski

14:45 – 15.00	GREEN PHARMA R.D.I.: Building a Research and Innovation Ecosystem for Rare Disease Drug Development	Nunzio Denora
15:00 –15:15	Targeting RIPK1 in CRIA Syndrome: Advancing an Ultra-Rare Disease Programme towards Clinical Development	Liisi Laaniste
15:15 –15:30	ADNP Syndrome: Clinical Insights and Emerging Therapeutic Perspectives	Michelina Armando
INVENTS paediatric Patient Expert Group (PEG) Parallel Session - *BALAB Room*		
14:00 - 15:30	Evaluation of Innovative Research Methodologies for Small Populations with Experts and PEG Members -***Facilitators:*** Sarah Zohar, Viviana Giannuzzi, Giorgio Reggiardo, Ana Muke, Francesco La Penna -***Young Representatives:*** Alberto Giandomenico, Eirini Daskalopoulou, Karol Słowik, Leonardo Fiore	*Moderator:* Emanuela Crea
15:30 - 16:00	**Coffee Break**	
THE ROLE OF PATIENT ENGAGEMENT IN SHAPING PAEDIATRIC RESEARCH		
16:00 - 17:30	ERDERA Planning of the 2027 Training Course for Young Rare Diseases Patients Advocates – Panel Discussion with ERDERA Experts and Young Representatives - ***Experts***: Dr. Aleksander Wiśniewski, Alessandra Simonetti, Eleonora Passeri, Annegret Dahlmann-Noor, Ines Alves, Manika Kreka, Mariagrazia Felisi, Mimoza Basholli-Salihu, Persephone Augoustides-Savvopoulou, Roseline Favresse, Gemma Rodriguez, Helin Ruf-Uçar, Viviana Giannuzzi ***Young Representatives:*** Anano Lartsuliani, Aaisha-Seddika Muminah, Alberto Giandomenico, Eirini Daskalopoulou, Francesco Meloni, Gabriella Monacelli, Karol Słowik, Leonardo Fiore, Thuraya Layla pearl derby, Valentina Jalby	*Moderator:* Suja Somanadhan
17:30 - 17:45	**Light Refreshment Break**	

RAISING AWARENESS: THE TEDDY KIDS' WAY - BIOTECH WEEK 2026 EVENT	
17:45 –17:50	**Welcome Session & Opening Remarks**
From Framework to Practice: The TEDDY Patient Engagement Model in Clinical Studies	
17:50 - 18:00	Patient Engagement in the GAPP Study: Approach and Planned Activities — Emanuela Crea

18:00 - 18:15	Patient Engagement in the MODERATO Study: Experience and Lessons Learned	Annegret Dahlmann-Noor
Science Meets the Next Generation		
18:15 - 18:25	Understanding Rare Diseases: A Young Person's Guide	Suja Somanadhan
18:25 - 18:35	Inside the Lab: How New Treatments Are Developed	Manika Kreka
18:35 - 18:45	Technology and Health: AI's Growing Role in Paediatric Care	Aleksander Wiśniewski
18:35 - 18:45	"MI VEDETE? - A Value-Based, Participatory Approach to Adolescent Mental Health in Italian Schools"	Giorgio Reggiardo
My Health, My Voice		
18:55 - 19:05	Why Patients' Rights Matter to Young People	Eirini Daskalopoulou
19:05 - 19:35	Having a Say: Youth Involvement in Clinical Research Decisions	TEDDY KIDS Members
Put Your Knowledge to the Test		
19:35 - 19:55	Live Quiz and Discussion	Francesco La Penna
19:55 - 20:00	Closing Remarks	Donato Bonifazi

