



EUROPEAN PAEDIATRIC TRANSNATIONAL RESEARCH INFRASTRUCTURE

General Assembly and Scientific Meeting Agenda

28–29 July 2026 – Warsaw, Poland

📍 **Children's Memorial Health Institute (CMHI)**

Instytut "Pomnik – Centrum Zdrowia Dziecka"

aleja Dzieci Polskich 20

04-736 Warsaw, Poland



EUROPEAN PAEDIATRIC TRANSNATIONAL RESEARCH INFRASTRUCTURE

DAY 1 AFTERNOON

28 July 2026

13:00–13:30 **Welcome & Registration**

FUTURE PERSPECTIVES IN PAEDIATRIC RESEARCH – EUROPEAN NETWORKS & INFRASTRUCTURES COLLABORATION

Chair: Marek Migdal

13:30–13:45	<i>Opening Remarks & Preliminary Results of the Paediatric Research Needs Survey</i>	Marek Migdal (CMHI – Poland, EPTRI)
13:45–14:00	<i>EPTRI Integrated Approach to Support Paediatric Research</i>	Karel Allegaert (KUL – Belgium, EPTRI)
14:00–14:25	<i>Perspectives on Enpr-EMA Strategic Plans 2026-2028</i>	Ricardo Fernandes (Enpr-EMA - Netherlands)
14:25–14:50	<i>ACT-EU Initiative - Multi-Stakeholder Approach to Accelerate Clinical Trials</i>	Donato Bonifazi (TEDDY Network – Italy, EPTRI)
14:50–15:15	<i>European Reference Networks (ERNs) – Contribution to Advancing Paediatric Research</i>	Luca Sangiorgi (IOR – Italy, ERN-BOND)
15:15–15:40	<i>Instruct-ERIC: Get Access to Advanced Structural Biology Services</i>	Harald Schwalbe (GUF – Germany, Instruct-ERIC)
15:40–16:05	<i>Creating Preclinical Models for Rare Diseases: RD-Factory as a Platform, Netherton Syndrome as a Case Study</i>	Radislav Sedlacek (CCP – Czech Republic, INFRAFRONTIER ERIC)
16:05–16:30	<i>Towards a Federated European Ecosystem for Rare Disease Research: ELIXIR Activities and Collaborative Synergies with EPTRI</i>	Emidio Capriotti (UNIBO – Italy, ELIXIR IT)

16:30–17:00 **Coffee Break**

STRATEGIC DIRECTIONS IN PAEDIATRIC MEDICAL DEVICES DEVELOPMENT

Chair: Roberta Nossa

17:00–17:25	<i>Strategic Directions in Paediatric Medical Devices Development</i>	Tom Melvin (UoG – Ireland)
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SESSION ON EMERGING TECHNOLOGIES FOR PAEDIATRIC PATIENTS

17:30–17:45	<i>Design of Technologies for Children: User Needs as a Point of Start</i>	Patrice L. Weiss (University of Haifa and ALYN Hospital - Israel)
17:45–18:00	<i>Innovative Neonatal Technologies</i>	Kathryn Beardsall (UCAM - England)

18:00–18:15	<i>Agilik: A New Exoskeleton for Children Rehabilitation in Clinic or at Home</i>	<i>Emilia Biffi (MEDEA - Italy)</i>
18:15–18:30	<i>OptiTrack Feasibility for Paediatric Gait Assessment in Achondroplasia: A Rare Disease Laboratory Use Case</i>	<i>Inês Alves (ANDO Portugal - Portugal)</i>
POSTER SESSION & NETWORKING COCKTAIL		
18:45–19:45	Poster Session	
19:45–21:00	Networking Cocktail	

DAY 2 MORNING

29 July 2026

EPTRI GENERAL ASSEMBLY

9:00–10:00	<i>EPTRI General Assembly</i>	<i>All EPTRI AISBL Members</i>
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REGULATORY CHALLENGES IN PAEDIATRIC RESEARCH

