

# Biennial meeting of the AEPC working group on Neurodevelopment and Psychosocial Care, from Fetus to Adult



ASSOCIATION FOR EUROPEAN  
PAEDIATRIC AND CONGENITAL  
CARDIOLOGY

## 25<sup>th</sup> – 27<sup>th</sup> of March 2020

IRCCS Policlinico San Donato, San Donato Milanese, Milan, Italy

### Wednesday 25<sup>th</sup> of March, 2020

**13:30 – 14:00** Registration

**14:00 – 14:15** Opening and Welcome, Institutional greetings IRCCS Policlinico San Donato - **E. Callus, Milan, Italy**

**14:15 – 14:30** Institutional Greetings: Università degli Studi di Milano, The impact of Information Communication and Technology in Medicine - **G. Haus, Milan, Italy**

#### **Session 1: The Family Perspective - Chair: Katya De Groot**

**14:30 – 14:45** The Impact of Children with Congenital Heart Defects on their Families according to Mothers' and Fathers' reports  
**C. Ryberg Göteborg, Sweden**

**14:45 – 15:00** Inclusivity of self-help groups for Families with Congenital Heart Defect children - **C. Ossenkopp-Wetzig, Fulda, Germany**

**15:00 – 15:15** Brothers and sisters in arms - **C. Sholten, Rotterdam, Netherlands**

**15:15 – 15:30** Psychosocial Wellbeing and Quality of Life in Siblings of Children with Congenital Heart Disease: A Systematic Review  
**A. Schamong, Köln, Germany**

**15:30 – 16:00** Psychosocial wellbeing in the families/update on the Northern Ireland Heart Study - **F. Casey, Northern Ireland, UK**

**16:00 – 16:30** Coffee Break

**16:30 – 17:30** **Keynote Lecture 1: Congenital heart disease over the years: from psychosocial outcomes to interventions - Elisabeth Utens, Rotterdam, Netherlands: Introduction Edward Callus**

#### **Session 2: Childhood and adolescence - Chair: Frank Casey**

**17:30 – 17:45** The Language of Infirmary – Integration of Children with CHD in daily school life: A Qualitative Research Study  
**R.D. Oberhuber, Linz, Austria**

**17:45 – 18:00** Quality of life monitoring online for optimizing the care of children and adolescents suffering from congenital heart disease (LQM),  
**H. Hövels-Gürich, Aachen, Germany**

**18:00 – 18:15** CHIP-Family intervention to improve the psychosocial wellbeing of young children with congenital heart disease and their families: results of a randomized - **M. Van der Mheen, Rotterdam, Netherlands**

**18:15 – 18:30** Investigating the effects of upper secondary educational support for young people with congenital heart disease  
**L. Osmunden, Sheffield, UK**

**19:30 – 21:30** Buffet dinner in the hospital



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# Thursday 26<sup>th</sup> of March, 2020



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## Session 3: Lifestyle and Transition - Chair: Edward Callus

- 9:00 – 9:15** A National Program on Transition in Italy - **S. Flocco, R. Caruso, Milan, Italy**
- 9:15 – 9:30** Overweight/Underweight Condition and Mental/Physical Factors of Adult Congenital Heart Disease Patient  
**Y. Mizuno, Tokyo, Japan**
- 9:30 – 10:00** Transition and lifestyle in congenital heart disease - **K. De Groote, Gent, Belgium**
- 10:00 – 11:00** **Keynote lecture: Moving beyond description: Psychosocial interventions for adults with congenital heart disease - Adrienne Kovacs, Portland, USA, Introduction Amy Verstappen**
- 11:00 – 11:30** Coffee Break

## Session 4: Long Term Care for Complex CHD Conditions - Chair: Elisabeth Utens

- 11:30 – 12:00** Long term care for adults with complex congenital heart disease conditions - **M. Chessa, Milan, Italy**
- 12:00 – 12:15** From patient to peer to peer supporter; the Bakken Award - **G. Campioni, Milan, Italy**
- 12:15 – 12:30** Supporting Teenagers with a Fontan Heart - **A. Katsatis, Birmingham, UK**
- 12:30 – 12:45** The Stress Experienced along the Single Ventricle Heart Disease pathway - **S.E. Hutchinson, Birmingham, UK**
- 12:45 – 13:00** From fetus to young adult: Introduction of a comprehensive care path in severe congenital heart disease. **D. Stuffert, Leiden, NL**

**13:00 – 14:00 LUNCH**

## Session 5: Psychosocial Interventions in Medical Settings - Chair: Amy Verstappen

- 14:00 – 14:30** The advancement in Pediatric Cardiology and the effects on CHD Patients - **A. Micheletti, Milan, Italy**
- 14:30 – 15:00** The role of the psychologist in a medical setting - **G. Pravettoni, Milan, Italy**
- 15:00 – 15:15** Psychosocial Challenges for Adults with congenital heart disease - **J. Enomoto, Tokyo, Japan**
- 15:15 – 16:30** **Round Table discussion on Recommendation for Adults in Congenital Heart Disease  
AEPC Psychosocial Working Group + ECHDO + Global Arch, Chaired by E. Callus**
- 16:30 – 17:00** Coffee Break

## Session 6: Public Health Policy and differences in Care Specifically in Congenital Heart Disease Chair: Enrico Giuseppe Bertoldo

- 17:00 – 17:30** The impact of cardiac surgery on ACHD: the current situation in Europe - **A. Giamberti, Milan Italy**
- 17:30 – 18:00** International co-operation in third world countries: a success story or failure? - **A. Frigiola, Milan, Italy**
- 18:00 – 18:30** Life beyond surgery: providing long term congenital heart care in middle income countries - **A. Verstappen, Philadelphia, USA**
- 19:30 – 21:30** Buffet dinner in the hospital



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# Friday 27<sup>th</sup> of March, 2020

## Session 7: Focus on Assessment of Patient Report Outcomes in Adults with Congenital Heart Disease I & II - Introduction and chair: Adrienne Kovacs

8.30 - 9.30 **Keynote Lecture 3: Update on APPROACH I & II**  
**Philip Moons, Leuven, Belgium**

9:30 – 10:00 Adapting the APPROACH study for clinical use - **E. Callus, Milan, Italy**

10:00 – 11:00 **Round table on Treatment preferences on Psychosocial needs**

**AEPC Psychosocial Working Group + ECHDO Board+ Global Arch, Chaired by E. G. Bertoldo**

11:00 – 11:30 Coffee Break

## Session 8, Neurological and Neuropsychological issues - Chair: Edward Callus

11:30 – 12:00 The brain in congenital heart defects - **A. Corno, Leicester, UK**

12:00 – 12:15 Brain aging in CHD - **L. Melazzini, Milan, Italy**

12:15 – 12:30 UK Brain MRI findings in pediatric congenital heart surgery: a systematic review - **F.J. Ablani, Leicester, UK**

12:30 – 13:00 Neuropsychological aspects in congenital heart disease: a lifelong perspectives - **E.G. Bertoldo, Milan, Italy**

13.00 – 13:15 Depression mediates the association between cognitive function and quality of life in older patients with congenital heart disease.

**J.R. Moon, Seoul, Korea**

13:15 – 13:30 Prizes and closure