Sunday 20 September - Morning

10:00 - 13:00	**Guided Tour**

SPEAKERS LIST

18 - 19 September 2026 · University of Bari, Bari, Italy

Friday 18 September - Afternoon

Opening Remarks

Dr. Donato Bonifazi	*TEDDY Network Chair*

The GAPP Study Roundtable

Dr. Eleonora Di Campi	*TEDDY Network*
Dr. Giorgio Reggiardo	*TEDDY Network*
Dr. Anna Szumowska	*Children's Memorial Health Institute, Warsaw*
Dr. Oscar della Pasqua	*University Collage of London \ TEDDY Stichting*
Dr. Paola Baiardi	*IRCSS Istituti Clinici Scientifici Maugeri*
Dr. Evelyne Jacqz-Aigrain	*Université Paris Cité,*
Dr. Tom de Leeuw	*Erasmus University Medical Center \ Sophia Children's Hospital*
**Muminah Aaisha-Seddika*	*TEDDY KIDS Network - Moorfields eye-YPAG, United Kingdom*
**Eirini Daskalopoulou*	*TEDDY KIDS Network - KIDS Rare Hellas, Greece*
**Francesco Meloni*	*Italian Association of Bladder Exstrophy and Epispadias ODV*
**Nepheli Mimi*	*TEDDY KIDS NETWORK*
**Martina Leandro*	*TEDDY KIDS NETWORK - KIDS Bari, Italy*
**Thuraya Layla Pearl Derby*	*TEDDY KIDS Network - Moorfields eye-YPAG, United Kingdom*
**Valeria Gatti*	*TEDDY KIDS NETWORK - KIDS Bari, Italy*
**Valentina Jalby*	*TEDDY KIDS NETWORK*

Friday 19 September - Morning

Innovation, evidence gaps and solutions for children

Dr. Giovanni Migliaccio	*TEDDY Network*
Dr. Gianluca Sferrazza	*Italian National Research Council*
Dr. Marek Migdal	*Children's Memorial Health Institute, Warsaw*

Dr. Grazia Tamma	*University of Bari Aldo Moro*
Dr. Madlen Gazarian	*University of New South Wales*
Dr. Annalisa Landi	*Fondazione per la Ricerca Farmacologica Gianni Benzi*
Dr. Giuseppe Pontrelli	*IRCCS Bambino Gesù Children's Hospital*
Dr. Anne Smits	*Katholieke Universiteit Leuven*
Dr. Pieter Annaert	*Katholieke Universiteit Leuven*

From Small Populations to Robust Evidence Panel Discussion

Dr. Viviana Giannuzzi	*Fondazione per la Ricerca Farmacologica Gianni Benzi*
Dr. Solange Corriol-Rohou	*Consultant EFPIA representative*
Dr. Flora Musuamba Tshinanu	*University of Namur*
Dr. Sarah Zohar	*French National Institute of Health and Medical Research, Université Paris Cité*

OrphaDev4Kids Patient Expert Committee (PEC) Parallel Session

Dr. Emanuela Crea	*TEDDY Network*
Dr. Franco Bartoloni	*Fondazione per la Ricerca Farmacologica Gianni Benzi ETS*
Dr. Ana Muke	*TEDDY Network*
Francesco La Penna	*TEDDY Network*
**Alberto Giandomenico*	*TEDDY KIDS NETWORK - KIDS Bari*
**Eirini Daskalopoulou*	*TEDDY KIDS Network - KIDS Rare Hellas, Greece*
**Karol Słowik*	*TEDDY KIDS Network - POLPEDNET KIDS Warsaw*
**Leonardo Fiore*	*TEDDY KIDS NETWORK - KIDS Bari*

Friday 19 September - Afternoon

From innovative concepts to trial readiness - advancing clinical research in rare diseases

Dr. Maurizio Scarpa	*University of Padua, European Reference Network for Hereditary Metabolic Diseases*
Dr. Valentina de Giorgis	*IRCCS Mondino Foundation*
Dr. Dariusz Adamczewski	*Children's Tumor Foundation Europe*
Dr. Nunzio Denora	*University of Bari*

Dr. Liisi Laaniste	*CoSyne Therapeutics*
Dr. Michelina Armando	*IRCCS Ospedale pediatrico bambino Gesù*

INVENTS paediatric Patient Expert Group (PEG) Parallel Session

Dr. Sarah Zohar	*French National Institute of Health and Medical Research, Université Paris Cité*
Dr. Viviana Giannuzzi	*Fondazione per la Ricerca Farmacologica Gianni Benzi*
Dr. Giorgio Reggiardo	*TEDDY Network*
Dr. Ana Muke	*TEDDY Network*
Francesco La Penna	*TEDDY Network*
**Aaisha-Seddika Muminah*	*TEDDY KIDS Network - Moorfields eye-YPAG, United Kingdom*
**Nefeli Mimi*	*TEDDY KIDS NETWORK*
**Valentina Jalby*	*TEDDY KIDS NETWORK*