Chair: Karel Allegaert

10:00–10:25	<i>Past, Present and Future of Regulatory Science for Paediatric Medicines</i>	<i>Viviana Giannuzzi (FGB - Italy)</i>
10:25–10:50	<i>Innovative Medicines for Children</i>	<i>Marc Dooms (UZ Leuven – Belgium, TRANSFORM)</i>
10:50–11:15	<i>Regulatory Challenges in Paediatric Medical Devices</i>	<i>Breda Kearney (BSI - United Kingdom)</i>
11:15–11:35	Coffee Break	

ADVANCING PAEDIATRIC RESEARCH THROUGH HEALTH DATA, AI AND DIGITAL APPROACHES

Chair: Emidio Capriotti

11:35–12:00	<i>Building a Federated Ecosystem for Paediatric Health Data</i>	<i>Rafał Bartczuk (CMHI - Poland)</i>
12:00–12:25	<i>AMIGO Proposal: A Concrete Use Case for Paediatric Innovation - From Fragmented Data to Integrated Translational Pathways</i>	<i>Daniel Weiss (LMU - Germany)</i>
12:25–12:50	<i>Unlocking the Potential of Real-World Health Data for Paediatric Clinical Research</i>	<i>Christophe Maes (i-HD - Belgium)</i>
12:50–13:15	<i>AI-Based Digital Platforms for Early Drug Repurposing Studies in Paediatric Diseases</i>	<i>Cosimo Altomare (UNIBA - Italy)</i>
13:15–14:15	Light Lunch	

DAY 2 AFTERNOON

29 July 2026

SUPPORTING THE PAEDIATRIC INNOVATION PIPELINE

Chair: Giovanni Migliaccio

14:15–14:35	<i>Gene Therapy for α-Thalassaemia: Towards an In Utero Therapeutic Approach</i>	Marios Phylactides (CING - Cyprus)
14:35–15:00	<i>Integrated Translational Perspectives in Neuromuscular Diseases:</i> <i>Disease-Modifying Therapies in Rare Neuromuscular Diseases: Where Do We Stand?</i> <i>Gait analysis in Duchenne Muscular Dystrophy: a selective tool for gene therapy functional evaluation</i>	Nicolas Deconinck (HUDERF - Belgium) Pablo Ruiz (HUDERF - Belgium)
15:00–15:20	<i>The Challenge Is Not the Therapy - It's the Population. An Industry Perspective on Paediatric Evidence Generation Beyond ATMPs</i>	Kun Shi-van Wielink (Santer Pharmaceutical – Netherlands)
15:20–15:40	<i>Industry Perspective on Paediatric Rare Disease Development</i>	Sean Kilbride (Regeneron – Ireland)
15:40–16:00	Coffee Break	

INNOVATIONS IN PAEDIATRIC CLINICAL RESEARCH AND TRANSLATIONAL SCIENCE

Chair: Donato Bonifazi

16:00–16:20	<i>SPIRIT-C and CONSORT-C Guidelines</i>	Karel Allegaert (KUL - Belgium)
16:20–16:40	<i>Innovative Methodologies Supporting Clinical Trials and Use Cases</i>	Oscar Della Pasqua (UCL - United Kingdom)
16:40–17:00	<i>Data Initiatives Driven for and by The Patients: The Duchenne Example</i>	Sergiu Siminiuc (DDF - Netherlands)
17:00–17:20	<i>From Molecules to Disease Models: Correlative Microscopy Approaches and Integrated Structural Biology for Multiscale Phenotyping of Fibrosis, Tissue Mechanics, and Cardiac Organoids</i>	Jan Přibyl (CEITEC MU - Czech Republic)
17:20–17:40	<i>Cryo-EM for Paediatric Disease Research at Leeds Instruct Centre</i>	Oksana Degtjarik (University of Leeds – United Kingdom)
17:40–18:00	<i>Advances in Paediatric Medicine Development through Direct Powder Extrusion 3D Printing</i>	Antonio Lopalco (UNIBA - Italy)
18:00–18:10	Closing Remarks	