

Biennial meeting of the AEPC working group on neuro-development and psychosocial care, from fetus to adult

13th – 15th March 2024



ASSOCIATION FOR EUROPEAN
PAEDIATRIC AND CONGENITAL
CARDIOLOGY

Wednesday 13th March

Time	Title	Speaker	Country
13:30 - 14:00	Registration and Welcome		
14:00 - 14:15	Opening and Congress Introduction	Sara Mariani Edward Callus	Italy

Session 1: Brain Abnormalities and Monitoring in CHD

Chair: Bea Latal

14:15 - 14:45	1.1	Keynote Lecture: Brain abnormalities and associated neurodevelopmental impairments across the life span	Melanie Ehrler	Switzerland
14:45 - 15:00	1.2	High Levels of Oxidative Stress Biomarkers Predict Poor Neurodevelopmental Outcomes in Newborns Undergoing Aortic Arch Surgery	Maria C. Escobar-Diaz	Spain
15:00 - 15:10	1.3	Description of biometric changes in the Corpus Callosum in patients with congenital heart disease: Does it have an impact on neurodevelopment?	Alba Rivas	Spain
15:10 - 15:20	1.4	A new Hybrid Diffuse Optical Monitor for continuous cerebral monitorization of infants with congenital heart defects in operation and NICU	Marta Camprubí-Camprubí	Spain
15:20 - 15:30	1.5	Oxidative stress and cerebral oxygenation during Cardiac surgery as early biomarkers of poor neurological outcome	Marta Camprubí-Camprubí	Spain
15:30 - 16:00		Coffee Break		



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Session 2: Neurodevelopmental Outcomes and Challenges in CHD

Chair: Katya de Groot

16:00 - 16:30	2.1 Keynote Lecture: Developmental Trajectories in children with congenital heart disease	Bea Latal	Switzerland
16:30 - 16:45	2.2 Brain Damage Biomarkers, Neuromonitoring and Neurodevelopmental Outcomes in Patients Undergoing Neonatal Cardiac Surgery	Marta Camprubí-Camprubí	Spain
16:45 - 17:00	2.3 Predictors Of Neurodevelopmental Outcomes In Children With Severe Congenital Heart Disease: Conceptualization Of An Epidemiological And Longitudinal Study	Raphael Oberhuber	Austria
17:00 - 17:15	2.4 Arterial switch and neurological outcomes	Antonio Corno	UK
17:15 - 17:25	2.5 Study of neurodevelopment in children with unoperated congenital heart diseases	Ismael Ibouroi	Senegal
17:25 - 17:35	2.6 Survival without neurodevelopmental impairments at school age in children with congenital heart disease	Rabia Liamlahi	Switzerland
17:35 - 17:45	2.7 School-aged children with complex congenital heart disease or born very preterm show similar profiles of executive function impairments	Céline Steiner	Switzerland
17:45 - 17:55	2.8 Autonomic Nervous System, Heart Rate Variability and Cognitive Functions in Adolescents with Congenital Heart Disease	Asuka Toyofuku	Switzerland
17:55 - 18:05	2.9 Navigating the recruitment challenges in clinical trials: Insights from a feasibility study on an executive function intervention for children with complex congenital heart disease	Alenka Schmid	Switzerland
18:05 - 18:15	Last questions/comments/wrap up		

Session 3: Resilience and Support Systems: Addressing Psychological and Educational Challenges in CHD Families

Chair: Johanna Calderon

9:00 - 9:30	3.1	Keynote Lecture: Overview talk on how the care of the child with CHD has changed in the past 20 years- new treatments and new perspectives on global outcome	Frank Casey	Northern Ireland
9:30-9:45	3.2	A qualitative exploration of parental wellbeing and perspectives on psychological intervention following a fetal diagnosis of congenital heart disease	Catherine Quinn	Northern Ireland
9:45 - 9:55	3.3	Exploring Relationships between Parental Stress, Coping and Psychological Outcomes for Parents of Infants with Congenital Heart Disease	Catherine Matthews	Ireland
9:55 -10:05	3.4	Let's Get Ready, A Psychological Guide to Paediatric Cardiac Surgery	Catherine Matthews	Ireland
10:05 - 10:15	3.5	Current Challenges facing Families and Teachers of School Children with Congenital Heart Disease	Sharon Millen	Northern Ireland
10:15 - 10:25	3.6	Psychosocial functioning in youngsters (8-17 years) with a congenital heart disease (CHD): the role of attachment, parental and youth emotion regulation strategies	Saskia Mels	Belgium
10:25 - 10:35	3.7	The use of self-help amenities in parents of children with congenital heart defects: Results of a nationwide survey with 827 affected families in Germany	Carola Ossenkopp-Wetzig	Germany
10:35 - 11:00		Wrap up un session 3 on Family Dynamics in CHD		
11:00 - 11:30		Coffee Break		

Session 4: Pathways to Resilience: Navigating Adolescent-to-Adult Transition in CHD

