

**PRELIMINARY CONGRESS PROGRAM**

**16<sup>th</sup> – 18<sup>th</sup> October 2024**

**ROOTS AND HORIZONS:**

**LEARNING FROM YESTERDAY, LIVING TODAY, SHAPING THE FUTURE**

**Wednesday, 16<sup>th</sup> October 2024**

Reception desk times:

Pre-Congress Workshops 08.00 - 08.30

Congress delegates 10.00 - 19.00

08.30 - 12.30 **Pre-congress Workshops**

12.30 - 13.30 **Lunch**

13.30 - 16.30 **Pre-congress Workshops**

**Pre-congress Workshops:**

**Course I: *Perinatal PPC***

Coordinators: Brian S. Carter, Maria Azucena Niño Tovar, Tanja Pedersen

**Course II: *Communicating Bad News***

Coordinators: Justin N. Baker, Esther H. Ammon, Michelle R. Brown, Alexis Morvant

**Course III: *The Management of Pain and Troublesome Symptoms in PPC***

Coordinators: Poh Heng Chong, Ross Drake, Michelle Koh

**Course IV: *Difficult Choices: Bioethical Strategy***

Coordinators: Joana Mendes, Marie Friedel, Daniel Garros

17.30 - 19.30 **Opening ceremony**

- Welcomes
- Keynote lecture: *The Roots of PPC* - Joanne Wolfe
- Keynote Lecture : *The Present Day* - Ana Lacerda
- Keynote Lecture : *Future Horizons* - Sophie Bertaud, Victoria Salvo, Elizabeth Seashore (Young Professional Committee)
- Young Researchers Award presented by the Vlček Family Foundation
- Vittorio Ventafridda Award

19.30 - 20.30 **Icebreaker Reception**

**SCIENTIFIC COMMITTEE**

Franca Benini, Chair - Italy  
Brian S. Carter, Co-chair - USA  
Ann Goldman, Honorary President - UK  
Huda Abu-Saad Huijjer - Lebanon  
Justin N. Baker - USA

Mercedes Bernadá - Uruguay  
Poh Heng Chong - Singapore  
Julia Downing - UK  
Ross Drake - New Zealand

Lorna Fraser - UK  
Stefan J. Friedrichsdorf - USA  
Anna Garchakova - Belarus  
Daniel Garros - Canada

Julie Hauer - USA  
Ulrika Kreicbergs - Sweden  
Ana Lacerda - Portugal  
Ricardo Martino Alba - Spain

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## PRELIMINARY CONGRESS PROGRAM

**Thursday, 17<sup>th</sup> October 2024**

Reception opens at 08.00 a.m.

08.30 - 09.00 **Plenary: Gaining insights**

- *AI and Robotics in PPC* - Alessandro Masserdotti

09.00 - 10.30 **Plenary: *Pushing the boundaries of PPC***

Moderators: Brian S. Carter, Danai Papadatou

- *High Tech: an Opportunity or a Limit?* - Daniel Garros
- *Extreme Preterm Neonates and Perinatal PPC* - Elvira Parravicini
- *Transitional Care of Young Adults* - Julie Hauer

10.30 - 10.45 **Young researcher Award 1<sup>st</sup> prize**

10.45 - 11.15 **Coffee break**

11.15 - 12.15 **Oral Abstract presentation session (3 in parallel)**

Auditorium (Basement Level)

### **Working session 1: Communication**

Moderators:

- *Beyond illness: a qualitative exploration of talking about the future in pediatrics with IMPACT* - Julie Brunetta
- *Identification of age-appropriate ACP communication in children with chronic medical conditions* - Leonie la Rondelle
- *Compassionate communication with families during evaluation for death by neurologic criteria* - Regina Okhuysen-Cawley
- *Parents communication with a child with Juvenile Neuronal Ceroid Lipofucinosi about the diagnosis* - Torun Marie Vatne

San Francesco Room (Ground Floor)

### **Working session 2: Caregivers and family**

Moderators:

- *Evaluating PPI activities within a paediatric palliative care research centre* - Laura Barrett
- *Critical and often missed steps in launching advance care planning for youth: parental perspectives* - Lucie Hrdličková
- *Interdisciplinary collaboration in pediatric palliative care: perceived barriers and facilitators* - Maureen Kemna
- *Understanding the Needs of Pediatric Palliative Caregivers in Washington, USA* - Nikhita Vaddineni

Room A (1<sup>st</sup> floor)

### **Working session 3: Bereavement 1**

Moderators:

- *Working with bereaved parents to develop digital grief resources to help staff and bereaved parents* - Rebecca Candon
- *Bereaved parents' decision-making about location of end-of-life care for children* - Ashleen Crowe
- *Messages from heaven: unexplainable experiences among bereaved parents* - Eva De Clercq

- *Bereaved parents' experiences of paediatric end-of-life care: a UK multi-site qualitative study* - Julia Hackett

12.15 - 13.30 **Lunch and Poster visit**

13.30 - 15.00 **Young Professionals Plenary: *Diversity, Equity and Inclusion in PPC***

Moderators: TBD

- *Racism, Ethics, and Palliative care* - Mehrunisha Suleman
- *Honouring Diverse Cultural and Religious Practices* - Joe El Khoury
- *Equity and the delivery of PPC in low and middle-income countries* - Julia Downing

15.00 - 16.15 **Poster visit (coffee station)**

16.15 - 17.15 **Oral Abstract presentation session (3 in parallel)**

Auditorium (Basement Level)

**Working session 4: Young Professional Session**

Moderators:

- *Parent and professional experiences of 24/7 paediatric end-of-life care: shining a light on inequity* - Laura Barrett
- *Transformed by Song: The Impact of Music on Adolescents and Young Adults Living With Advanced Cancer* - Robert Bennett
- *Breaking Barriers: Access to Pain Medicines for Paediatric Palliative Care Worldwide* - Julia Downing
- *Rapid review of patient and public involvement work with parents of children with serious illness* - Pru Holder

San Francesco Room (Ground Floor)

**Working session 5: The importance of Team**

Moderators:

- *Training teams in pediatric advance care planning: transfer of knowledge and communication skills* - Marijanne Engel
- *Resources required to provide neonatal palliative care: Supporting the nursing workforce* - Alexandra Mancini-Smith
- *Successful implementation of a Pediatric Palliative Care and Hospital at Home Program* - Andres Piolatti-Luna
- *Collaborative working improves access to paediatric palliative care* - Joanna Woolley

Room A (1<sup>st</sup> floor)

**Working session 6: Miscellaneous**

Moderators:

- *Systemic Development of Paediatric Palliative Care in the Czech Republic: Lesson-Drawing* - Jiri Krejci
- *Impact of a pediatric palliative care program on regional children's healthcare utilization and cost* - David Lawrence Lysecki
- *Networks in Developing Palliative Care for Children* - Joan Marston
- *State-of-Play in Pediatric Palliative Care in Luxembourg: An Exploratory Mixed Methods Study* - Micha Massaad

17.15 - 17.30 Room Change

17.30 - 18.30 **Focus Sessions (in parallel)**

- *Shared Care Planning - Why, When, Where* - Sergi Navarro Vilarrubí
- *Palliative Sedation: When and How* - Marco Bolognani
- *Self-compassion, Growth and Development for Healthcare Professionals in PPC* - Jared Rubenstein

## PRELIMINARY CONGRESS PROGRAM

### Friday, 18<sup>th</sup> October 2024

Reception opens at 08.00 a.m.

#### 08.30 - 09.00 **Plenary: Gaining insights**

- *The Use of Telephone Interview for Emergencies at Home* - María Avilés Martínez

#### 09.00 - 10.30 **Plenary: Using Assessment Tools in PPC**

Moderators: Huda Abu-Saad Huijjer, Poh Heng Chong

- *Quality of Care Assessment Tools* - Prasanna Ananth
- *Using Tools for Outcome Measurement in PPC* - Richard Harding
- *Opportunities and Limits* - Lorna Fraser

#### 10.30 - 11.00 **Coffee break**

#### 11.00 - 12.00 **Oral Abstract presentation session (3 in parallel)**

Auditorium (Basement Level)

##### **Working session 7: Pain and severe discomfort - identification and control**

Moderators:

- *Advancing Pediatric Pain Management: Global Comfort Promise Successes in Latin America* - Ximena Garcia-Quintero
- *Transforming Pediatric Palliative Practice: The Comfort Promise Initiative for Reducing Needle Pain* - Gezy Giwangkencana
- *Shedding Light on Sleep: Evaluating Diagnostic Measures for Children with Life-Limiting Conditions* - Larissa Kubek
- *Neuro-irritability: The Great Unknown* - Anna Mercante

San Francisco Room (Ground Floor)

##### **Working session 8: Tools and Technology**

Moderators:

- *A novel co-designed tool to support CPC providers worldwide explore and utilize their service data* - Laura Dale-Harris
- *Virtual Reality (VR) in Palliative Care within Home Healthcare for Children and Adolescents* - Daniel Kemppi
- *Quality of care on an inpatient pediatric palliative care unit* - Pia Schmidt
- *The Use of Social Media for Sharing Information on PPC Needs: A Social Media Analysis* - Sofia Germinario

Room A (1<sup>st</sup> floor)

##### **Working session 9: Siblings, parents and Family**

Moderators:

- *Provision of psychological support for siblings of seriously ill children from parental perspective* - Grazina Kokesova Kleinova
- *Maternal role in caring for children with severe cognitive impairment in pediatric palliative care* - Anna Santini
- *Changing Focus: Parents Reflecting on Hope During Hospice through Photovoice* - Allie Superdock
- *MiniSIBS, a intervention supporting preschool siblings of children with life limiting disorders* - Torun Marie Vatne

12.00 - 13.30 **Lunch and Poster visit**

13.30 - 14.30 **Oral Abstract presentation session (3 in parallel)**

Auditorium (Basement Level)

**Working session 10: Survey and systematic reviews**

Moderators:

- *Nationwide 24/7 Paediatric Palliative Care in Denmark. Data from 2016-2023* - Maja Abitz
- *Survey of pediatric intensive care team professionals regarding pediatric palliative care* - Mercedes Bernadá
- *Factors affecting child development in the context of serious illness: a scoping review* - Leonie la Rondelle
- *Specialized Palliative Care in Inherited Metabolic Diseases - a MetabERN survey* - Anja Lee

San Francesco Room (Ground Floor)

**Working session 11: Miscellaneous 2**

Moderators:

- *The importance of specialized palliative care on pediatric cancer patients' choice of place of death* - Thea Marie Traun Andersen
- *Pediatric Palliative Care and Emergency Department: how taking charge changes admissions* - Valentina Folgheraiter
- *Coming of age: Development of a pediatric palliative care program in the standard-of-care era* - David Lawrence Lysecki
- *Mapping trajectories of care in the last year of life in cardiovascular complex chronic conditions* - Ashley Ridley

Room A (1<sup>st</sup> floor)

**Working session 12: End of life care**

Moderators:

- *Professionals' experiences of delivering paediatric end-of-life care: a multi-site qualitative study* - Julia Hackett
- *Health and social care professional views on decision-making for place of a child's end-of-life care* - Rachel McCauley
- *Compassionate Extubation at Home (CEAH) in Paediatric Palliative Care: A Case Series* - Mei Chan Grace Ng
- *Complex chronic conditions (CCCs) vs. life-limiting conditions (LLCs)...how do these lists compare?* - Samantha Smith

14.30 - 15.30 **Poster visit (coffee station)**

15.30 - 17.00 **Plenary: *Managing Serious Illness in the Home***

Moderators: Mercedes Bernadá, Anna Garchakova

- *Pain and Symptom Management* - Renée McCulloch
- *Support for Family Members and Strategies for Engaging the Community* - Ulrika Kreicbergs
- *End-Of-Life Care* - Ricardo Martino Alba

17.00 - 17.30 **Closing Ceremony**

- *Conclusions* - Ann Goldman & Brian Carter
- *Thanks & Arrivederci* - Franca Benini & Silvia Lefebvre D'Ovidio