

# CONFERENCE PROGRAMME



**eurolinkcat**  
Establishing a linked European Cohort of  
Children with Congenital Anomalies



All listed times are Central European Summer Time (CEST)

## Thursday 7 April 2022

12:00-14:00

Student poster presentations

14:15-15:45

OPENING SESSION

**Chairs:** Prof Anna Latos Bielenska, Prof Joan Morris

**Conference Welcome**

Speaker: Prof Anna Latos Bielenska

**EUROlinkCAT: Why create a linked European cohort of children with congenital anomalies?**

Speaker: Prof Joan Morris

**EUROCAT: Maximising EUROCAT's potential**

Speaker: David Tucker

**Multi-stakeholder engagement to support person-centred health outcomes**

Speaker: Dr Sylvia Roozen

15:45-16:00

Break

16:00-17:50

SESSION 1

The Voice of Parents and Science:

Health care and education of children with congenital anomalies

**Chair:** Prof Ingeborg Barisic **Co-Chair:** Dr Amanda Neville

**The voice of the parents**

Speaker: Dr Kristina Garne Holm

**The information and support needs of parents of children with congenital anomalies: an online survey in 10 European countries**

Speaker: Dr Elena Marcus

**Some insights into educational achievements in children born with a congenital anomaly**

Speaker: Prof Judith Rankin

**Panellists' presentations**

Speakers: Dorica Dan, Dominika Madaj-Solberg, Prof Jolanta Wierzba

**Panel discussion**

17:50-18:00

Break

18:00-20:00

Virtual discussion rooms

*(for anyone to discuss posters, parents' experiences, foundations and associations)*



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## Friday 8 April 2022

8:15-8:35	<b>Winning student poster presentations</b>
8:35-9:00	<b>How do you create a linked European cohort of children with congenital anomalies?</b> Speaker: Prof Joan Morris
9:00-10:45	<b>SESSION 2</b> <b>Medications for chronic diseases in children with and without congenital anomalies</b>
	<b>Chair:</b> Dr Maria Loane <b>Co-Chair:</b> Dr Mads Damkjær  <b>Type 1 diabetes mellitus in children up to ten years of age</b> Speaker: Dr Joanne Given  <b>Anti-asthmatic prescriptions in children with and without congenital anomalies</b> Speaker: Natalie Divin  <b>Prescription of cardiovascular medication to children with congenital heart defects</b> Speaker: Dr Mads Damkjær  <b>Panellists' presentations</b> Speakers: Dr Tania Schink, Prof Anne-Marie Nybo Andersen, Dr Christine Damase-Michel  <b>Panel discussion</b>
10:45-11:15	<b>Break</b>
11:15-13:05	<b>SESSION 3</b> <b>Hospitalisations and surgeries in children with and without congenital anomalies</b>
	<b>Chair:</b> Dr Ester Garne <b>Co-Chair:</b> Dr Mads Damkjær  <b>Length of children's hospital stays</b> Speaker: Dr Stine Kjaer Urhoj  <b>Timing, numbers and mortality of surgical interventions in children with congenital anomalies</b> Speaker: Dr Mads Damkjær  <b>Intensive care and mechanical ventilation in children</b> Speaker: Dr Cecilia Martellucci  <b>Are permanent feeding tubes used by children with congenital anomalies?</b> Speaker: Dr Ester Garne  <b>Panellists' presentations</b> Speakers: Dr Luca Autelitano, Prof Damien Bonnet, Prof Irene Petersen  <b>Panel discussion</b>
13:05-14:05	<b>Lunch break</b>



## Friday 8 April 2022 (continued)

14:05-15:55	<b>SESSION 4</b> <b>Survival of children born with congenital anomalies</b>
	<b>Chair:</b> Prof Judith Rankin <b>Co-Chair:</b> Dr Anna Pierini  <b>Temporal and geographical variations in survival of children born with congenital anomalies in Europe</b> Speaker: Dr Michele Santoro  <b>Ten-year survival of children born with major congenital anomalies</b> Speaker: Dr Svetlana Glinianaia  <b>Survival of children with rare structural congenital anomalies</b> Speaker: Dr Alessio Coi  <b>Difficulties in combining data on the survival of children with congenital anomalies</b> Speaker: Matt Pryce  <b>Panellists' presentations</b> Speakers: Prof Ruth Gilbert, Prof Paul Romitti, Dr Jennita Reefhuis  <b>Panel discussion</b>
15:55-16:25	<b>Break</b>
16:25-18:25	<b>SESSION 5</b> <b>Evaluating and Enhancing the use of Hospital Discharge Data in the Surveillance of Congenital Anomalies</b>
	<b>Chair:</b> Dr Hermien de Walle <b>Co-Chair:</b> Prof Joan Morris  <b>Accuracy of congenital anomaly coding on live birth children recorded in health care databases</b> Speaker: Dr Marian Bakker  <b>Using EUROlinkCAT data to evaluate cause of death from vital statistics</b> Speaker: Dr Anke Rissmann  <b>Algorithms for use in health care databases to improve the surveillance of congenital anomalies</b> Speaker: Dr Cecilia Martellucci  <b>Lessons learned from the EUROlinkCAT study on the quality of data in health care databases</b> Speaker: Dr Ester Garne  <b>Panellists' presentations</b> Speakers: Prof Domenica Taruscio, Prof Sonia Hernández-Díaz, Prof Helen Dolk, Prof Robert Smigiel  <b>Panel discussion</b>
18:25-18:45	<b>CONFERENCE CLOSING SESSION</b>

