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ERN PaedCan General Assembly meeting



Meeting Venue: Brussels, Renaissance Hotel
Host: SIOPE, Brussels, Belgium
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Draft Agenda Thursday, 01.02.2018 – BALLROOM 1+2

Agenda Item	Leader and Remarks	Start	End
ERN PaedCan SIOPE CRC expert meeting		09:00	13:00
ARRIVAL AND REGISTRATION		13:30	14:00
ERN PaedCan GA meeting			
Session I: ERN PaedCan Strategic Actions & Joint Actions			
Chair: Gilles Vassal		14:00	15:55
Welcome by the SIOPE President and the ERN PaedCan Coordinator	Martin Schrappe & Ruth Ladenstein SIOPE President & ERN PaedCan Coordinator	14:00	14:05
ERNs: Current status and upcoming opportunities	Enrique Terol (TBC) DG Santé, European Commission, Policy officer, Cross-Border Healthcare & eHealth	14:05	14:25
ERN Coordinators Group: Aims, Tasks and Achievements	Maurizio Scarpa Die HELIOS Dr. Horst Schmidt Kliniken Wiesbaden, Metab ERN Coordinator & ERN Chair of Coordinators	14:25	14:45
Research in ERNs & Horizon 2020 calls	Eduardo López Granados Hospital Universitario La Paz-IdiPAZ, ERN-TransplantChild & ERN Research WG EC (TBC) European Commission,	14:45	15:15
Clinical Patient Management System (CPMS) live: First experiences and next steps	Herman Brand DG Santé, European Commission, Head of Unit, Information System	15:15	15:35
CEF call results: Advantages for ERN PaedCan CPMS: The Coordinators perspective	Ruth Ladenstein CCRI, ERN PaedCan Coordinator	15:35	15:55
COFFEE BREAK		15:55	16:15
Chair: Martin Schrappe		16:15	19:15
ERN PaedCan Current Activities & Outlook	Ruth Ladenstein CCRI, ERN PaedCan Coordinator	16:15	16:35
ERN PaedCan Project Management: Practicalities	Melanie Brunhofer CCRI, ERN PaedCan Project Manager	16:35	16:45
Awareness, Dissemination & Education	Samira Essiaf SIOPE	16:45	17:00
Twinning Programmes & Current twinning Activities & Expectations	Ruth Ladenstein CCRI, ERN PaedCan Coordinator Jerzy Kowalczyk Medical University of Lublin Jelena Rascon University Children's Hospital, Vilnius Dobrin Konstantinov SBALDOHZ- Specialized Children's Oncohematology Hospital	17:00	17:30

The ERN PaedCan received funding by the European Union's Health Programme (2014-2020), grant agreement nr. 768967.



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SIOP Europe
the European Society for Paediatric Oncology



**European
Reference
Network**
for rare or low prevalence
complex diseases



Network
Paediatric Cancer
(ERN PaedCan)
Coordinator
St. Anna Kinderspital &
St. Anna Kinder-
krebsforschung — Austria

Session II: Roadmap Development			
Introduction: ERN PaedCan Roadmap Development Status Quo and planned action	Ruth Ladenstein ERN PaedCan Coordinator, CCRI, Vienna	17:30	17:40
ERN PaedCan Roadmap development:			
Patients´ and Parents´ Organisation	Anita Kienesberger Childhood Cancer International- Europe, Vienna	17:40	17:50
The SIOP Brain Tumour Network	Stefan Rutkowski Hamburg-Eppendorf, Germany	17:50	18:00
Familial Leukaemia	Brigitte Schlegelberger Medizinische Hochschule Hannover, Germany	18:00	18:10
Langerhans Cell Histiocytosis (LCH)	Milen Minkov St. Anna Kinderspital	18:10	18:20
ERN PaedCan Webinars and Movies	François Doz Institut Curie, Paris / University Medical Center	18:20	18:30
Session V: Surpass			
Actions undertaken in Year 1 and next steps	Riccardo Haupt IRCCS Istituto G. Gaslini , Genoa	18:30	18:50
Update on Austrian developments	Günter Schreier AIT, GRAZ	18:50	19:10
Wrap up	Ruth Ladenstein CCRI, ERN PaedCan Coordinator	19:10	19:15
NETWORKING DINNER (Renaissance Hotel)			19:30

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Agenda Friday, 02.02.2018 – BALLROOM 1+2

Agenda Item	Leader and Remarks	Start	End
ARRIVAL AND REGISTRATION		8:00	09:00
Session III: ERN Collaboration and future efforts			
Chair: Pamela Kearns		09:00	12:00
Introduction	Martin Schrappe SIOPE President	9:00	9:10
Rare Cancer perspectives for collaborations and JARC activities	Paolo Casali EUROCAN representative Gilles Vassal Institut de Cancérologie Gustave-Roussy Olga Kozhaeva Senior Policy and Public Affairs Coordinator, SIOPE Ines Brecht (TBC) Kinder- und Jugendklinik des Universitätsklinikums Erlangen Vincent Bours ERN GENTURIS representative	9:10	10:20
Epidemiological cancer registries in JARC	Kathy Pritchard Jones University College London Great Ormond Street Institute of Child Health	10:20	10:40
JARC WP4 – Epidemiology	Gemma Gatta (TBC) Fondazione Istituto Nazionale Tumori, Milano, Italy	10:40	11:00
COFFEE BREAK		11:00	11:20
Session IV: Quo Vadis Registries			
Joint Research Centre: The EC unified EU registry	Simona Martin Joint Research Centre, European Commission	11:20	11:40
PARTNER - Joint Very Rare Tumour Registries	Gianni Bisogno University of Padova PARTNER project coordinator	11:40	12:00
Closing remarks	Martin Schrappe & Ruth Ladenstein SIOPE President & ERN PaedCan Coordinator	12:00	12:05
Networking Lunch		12:05	13:05
PARTNER kick off meeting		12:35	16:00

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