

Newsletter January 2021



Dear colleagues,

As you all know, the AEPC annual meeting was originally planned for May 2020 but had to be cancelled due to the Covid-19 pandemic. As it remains hard to predict the future course of the pandemic, the AEPC Council decided to organize **a completely virtual meeting in 2021**. Over the past year, where the pandemic challenged our traditional ways of working, web-based education and meetings have been set up as a substitute for traditional face to face meetings.

We are proud to invite you to an exciting virtual congress with presentations, abstract and poster sessions and a virtual exhibition. Although we would have looked so much forward to seeing you all in real life, let's join in an effort to present and discuss all the scientific work being done in the field of pediatric and adult cardiology. The programme below will be confirmed and updated as soon as possible.

We are very pleased to inform you that our working group on Nursing and Allied Health Professionals will have our **first pre-conference Nursing Education Day on Tuesday May 25th, 2021**. The overall topic of this day will be **"Care for patients with single ventricle from a life-cycle perspective"**. During this training day, several topics will be discussed, starting with the definition and the physiology, prenatal care aspects, challenges for the patients and their family towards long-term management by multidisciplinary teams.

Registration for this pre-conference Education Day will be **free of charge!**

Go visit the AEPC conference webpage <https://www.aepc2021.org> for further information and check out the programme. If you become a member of our working group, you will profit from a significant price reduction and our widespread activities such as networking, exchanging ideas in the field of research and practice with colleagues and the annual registration to journal "Cardiology in the Young".

Please contact us for further questions.

Looking forward to our first virtual congress and best wishes for the year 2021!

Best wishes,

Eva Goossens, Ewa-Lena Bratt, Lynda Shaughnessy & Gaby Stoffel

Council of the Working Group Nursing and Allied Health Professionals

Nursing and Allied Health Professionals Sessions:

Wednesday 26 May 2021 8.30-10.00

Ethical issues in prenatal and fetal cardiology

Chairs: Frank Casey and Mats Mellander

- Viewpoint from a (paediatric) cardiologist – Dr. Katya De Groot, Belgium
- Viewpoint from an ethicist – Christian Munthe, Sweden
- Viewpoint of a nurse – Susana De Sousa, UK
- Viewpoint of parent(s)/patient(s) – Henriette Sterner, Sweden

Advance care planning in CHD 10h30-12h00

Chairs: Prof. dr. Eva Goossens & Prof. dr. Werner Budts

- Rationale, knowledge and training of staff in ACP clinic – Prof. dr. Lorna Swan, Scotland
- How to initiate the conversation with patients and families? – Prof. dr. Piotr Sobanski, Switzerland
- Staged implementation is key, but how do you implement this? – Prof. dr. Markus Schwerzmann, Switzerland
- End-of-life care, is it the same as palliative care? – Prof. dr. Werner Budts, Belgium

Florence Nightingale Lecture 12h20-13h00

- The contribution of empirical research in nursing to the care for patients with CHD: reflection on the past and the future - Prof. Dr. Philip Moons

Thursday 27 May 2021

Cardiomyopathy: How to manage uncertainty? 08h30-10h00

Chairs: Prof. dr. Ruth Heyning & Lynda Shaughnessy

- Counselling patients with cardiomyopathy regarding physical activity and sport participation? Michael Papadakis, UK
- Genetic counselling of families afflicted with cardiomyopathy – Kathleen Dady,
- UK Management of patients with cardiomyopathy towards the future – Juan Pablo Kaski, UK
- Psychosocial impact of a diagnosis of cardiomyopathy – Hannah Levy

Abstract session Nursing and Allied Health Professionals & Neurodevelopment and Psychosocial Care 10h30-12h00

PROMS and PREMS: do we really capture what is important to patients? 13h30-15h00

Chairs: dr. Malin Berghammer & Prof. dr. Eva Goossens

- Patient- or Person-Centred Care: What difference does it make? – Lilas Ali, Sweden
- How to measure person-centeredness of care? – Nina Ekman, Sweden
- How to select and measure PROMS and PREMS? – Prof. dr. Philip Moons, Belgium
- Hearing the voices of children and young people: Measuring PROMS/PREMS in outpatient clinics – Prof. dr. J Wray, UK

Transfer and transition: Does one size fit all? PRO and CON debate 15h30-17h00

Chairs: Prof. dr. Philip Moons & Prof. dr. Ewa-Lena Brat

- Delivering transition interventions for the future – Dr. Gwen Rempel, Canada
- Empowerment: a central outcome for transition care in young people – Dr. Mariela Acuna Mora, Sweden
- Transition readiness: is it possible to objectively measure when patients are ready? – Dr. Adrienne Kovacs, USA
- Participation of young people in transition programs: Lessons learned – Markus Saarijärvi, Sweden