Friday 19 September - Afternoon

The role of patient engagement in shaping paediatric research

Dr. Aleksander Wiśniewski	*Children's Memorial Health Institute\ POLPEDNET KIDS Warsaw*
Dr. Suja Somanadhan	*University College Dublin|KIDS RAiN*
Dr. Alessandra Simonetti	*INCiPiT Network – Ospedale Pediatrico Bambino Gesù*
Dr. Eleonora Passeri	*Rare Special Powers APS\KIDS Umbria*
Dr. Annegret Dahlmann-Noor	*Moorfields eye- Hospital NHS Foundation Trust*
Dr. Ines Alves	*National Association of Skeletal Dysplasias Portugal*
Dr. Manika Kreka	*Clinical validation From Biopharmaceutical Finding\KIDS Albania*
Dr. Mariagrazia Felisi	*Clinical validation From Biopharmaceutical Finding*
Dr. Mimoza Basholli-Salihu	*University of Prishtina| Panhellenic Association for Inherited Metabolic Diseases| KIDS Rare Hellas*
Dr. Persephone Augoustides-Savvopoulou	*Panhellenic Association for Inherited Metabolic Diseases \ KIDS Rare Hellas*
Dr. Roseline Favresse	*EURORDIS*
Dr. Gemma Rodriguez	*EURORDIS*
Dr. Helin Ruf-Uçar	*European Rare Diseases Research Alliance*

Dr. Viviana Giannuzzi	*Fondazione per la Ricerca Farmacologica Gianni Benzi*
**Anano Lartsuliani*	*SMA Foundation Georgia*
**Aaisha-Seddika Muminah*	*TEDDY KIDS Network -Moorfields eye-YPAG*
**Alberto Giandomenico*	*TEDDY KIDS NETWORK - KIDS Bari*
**Eirini Daskalopoulou*	*TEDDY KIDS Network - KIDS Rare Hellas*
**Francesco Meloni*	*Italian Association of Bladder Exstrophy and Epispadias ODV*
**Gabriella Monacelli*	*TEDDY KIDS NETWORK - KIDS Bari*
**Karol Słowik*	*TEDDY KIDS Network - Polpednet KIDS Warsaw*
**Leonardo Fiore*	*TEDDY KIDS NETWORK - KIDS Bari*
**Thuraya Layla pearl derby*	*TEDDY KIDS Network -Moorfields eye-YPAG*
**Valentina Jalby*	*TEDDY KIDS NETWORK*

RAISING AWARENESS: THE TEDDY KIDS' WAY - BIOTECH WEEK 2026 event

Dr. Emanuela Crea	*TEDDY Network*
Dr. Annegret Dahlmann-Noor	*Moorfields eye- Hospital NHS Foundation Trust*
Dr. Suja Somanadhan	*University College Dublin|KIDS RAiN*
Dr. Manika Kreka	*Clinical validation From Biopharmaceutical Finding\ KIDS Albania*
Dr. Aleksander Wiśniewski	*Children's Memorial Health Institute, Warsaw \POLPEDNET KIDS Warsaw*
Dr. Giorgio Reggiardo	*TEDDY Network*
**Eirini Daskalopoulou*	*TEDDY KIDS Network - KIDS Rare Hellas,*
**Alberto Giandomenico*	*TEDDY KIDS NETWORK - KIDS Bari*
**Gabriella Monacelli*	*TEDDY KIDS NETWORK - KIDS Bari*
**Jasmine Noor*	*TEDDY KIDS Network - NIHR Moorfields eye-YPAG*
**Leonardo Fiore*	*TEDDY KIDS NETWORK - KIDS Bari*
**Valeria Gatti*	*TEDDY KIDS NETWORK - KIDS Bari*
Francesco la Penna	*TEDDY Network*
Dr. Donato Bonifazi	*TEDDY Network*

Young representatives