



6TH

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ROME
16TH - 18TH
OCTOBER
2024

ON PAEDIATRIC
PALLIATIVE CARE

PROGRAM



WI-FI

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Dear Friends and Colleagues,

Welcome to Rome and welcome to the 6th Maruzza International Congress on Paediatric Palliative Care. First and foremost, we would like to express our heartfelt thanks to everyone who has travelled here to contribute to this event; since the first Maruzza Congress, in 2012, we have relentlessly strived to create a stimulating meeting with inspirational talks, opportunities for knowledge-sharing and invaluable interaction with like-minded individuals from all over the globe, but it is ultimately the support and enthusiasm of those participating that creates the Congress's success.

This year, the Maruzza Foundation celebrates 25 years of activity in the paediatric palliative care sector in Italy and beyond. This important milestone provided us with an opportunity to take stock of where we are on this challenging journey from a relatively unknown, emerging therapeutic approach to a widely recognized and rapidly developing, integrated, paediatric healthcare discipline.

This commemoration, above all, gave us the inspiration for the main theme of this year's Congress: 'ROOTS AND HORIZONS: Learning From Yesterday, Living Today, Shaping The Future'; looking back can help us to gain perspective on important goals attained and valuable lessons learned, it can also spark the enthusiasm to look forward and focus on a new vision of ambitious yet realisable goals.

We firmly believe that to guarantee the continuation of quality care for children with serious illness, we must invest in a new generation of professionals who will shape the future of this discipline.

For this 6th Maruzza Congress, we were keen to involve in the Scientific Board, alongside the established international experts, a sub-committee of young professionals working with diverse roles in the children's palliative care sector to whom we allocated the organisation of a half-day of the congress program.

We sincerely hope this is an enriching and gratifying enhancement for everyone attending.

Furthermore, in addition to the customary Young Researchers Award for the best abstract submitted by Presenting Authors under thirty-five, which is generously supported this year by the Vlček Foundation, we have conferred, for the second year running, two scholarships for the Master's Degree programme in Paediatric Palliative Care and Pain Management at Padua University. This was made possible thanks to the support of the family of Mauro Sentinelli who was a long-term member of the Maruzza Foundation's Board of Directors.

To conclude, we wish everyone a fulfilling and rewarding congress and, above all, we hope you enjoy every moment!

Silvia Lefebvre D'Ovidio
President of the Maruzza Foundation

Franca Benini
Chair of the Maruzza Congress

SCIENTIFIC COMMITTEE

- * Franca Benini (Italy) - Chair
- * Brian S. Carter (USA) - Co Chair
- * Ann Goldman (UK) - Honorary President
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- * Justin N. Baker (USA)
- * Mercedes Bernadá (Uruguay)
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- * Julia Downing (UK/ Uganda)
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- * Ana Lacerda (Portugal)
- * Ricardo Martino Alba (Spain)

YOUNG PROFESSIONAL COMMITTEE

- * Sophie Bertaud (UK)
- * Victoria Salvo (Uruguay)
- * Elizabeth Seashore (USA)



Congress program

Roots and horizons:

Learning from yesterday, living today, shaping the future

16th **Wednesday**
October 2024

17th **Thursday**
October 2024

18th **Friday**
October 2024

16th

Wednesday, 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

Course I: Perinatal PPC

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

SAN BERNARDINO ROOM (Ground Floor)

Course II: Communicating Bad News

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

ROOM A (1st 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

JACOPONE DA TODI ROOM (Ground Floor)

12.30 - 13.30

Lunch

13.30 - 16.30

Pre-congress Workshops (continued)

Course I: **SAN BERNARDINO ROOM (Ground Floor)**

Course II: **ROOM A (1st floor)**

Course III: **SAN FRANCESCO ROOM (Ground Floor)**

Course IV: **JACOPONE DA TODI ROOM (Ground Floor)**

17.30 - 20.00

Opening ceremony

AUDITORIUM (Basement level)

- **Welcomes** - Silvia Lefebvre D'Ovidio, Franca Benini, Ann Goldman, Brian S. Carter
- **Keynote lecture: The Roots of PPC** - Joanne Wolfe
- **Presentation Vittorio Ventafridda Award**
- **Keynote Lecture : The Present Day** - Ana Lacerda
- **Presentation Mauro Sentinelli Scholarships**
- **Keynote Lecture : Future Horizons** - Sophie Bertaud, Victoria Salvo, Elizabeth Seashore (Young Professional Committee)
- **Young Researchers Award** presented by the Vlček Family Foundation
- **Entertainment Interlude**
- **Icebreaker**

17th

Thursday, October 2024

Reception opens at 08.00 a.m.

08.30 - 09.00

AUDITORIUM (Basement Level)

Plenary: Gaining insights

- **AI and Robotics in PPC** - Alessandro Masserdotti

09.00 - 10.30

AUDITORIUM (Basement Level)

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: for Everyone?** - Ricardo Martino
Alba

10.30 - 10.45

AUDITORIUM (Basement Level)

Vlček Family Foundation Young Researcher Award-1st prize

- **Cultural differences in shared decision-making in pediatric palliative care** - Luca Nicot

10.45 - 11.15

Coffee break

11.15 - 12.15

Oral Abstract presentation session

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 (1st 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, pg. 20-23)

17th

Thursday, October 2024

13.30 - 15.00

AUDITORIUM (Basement Level)

Young Professionals Plenary: Diversity, Equity and Inclusion in PPC

Moderators: Sophie Bertaud, Elizabeth Seashore

- **Racism, Ethics, and Palliative Care** - Jonathan Koffman
- **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 (Session 2, pg. 24-27)

16.15 - 17.15

Oral Abstract presentation session

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** - Verna Hendricks-Ferguson
- **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 FRANCISCO 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 (1st 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
- **Bereavement in pediatrics: the experience of the nurses of an Italian pediatric hospital** - Federico Pellegatta
- **State-of-play in pediatric palliative care in Luxembourg: an exploratory mixed methods study** - Micha Massaad

17.30 - 18.30

Focus Sessions

AUDITORIUM (Basement Level)

- **Self-compassion, Growth and Development for Healthcare Professionals in PPC** - Jared Rubenstein

ROOM A (1st floor)

- **Shared Care Planning - Why, When, Where** - Sergi Navarro Vilarrub

SAN FRANCESCO ROOM (Ground Floor)

- **Palliative Sedation: When and How** - Marco Bolognani

18th

Friday, October 2024

Reception opens at 08.00 a.m.

08.30 - 09.00

AUDITORIUM (Basement Level)

Plenary: Gaining insights

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

09.00 - 10.30

AUDITORIUM (Basement Level)

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

AUDITORIUM (Basement Level)

Working session 7: Pain and Severe Discomfort - Identification and Control

Moderators: Stefan J. Friedrichsdorf, Joe El Khoury

- **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: 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 (1st 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, pg. 28-31)

18th

Friday, October 2024

13.30 - 14.30

Oral Abstract presentation session

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 FRANCISCO 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 (1st 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 (Session 4, pg. 32-35)

15.30 - 17.00

AUDITORIUM (Basement Level)

Plenary: Managing Serious Illness in the Home

Moderators: Mercedes Bernad, Anna Garchakova

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

17.00 - 17.30

AUDITORIUM (Basement Level)

Closing Ceremony

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

Posters

17th **Thursday**
October 2024

18th **Friday**
October 2024

17th

Thursday, October 2024

Session 1 - Monitor A

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

Session 1 - Monitor B

| N° - Time | Name and Title |
|--------------------------|---|
| B1 12.30-12.40 | Karin Bäckdahl Formation of a Pediatric Palliative Care team at Astrid Lindgren's Children's Hospital, Sweden |
| B2 12.40-12.50 | Jitka Barlová Innovative Approach to Quality of Supporting children in PC: The Power of Visual Stimulation |
| B3 12.50-13.00 | Giulia Baron Pain and discomfort in neonates eligible for Pediatric Palliative Care: assessment tools comparison |
| B4 13.00-13.10 | Monalisa Nascimento dos Santos Barros Beyond pain - Emotional support project for perinatal grief |

B5 Julie Bayliss
13.10-13.20 Joint Specialist Nursing Posts between Hospices & a Tertiary Palliative Care Centre

B6 Alessia Bellizzi
13.20-13.30 The Rehabilitator Between Intensive Care and Palliative Care: A Pediatric Clinical Case

Session 1 - Monitor C

| N° - Time | Name and Title |
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|--------------------------|---|
| C1 12.30-12.40 | Maria Beltrame Advance Care Planning And Multiculturality In Pediatric Palliative Care: A Review of The Literature |
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| C2 12.40-12.50 | Mathilde Bøås Building Relations through Time and Music - Case Presentations from a newly startet PPW in Norwayre |
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| C3 12.50-13.00 | Alexandra Borda Holistic approach and palliative intervention in supratentorial brain tumors- A retrospective study |
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| C4 13.00-13.10 | Francesca Burlo Care maps: an effective tool to evaluate complexity and needs in pediatric palliative care |
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| C6 13.10-13.20 | Mairead Cassidy Sleep difficulties are common in children attending a Hospice Service |
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17th

Thursday, October 2024

Session 1 - Monitor D

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

Session 1 - Monitor E

| N° - Time | Name and Title |
|--------------------------|--|
| E1 12.30-12.40 | Iñigo de Noriega Referral Predictors and Benefits of a Home-Hospital Palliative Program for Pediatric Cancer Patients |
| E2 12.40-12.50 | Iñigo de Noriega Oncological support measures while follow-up by a pediatric palliative care unit for cancer patients |
| E3 12.50-13.00 | Luisa Silva Di Maggio Clinical Case: accompanying an educational center in the grief of a student |
| E4 13.00-13.10 | Megan Doherty Building Pediatric Palliative Care Leadership Capacities: A Collaborative Initiative for South Asia |

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| E5 | Megan Doherty |
| 13.10-13.20 | Pediatric palliative care attitudes and educational needs among humanitarian health professionals |
| E6 | Megan Doherty |
| 13.20-13.30 | Palliative Care Perceptions and Educational Needs Amongst Humanitarian Healthcare Professionals |

Session 1 - Monitor F

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

17th

Thursday, October 2024

Session 2 - Monitor A

N° - Time

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

Session 2 - Monitor B

N° - Time

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|--------------------------|---|
| B7 15.00-15.10 | Ximena Garcia-Quintero Bridging the Bereavement Support Gap in India: A Model for Global Application |
| B8 15.10-15.20 | Anna Habimana Need for training in psycho-emotional management front of serious illness and end-of-life |
| B9 15.20-15.30 | Julia Hackett The impact of Parent Involvement on a cohort study of home-blended diets in gastrostomy fed children |

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| B10 | Cate Harper |
| 15.30-15.40 | Supporting a Multidisciplinary approach to promote safe sleep at a childrens' hospice |
| B11 | Pru Holder |
| 15.40-15.50 | Barriers and facilitators to paediatric palliative care referral: a scoping review of the evidence |
| B12 | Lucie Hrdličková |
| 15.50-16.00 | Feasibility of implementing international pediatric palliative care standards in the Czech Republic |
| B13 | Lucie Hrdličková |
| 16.00-16.10 | Palliative consultations tailored specifically to the unique needs of children with serious illness |

Session 2 - Monitor C

| N° - Time | |
|-------------|--|
| C7 | Laura Houlihan |
| 15.00-15.10 | A rapid scoping review of sleep difficulties in children with palliative care needs |
| C8 | Chiara Hruby |
| 15.10-15.20 | Pediatric Advanced Care Planning: development of tools for families and healthcare professionals |
| C9 | Kerstin Ivéus |
| 15.20-15.30 | Parents long-term retention of the Family Talk Intervention in pediatric oncology |
| C10 | Da Hye Je |
| 15.30-15.40 | Understanding Family Caregivers' Experience with Medically Complex Children at Home |
| C11 | Jiya Joy |
| 15.40-15.50 | Parental Perspective of Children With Life-Limiting Conditions Availaing of a Respite Stay |
| C12 | Victoria Kammin |
| 15.50-16.00 | Experiences of Music Therapy in Paediatric Palliative Care |
| C13 | Carolina Kasa |
| 16.00-16.10 | Volunteer team in the prevention and relief of pain in needle procedures – Comfort Promise Project |

17th

Thursday, October 2024

Session 2 - Monitor D

N° - Time

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

Session 2 - Monitor E

N° - Time

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|--------------------------|---|
| E7 15.00-15.10 | Larissa Kubek Evaluating Pathways to Better Care for Pediatric Complex Chronic Conditions:The KoCoN Study Protocol |
| E8 15.10-15.20 | Leonie la Rondelle Effective communication in pediatric palliative care from the perspective of children and parents |
| E9 15.20-15.30 | Winsome Y Y Lam Nurse parental support using a mobile App in symptom management for children with medical complexity |

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| E11 | Ji Weon Lee |
| 15.30-15.40 | Factors associated with Paediatric Palliative Screening Scale (PaPaS) scores: A retrospective study |
| E12 | Therése Kjellin |
| 15.40-15.50 | Training and implementation of palliative care representatives at Astrid Lindgren Childrens Hospital |
| E13 | Tina Lundberg |
| 15.50-16.00 | The Family Talk Intervention among families with palliative care needs - Social Workers' experiences |

Session 2 - Monitor F

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

18th

Friday, October 2024

Session 3 - Monitor A

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

Session 3 - Monitor B

| N° - