

**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  
*Jacopone da Todi Room (Ground Floor)*

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

Coordinators: Justin N. Baker, Esther H. Ammon, Michelle R. Brown, Alexis Morvant  
*Room A (1<sup>st</sup> floor)*

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

Coordinators: Poh Heng Chong, Ross Drake, Michelle Koh  
*San Francesco Room (Ground Floor)*

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

Coordinators: Joana Mendes, Marie Friedel, Daniel Garros  
*San Bernardino Room (Ground Floor)*

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
- Mauro Sentinelli Scholarships
- 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: Justin N. Baker, Jared Rubenstein  
                       • *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: Stefan J. Friedrichsdorf, Huda Abu-Saad Huijjer  
                       • *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: Anna Garchakova, Ulrika Kreicbergs  
                       • *Working with bereaved parents to develop digital grief resources to help staff and bereaved parents* - Rebecca Candon/Breffni McGuinness  
                       • *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** (Session 1, see list on page 6, 7)
- 13.30 - 15.00    **Young Professionals Plenary: *Diversity, Equity and Inclusion in PPC***  
 Moderators: Sophie Bertaud, Elizabeth Seashore  
                       • *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)** - (Session 2 see list on page 8, 9)

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

Auditorium (Basement Level)

**Working session 4: Young Professional Session**

Moderators: Sophie Bertaud, Victoria Salvo

- *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: Poh Heng Chong, Daniel Garros

- *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: Mercedes Bernad, Lorna Fraser

- *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 Vilarrub
- *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 Huijer, 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: Stefan J. Friedrichsdorf, Julie Hauer

- *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 Giwangkancana
- *Shedding light on sleep: evaluating diagnostic measures for children with life-limiting conditions* - Larissa Kubek
- *Neuro-irritability: The great unknown* - Anna Mercante

San Francesco Room (Ground Floor)

**Working session 8: Tools and Technology**

Moderators: Ross Drake, Richard Harding

- *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: Renée McCulloch, Danai Papadatou

- *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** - (Session 3, see list on page 10, 11)

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

Auditorium (Basement Level)

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

Moderators: Julia Downing, Ross Drake

- *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: Ana Lacerda, Joanne Wolfe

- *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: Justin N. Baker, Joana Mendes

- *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)** - (Session 4, see list on page 12, 13)

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

## 17<sup>th</sup> October

### SESSION 1 - MONITOR A

| N° | Title   | Presenting Author       | Time        |
|----|---|-------------------------|-------------|
| A1 | Pharmacists and Compliance: Can counselling improve adherence?                                    | Azza Abdel-Aty          | 12.30-12.40 |
| A2 | Danish Network for Paediatric Palliative Care. Creating Change                                    | Maja Abitz              | 12.40-12.50 |
| A3 | Novel needs tool supporting interdisciplinary collaboration around children with palliative needs | Emma AlKhabbaz          | 12.50-13.00 |
| A4 | Respite days in the pediatric palliative care Day Care in Emilia-Romagna: a pilot project         | Sergio Amarri           | 13.00-13.10 |
| A5 | DMD-YOUNG: Paediatric palliative care for a life-limiting disorder in transition to adulthood     | Ellen Johanne Annexstad | 13.10-13.20 |
| A6 | Children with cancer and sibling's experiences of participation in the Family Talk Intervention   | Maria Ayoub             | 13.20-13.30 |

### SESSION 1 - MONITOR B

| N° | Title   | Presenting Author                     | Time        |
|----|---|---------------------------------------|-------------|
| B1 | Formation of a Pediatric Palliative Care team at Astrid Lindgren's Children's Hospital, Sweden      | Karin Bäckdahl                        | 12.30-12.40 |
| B2 | Innovative Approach to Quality of Supporting children in PC: The Power of Visual Stimulation        | Jitka Barlová                         | 12.40-12.50 |
| B3 | Pain and discomfort in neonates eligible for Pediatric Palliative Care: assessment tools comparison | Giulia Baron                          | 12.50-13.00 |
| B4 | Beyond pain - Emotional support project for perinatal grief   | Monalisa Nascimento dos Santos Barros | 13.00-13.10 |
| B5 | Joint Specialist Nursing Posts between Hospices & a Tertiary Palliative Care Centre                 | Julie Bayliss                         | 13.10-13.20 |
| B6 | The Rehabilitator Between Intensive Care and Palliative Care: A Pediatric Clinical Case             | Alessia Bellizzi                      | 13.20-13.30 |

### SESSION 1 - MONITOR C

| N° | Title   | Presenting Author     | Time        |
|----|---|-----------------------|-------------|
| C1 | Advance Care Planning And Multiculturality In Pediatric Palliative Care: A Review of The Literature | Maria Beltrame        | 12.30-12.40 |
| C2 | Building Relations through Time and Music - Case Presentations from a newly startet PPW in Norway   | Mathilde Bøås         | 12.40-12.50 |
| C3 | Holistic approach and palliative intervention in supratentorial brain tumors- A retrospective study | Alexandra Borda       | 12.50-13.00 |
| C4 | Care maps: an effective tool to evaluate complexity and needs in pediatric palliative care          | Francesca Burlo       | 13.00-13.10 |
| C5 | Experience of Psychological Care in a Pediatric Palliative Care Center: A Descriptive Analysis      | Alessandra Buzzonetti | 13.10-13.20 |
| C6 | Sleep difficulties are common in children attending a Hospice Service                               | Mairead Cassidy       | 13.20-13.30 |

### SESSION 1 - MONITOR D

| N° | Title   | Presenting Author              | Time        |
|----|---|--------------------------------|-------------|
| D1 | Evaluation of a Perinatal Palliative Care Program by SWOT Analysis                                  | Chiara Locatelli               | 12.30-12.40 |
| D2 | Children with Complex Chronic Condition in school setting   | Giulia Cervi                   | 12.40-12.50 |
| D3 | Development of a children's palliative care network in the Vysočina Region - Czech Republic         | Magdalena Chvilova<br>Weberova | 12.50-13.00 |
| D4 | Transcending - self and frontiers   | Cláudia Constantino            | 13.00-13.10 |
| D5 | Ensuring Quality Care: The Vital Role of Needs Assessment in Children's Palliative Care Development | Alex Daniels                   | 13.10-13.20 |
| D6 | Two letters compared: psychologist and adolescent dialogue about turning limits into resources      | Valentina De Tommasi           | 13.20-13.30 |

### SESSION 1 - MONITOR E

| N° | Title  | Presenting Author     | Time        |
|----|--|-----------------------|-------------|
| E1 | Referral Predictors and Benefits of a Home-Hospital Palliative Program for Pediatric Cancer Patients | Iñigo de Noriega      | 12.30-12.40 |
| E2 | Oncological support measures while follow-up by a pediatric palliative care unit for cancer patients | Iñigo de Noriega      | 12.40-12.50 |
| E3 | Clinical Case: accompanying an educational center in the grief of a student                          | Luisa Silva Di Maggio | 12.50-13.00 |
| E4 | Building Pediatric Palliative Care Leadership Capacities: A Collaborative Initiative for South Asia  | Megan Doherty         | 13.00-13.10 |
| E5 | Pediatric palliative care attitudes and educational needs among humanitarian health professionals    | Megan Doherty         | 13.10-13.20 |
| E6 | Palliative Care Perceptions and Educational Needs Amongst Humanitarian Healthcare Professionals      | Megan Doherty         | 13.20-13.30 |

### SESSION 1 - MONITOR F

| N° | Title  | Presenting Author          | Time        |
|----|--|----------------------------|-------------|
| F1 | What Support Do Families Need Most in Perinatal Palliative Care? A Retrospective Chart Review Study  | Hana Marie Dvorakova       | 12.30-12.40 |
| F2 | Navigating Needle Pain in Pediatric Cancer: Insights from a Low-Resource Setting                     | Samaher Fadhil             | 12.40-12.50 |
| F3 | Integration of research and implementation to support advance care planning: a nationwide approach   | Jurriane C Fahner          | 12.50-13.00 |
| F4 | Raising awareness: Real world data on palliative care for advanced pediatric cancers                 | Felicitas Ferrari-von Klot | 13.00-13.10 |
| F5 | Acceptability and feasibility of the Paediatric Palliative Scoring Scale among nurses and physicians | Solfrid Gjevik Festøy      | 13.10-13.20 |
| F6 | Therapeutic Powers of Play Meeting the needs of children in Palliative Care                          | Helena Fitzgerald          | 13.20-13.30 |

### SESSION 2 - MONITOR A

| N°  | Title   | Presenting Author           | Time         |
|-----|---|-----------------------------|--------------|
| A7  | Perceptions of Bereaved Mothers After Grief Support Groups: Analysis of Open-Ended Survey Responses | Ayaka Fujita                | 15.00-15.10  |
| A8  | Level of overload of the main caregiver of pediatric palliative patients when they begin follow-up  | Antonia Gámez               | 15.10-15.20  |
| A9  | The volunteer role in Pediatric Palliative Care   | Carlotta Ghironi            | 15.20-.15.30 |
| A10 | Lived experience of parents of a child in palliative care: a phenomenological study                 | Carlotta Ghironi            | 15.30-15.40  |
| A11 | Strategies to Alleviate Pain Undergoing Needle Procedures at a Pediatric Oncology Hospital          | Angela Grassato de Carvalho | 15.40-15.50  |
| A12 | Diffuse intrinsic pontine glioma: When is timing to Palliative care                                 | Angela Grassato de Carvalho | 15.50-16.00  |
| A13 | Pyridostigmine and neostigmine for intestinal dysmotility in pediatric palliative care: case series | Gabriella Guida             | 16.00-16.10  |

### SESSION 2 - MONITOR B

| N°  | Title  | Presenting Author      | Time         |
|-----|--|------------------------|--------------|
| B7  | Bridging the Bereavement Support Gap in India: A Model for Global Application                        | Ximena Garcia-Quintero | 15.00-15.10  |
| B8  | Need for training in psycho-emotional management front of serious illness and end-of-life            | Anna Habimana          | 15.10-15.20  |
| B9  | The impact of Parent Involvement on a cohort study of home-blended diets in gastrostomy fed children | Julia Hackett          | 15.20-.15.30 |
| B10 | Supporting a Multidisciplinary approach to promote safe sleep at a childrens' hospice                | Cate Harper            | 15.30-15.40  |
| B11 | Barriers and facilitators to paediatric palliative care referral: a scoping review of the evidence   | Pru Holder             | 15.40-15.50  |
| B12 | Feasibility of implementing international pediatric palliative care standards in the Czech Republic  | Lucie Hrdličková       | 15.50-16.00  |
| B13 | Palliative consultations tailored specifically to the unique needs of children with serious illness  | Lucie Hrdličková       | 16.00-16.10  |

### SESSION 2 - MONITOR C

| N°  | Title  | Presenting Author | Time         |
|-----|--|-------------------|--------------|
| C7  | A rapid scoping review of sleep difficulties in children with palliative care needs              | Laura Houlihan    | 15.00-15.10  |
| C8  | Pediatric Advanced Care Planning: development of tools for families and healthcare professionals | Chiara Hruby      | 15.10-15.20  |
| C9  | Parents long-term retention of the Family Talk Intervention in pediatric oncology                | Kerstin Ivéus     | 15.20-.15.30 |
| C10 | Understanding Family Caregivers' Experience with Medically Complex Children at Home              | Da Hye Je         | 15.30-15.40  |
| C11 | Parental Perspective of Children With Life-Limiting Conditions Availaing of a Respite Stay       | Jiya Joy          | 15.40-15.50  |
| C12 | Experiences of Music Therapy in Paediatric Palliative Care                                       | Victoria Kammin   | 15.50-16.00  |



|     |  |               |             |
|-----|--|---------------|-------------|
| C13 | Volunteer team in the prevention and relief of pain in needle procedures – Comfort Promise Project | Carolina Kasa | 16.00-16.10 |
|-----|--|---------------|-------------|

### SESSION 2 - MONITOR D

| N°  | Title   | Presenting Author          | Time         |
|-----|---|----------------------------|--------------|
| D7  | How did the Preference for Child Home Deaths Change at GOSH, Through the COVID-19 Pandemic?     | Mathura Kathirgamanathan   | 15.00-15.10  |
| D8  | Care doesn't end at death: provision of post-death care for children in England                 | Tara Kerr-Elliott          | 15.10-15.20  |
| D9  | Specialized palliative home care for children decreases hospital care needs - a pilot study     | Jenny Klintman             | 15.20-.15.30 |
| D10 | Two entirely different stories. (From the communication "off stage".)                           | Marketa Kralovcova         | 15.30-15.40  |
| D11 | Forgotten Classics. Early Elisabeth Kübler Ross unread, misinterpreted and misunderstood        | Jiri Kralovec              | 15.40-15.50  |
| D12 | Parents' experiences of a novel disease-modifying therapy for spinal muscular atrophy in Sweden | Ulrika Kreicbergs          | 15.50-16.00  |
| D13 | "Hero caravan" creating memories, normality and playful relations                               | Dorte Brinkmann Kristensen | 16.00-16.10  |

### SESSION 2 - MONITOR E

| N°  | Title   | Presenting Author  | Time         |
|-----|---|--------------------|--------------|
| E7  | Evaluating Pathways to Better Care for Pediatric Complex Chronic Conditions: The KoCoN Study Protocol | Larissa Kubek      | 15.00-15.10  |
| E8  | Effective communication in pediatric palliative care from the perspective of children and parents     | Leonie la Rondelle | 15.10-15.20  |
| E9  | Nurse parental support using a mobile App in symptom management for children with medical complexity  | Winsome Y Y Lam    | 15.20-.15.30 |
| E10 | Exploring the meaning of dying and death for children in Canadian and Global Health contexts          | Christina Lamb     | 15.30-15.40  |
| E11 | Factors associated with Paediatric Palliative Screening Scale (PaPaS) scores: A retrospective study   | Ji Weon Lee        | 15.40-15.50  |
| E12 | Training and implementation of palliative care representatives at Astrid Lindgren Childrens Hospital  | Malin Lövgren      | 15.50-16.00  |
| E13 | The Family Talk Intervention among families with palliative care needs - Social Workers' experiences  | Tina Lundberg      | 16.00-16.10  |

### SESSION 2 - MONITOR F

| N°  | Title   | Presenting Author       | Time         |
|-----|---|-------------------------|--------------|
| F7  | 20 years of Growth of Palliative Care Services in Ireland                         | Marie Lynch             | 15.00-15.10  |
| F8  | Introducing a Community Model of Palliative Care for Children: Family Feedback    | Marie Lynch             | 15.10-15.20  |
| F9  | Babywearing as a child care tool in Pediatric Palliative Care                     | Priscilla Manfra        | 15.20-.15.30 |
| F10 | Utilizing Virtual Reality to Alleviate Anxiety in Severely Ill Pediatric Patients | Anna Zubkova            | 15.30-15.40  |
| F11 | Advocacy for children needing Palliative Care in humanitarian settings            | Joan Marston            | 15.40-15.50  |
| F12 | From hospital to home: implementation of a hospital discharge checklist           | Irene Martín Romero     | 15.50-16.00  |
| F13 | Family needs and health technology in home-based pediatric palliative care        | Linda Johanne Martinsen | 16.00-16.10  |

## 18th October

### SESSION 3 - MONITOR A

| N°  | Title   | Presenting Author | Time        |
|-----|---|-------------------|-------------|
| A14 | “Parenting Pills”: a project proposal for parental empowerment promotion                          | Chiara Mastella   | 12.15-12.25 |
| A15 | Meeting the individual needs of pupils in pediatric palliative situation                          | Susanne Mauss     | 12.25-12.35 |
| A16 | Who are the Children? Point Prevalence Survey to Understand who Needs Children’s Palliative Care  | Linda Maynard     | 12.35-12.45 |
| A17 | How do regional multidisciplinary children’s palliative care meetings support system development? | Linda Maynard     | 12.45-12.55 |
| A18 | What Care Service Tools Can Help Palliative Care Teams Learn From Expected Childhood Deaths?      | Linda Maynard     | 12.55-13.05 |
| A20 | Ultrasound guided long peripheral cannula: a pain control device in pediatric patients            | Lucrezia Menotti  | 13.05-13.15 |

### SESSION 3 - MONITOR B

| N°  | Title  | Presenting Author       | Time        |
|-----|--|-------------------------|-------------|
| B14 | Quality of sleep in caregivers of children eligible for Pediatric Palliative Care                    | Anna Milani             | 12.15-12.25 |
| B15 | The effectiveness of a virtual physical therapy training program for carers with SMA at home         | Reham Mohammed          | 12.25-12.35 |
| B16 | Enrollment Barriers on a Palliative Care Communication Trial for Parents of Children with Cancer     | Karen Moody             | 12.35-12.45 |
| B17 | Guilt in caregivers of pediatric cancer and its associations with meaning-making processes           | Valeria Moriconi        | 12.45-12.55 |
| B18 | Tracheostomy decision-making in pediatric palliative care: systematic review of qualitative research | Vera Morsellino         | 12.55-13.05 |
| B19 | Case Report: The Nutritional Intake of Neonates at End of Life and the Feeding Concerns of Parents   | Sarah Naughton          | 13.05-13.15 |
| B20 | Palliakid: Comprehensive Paediatric Palliative Care Approach   | Sergi Navarro Vilarrubi | 13.15-13.25 |

### SESSION 3 - MONITOR C

| N°  | Title  | Presenting Author         | Time        |
|-----|--|---------------------------|-------------|
| C14 | Organ donation in home-based Pediatric Palliative Care, is it possible?                              | Alvaro Navarro-Mingorance | 12.15-12.25 |
| C15 | High-Flow Oxygen In Patients with Acute Respiratory Failure in a Pediatric Palliative Care Unit      | Alvaro Navarro-Mingorance | 12.25-12.35 |
| C16 | RESPECT: Recommendations for Providing Pediatric Palliative Care to Families from Different Cultures | Barbora Nebáznivá         | 12.35-12.45 |
| C17 | Shifting attention of children with life-threatening illness from needs to desires                   | Josef Nedorostek          | 12.45-12.55 |
| C18 | ePROMs for symptom assessment in pediatric palliative home care                                      | Alexander Voelzke         | 12.55-13.05 |
| C19 | The Human Cost of the COVID-19 Pandemic: Implications for Pediatric Palliative Care Providers        | Regina Okhuysen-Cawley    | 13.05-13.15 |
| C20 | The Plight of Migrant Children with Palliative Care Needs in the Americas                            | Regina Okhuysen-Cawley    | 13.15-13.25 |

### SESSION 3 - MONITOR D

| N°  | Title   | Presenting Author     | Time        |
|-----|---|-----------------------|-------------|
| D14 | A training curriculum to enable governance and operational arrangements: Education nurtures service | Aisling Ni Nualláin   | 12.15-12.25 |
| D15 | Storytelling to Support Legacy-Making for Bereaved Parents of Children with Cancer                  | Trisha Paul           | 12.25-12.35 |
| D16 | Post-traumatic growth in parents who lost a child to cancer: A multicentre survey in Switzerland    | Eddy Carolina Pedraza | 12.35-12.45 |
| D17 | Berevement in Pediatrics: The Experience of The Nurses of an Italian Pediatric Hospital             | Federico Pellegatta   | 12.45-12.55 |
| D18 | The Pediatric Day Hospice: a place for Pediatric Palliative Care                                    | Federico Pellegatta   | 12.55-13.05 |
| D19 | Training caregivers to care for italian children in pediatric palliative care: single-centre study  | Federico Pellegatta   | 13.05-13.15 |
| D20 | Towards appropriate advance care planning in pediatric palliative care: a medical record review     | Sophie Tooten         | 13.15-13.25 |

### SESSION 3 - MONITOR E

| N°  | Title  | Presenting Author    | Time        |
|-----|--|----------------------|-------------|
| E14 | Training Caregivers of Children with Home Invasive Mechanical Ventilation: From the ICU to Home      | Andrés Piolatti Luna | 12.15-12.25 |
| E15 | How acces to a pediatric palliative care unit influences on the choice of place of death             | Andrés Piolatti Luna | 12.25-12.35 |
| E16 | Complex pain case management in a 12-year old girl with a severe form of epidermolysis bullosae      | Andrés Piolatti Luna | 12.35-12.45 |
| E17 | New strategies, old strategies: handling pain in an adolescent with cancer, a case report            | Andreana Pipolo      | 12.45-12.55 |
| E18 | Palliative sedation in pediatric patients: preliminary data from a retrospective study               | Andreana Pipolo      | 12.55-13.05 |
| E19 | Epidemiological estimation for paediatric end-of-life and palliative care in Greece                  | Dimitrios Protogiros | 13.05-13.15 |
| E20 | Comprehensive well-being, wish to change and concerns of children in palliative care: scale qESNA-14 | Daniel Toro Pérez    | 13.15-13.25 |

### SESSION 3 - MONITOR F

| N°  | Title  | Presenting Author    | Time        |
|-----|--|----------------------|-------------|
| F14 | Characterization of resources provide PPC in LATIN AMERICA: PedPaLatam-2024 preliminary report | Jorge Ramos-Guerrero | 12.15-12.25 |
| F15 | The experience of nurse managers supporting nurses caring for children at the end of life      | Aisling Reilly       | 12.25-12.35 |
| F16 | Collaboration in Children's Palliative Care - Everyone Gains                                   | Aisling Reilly       | 12.35-12.45 |
| F17 | Quality Office Role in KHCC Global Comfort Promise project                                     | Dema Remawi          | 12.45-12.55 |
| F18 | Physician Lead Role in the Global Comfort Promise at KHCC                                      | Dema Remawi          | 12.55-13.05 |
| F19 | Nursing Role in Managing Procedural Pain; KHCC (Global Comfort Promise)                        | Dema Remawi          | 13.05-13.15 |
| F20 | Coordinating Children's Palliative Care in Municipalities: A Qualitative Study                 | Gro Trae             | 13.15-13.25 |

### SESSION 4 - MONITOR A

| N° | Title | Presenting Author | Time |
|----|-------|-------------------|------|
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|-----|---|---------------------|-------------|
| A21 | Every Moment Matters  | Ivana Plechatá      | 14.30-14.40 |
| A22 | Bridging Intensive and/or Palliative Care in Sma Type 1? A Case Report                            | Federico Pellegatta | 14.40-14.50 |
| A23 | Which Minors are Eligible for Palliative Care? A Tool for the Training of Healthcare Professional | Federico Pellegatta | 14.50-15.00 |
| A24 | The challenges of the pediatrics palliative care in Kharkiv                                       | Olena Riga          | 15.00-15.10 |
| A25 | The best “quality of life” in PPC: from quality of life to quality of life relationships          | Rossana Ruggiero    | 15.10-15.20 |
| A26 | Memory-Making Interventions in Pediatric Palliative and Bereavement Care: A Systematic Review     | Razieh Safarifard   | 15.20-15.30 |

#### SESSION 4 - MONITOR B

| N°  | Title  | Presenting Author | Time        |
|-----|--|-------------------|-------------|
| B21 | Palliative Care in Children: Italian translation and validation of a questionnaire         | Claudia Sansone   | 14.30-14.40 |
| B22 | School inclusion of children and youth in pediatric palliative care: a retrospective study | Anna Santini      | 14.40-14.50 |
| B23 | KoCoN: A new horizon for children with chronic complex neurological conditions             | Pia Schmidt       | 14.50-15.00 |
| B24 | "Your Presence Matters": A Journey of Pediatric Palliative Care in Nepal                   | Amrita Shrestha   | 15.00-15.10 |
| B25 | Syringe Driver Usage in Paediatric Oncology Patients at End of Life                        | Emily Skinner     | 15.10-15.20 |
| B26 | FamilieFOKUS Psycho-social support to families   | Hilde Skrudland   | 15.20-15.30 |

#### SESSION 4 - MONITOR C

| N°  | Title  | Presenting Author   | Time        |
|-----|--|---------------------|-------------|
| C21 | Current Models of Providing Perinatal Palliative Care in 4 Perinatal Centres in the Czech Republic | Zuzana Stanickova   | 14.30-14.40 |
| C22 | Barriers & Opportunities for Perinatal Palliative Care: A Nation-wide Mixed-Method Study           | Zuzana Stanickova   | 14.40-14.50 |
| C23 | Experiences of parents caring for a child with a life-limiting condition in an inpatient setting   | Sophie Stößlein     | 14.50-15.00 |
| C24 | Palliative care for children with neuromuscular diseases (NMD) in Kazakhstan                       | Yuliya Streletskaya | 15.00-15.10 |
| C25 | Spiritual Dialogue between Pediatric Neuro-oncologists, Patients, & Caregivers                     | Allie Superdock     | 15.10-15.20 |
| C26 | Understanding sleep and mental health outcomes in parents of children with LLCs/LTIs               | Aoife Talbot        | 15.20-15.30 |

#### SESSION 4 - MONITOR D

| N°  | Title  | Presenting Author | Time        |
|-----|--|-------------------|-------------|
| D21 | End of life care utilization in pediatric oncology patients in Latvia: An observational study        | Sofja Tomase      | 14.30-14.40 |
| D22 | Methodology of system integration of palliative care in pediatric patients with high-grade gliomas   | Katerina Trkova   | 14.40-14.50 |
| D23 | Psychosocial support in paediatric palliative care – a teamwork                                      | Camilla Udo       | 14.50-15.00 |
| D24 | Navigating Emotional Turmoil: A Case Study in Paediatric Palliative Care for a Boy with Brain Tumour | Simona Ulrich     | 15.00-15.10 |

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| D25 | There's always a way... to play. Insight into the diary of a child life specialist in palliative care | Michaela Váňová | 15.10-15.20 |
| D26 | Shepherding parents in end-of-life decision-making for children with life-limiting conditions         | Sid Vemuri      | 15.20-15.30 |

**SESSION 4 - MONITOR E**

| <b>N°</b> | <b>Title</b>  | <b>Presenting Author</b> | <b>Time</b> |
|-----------|---|--------------------------|-------------|
| E21       | The impact of the war in Ukraine on pediatric palliative care: a study from our center              | Vita Voloshchuk          | 14.30-14.40 |
| E22       | The realities of children's hospice in Ukraine with challenges and opportunities                    | Vita Voloshchuk          | 14.40-14.50 |
| E23       | Creation of an online GP referral app for inhouse requests within a Children's Hospice              | Fiona Woods              | 14.50-15.00 |
| E24       | Ethnicity and Cultural Diversity in a Children's Hospice  | Fiona Woods              | 15.00-15.10 |
| E25       | Access to 24/7 telephone advice from specialist paediatric palliative care nurses improves choice   | Joanna Woolley           | 15.10-15.20 |
| E26       | A project to develop, implement and evaluate a blended learning model in paediatric palliative care | Joanna Woolley           | 15.20-15.30 |