Chair: Gaby Stoffel

11:30 - 11:45	4.1	Educational Support's Impact on Young People with Congenital Heart Disease in Upper Secondary Education	Lene Osmundsen	Norway
11:45 - 12:00	4.2	Navigating Lifestyle Challenges with Congenital Heart Disease	Rosario Caruso	Italy
12:00 - 12:15	4.3	Summer Residential Camps improve teenagers with congenital heart disease feelings of Stress, Anxiety and Depression	Scott Kendall	Northern Ireland
12:15 - 12:30	4.4	The Journey of Establishing a Transition Clinic.	Arianna Magon	Italy
12:30 - 13:00	4.5	Keynote lecture Allied Professionals WG: Transfer and transition: pitfalls and how to overcome them	Eva Goossens	Belgium
13:00 - 14:00		Lunch		

Session 5: The Long View: Understanding Identity, Well-being, and Life Stories in ACHD

Chair: Edward Callus

14:00 - 14:30	5.1	Keynote lecture: Psychopathology in Adults with CHD: A 40-53 years follow up study	Elisabeth Utens	The Netherlands
14:30 - 14:45	5.2	Identity formation of patients with congenital heart disease over life course: a social context perspective	Junko Enomoto	Japan
14:45 - 15:00	5.3	Health-Related Quality of Life of Adult Congenital Heart Disease Patients with Chronic Heart Failure in Japan	Yoshiko Miuzno	Japan
15:00 - 15:15	5.4	Adults with congenital heart disease and their quality of life	Raphael Oberhuder	Austria
15:15 - 15:30	5.5	Life story with Complex Heart Disease	Giovanna Campioni	Italy

Session 6: Shaping Futures: Interventional Strategies Across the Lifespan in CHD

Chair: Antonio Corno

15:30 - 16:00	6.1	Keynote Lecture: Focus on trauma and illness: EMDR	Isabel Fernandez	Italy
16:00 - 16:30		Coffee break		
16:30 - 16:45	6.2	History and Development of Psychosocial Support in Hospital and Patient Pathways	Massimo Chessa	Italy
16:45 - 17:00	6.3	Interplay of Scars and Art in Healing and Identity: Art, Cut and Scar	Alessandro Giamberti	Italy
17:00 - 17:15	6.4	An Innovative Approach to Addressing Unmet Mental Health Needs of the Heart Community	Sydney Philpott-Streiff	USA
17:15 - 17:30	6.5	Exploring the Impact of Support Interventions on Clinician Satisfaction and Patient Care in CHD: A European Perspective	Lene Osmondsen	Norway
17:30 - 17:40	6.6	The Fontan Outcomes Network's Single Ventricle Patient Day: Engagement, Empowerment, and Education	Meg Didier	USA
17:40 - 17:50	6.7	The Impact of Multicultural Psychological Support in Pediatric Congenital Heart Patients from Romania: Presentation of a Case Report	Raluca B Nedesca	Italy
17:50 - 18:00	6.8	Approbation of a psychological training program in fear coping skills for young people with congenital heart disease	Mila Markova	Bulgaria
18:00 - 18:30	6.9	Keynote lecture: Monitoring mental health of ACHD in the patient pathway: recommendations and a case example	Edward Callus	Italy

Session 7: Resilience and Evolution: Family-Centric Approaches in CHD Management

Chair: Frank Casey

8:30 - 9:00	7.1	Neurodevelopmental Follow-up for Children with Congenital Heart Disease in Europe: Guidelines for Developmental and Psychosocial Care	Johanna Calderon & Bea Latal	France & Switzerland
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CHIP Symposium

9:00 - 9:15	7.2	The Congenital Heart Disease Intervention Programme (CHIP) – Past, Present and Future	Christopher McCusker	Ireland
9:15 - 9:30	7.3	Long-term neuropsychological and psychological outcomes for young adults with significant CHD – Wave 3 of the CHIP study.	Christopher McCusker	Ireland
9:30 - 9:45	7.4	How do parents of young adults with congenital heart disease construct their parenting experiences across development – did an early family focused intervention make a difference?	Nicola Doherty	Northern Ireland
9:45 - 10:00	7.5	Implementation of CHIP-Infant: A Psychosocial Intervention for Parents of Newborns with Congenital Heart Defects in Sweden	Carmen Ryberg	Sweden
10:00 - 10:15	7.6	CHIP – Strengthening family resilience in the context of congenital heart defect.	Petra Bostrom	Sweden
10:15 - 11:00	7.7	Keynote lecture: Stress / mental health of the caregivers	Katya De Groote	Belgium
11:00 - 11:30		Coffee Break		



Session 8: Socioeconomic Challenges and Inclusive Support in CHD

Chair: Lene Osmundsen

11:30 - 12:00	8.1 Keynote Lecture: Beyond Mental Health: Social and economic well-being in the Global ACHD Community	Amy Verstappen	USA
12:00 - 12:15	8.2 Analysis of the situation of people with Congenital Heart Disease on disability and early care	Ana Belén Hernández	Spain
12:15 - 12:30	8.3 A Qualitative Exploration of Parent/Caregiver Experiences Raising an Adolescent with Down's Syndrome, Research Experiences and the Lived Experience of Adolescent's with Down's Syndrome.	Kiai Chambers	Northern Ireland
12:30 - 12:45	8.4 Development and wellbeing of individuals with Down syndrome and congenital heart disease: a scoping review	Aoife Grenham Mcnamee	Northern Ireland
12:45 - 13:15	8.5 Keynote Lecture Allied Professionals WG: The role of the Advanced Practice Nurse (APN) in the care for CHD patients and their families	Gaby Stoffel	Switzerland
13:15 - 13:30	Prizes and Closure		



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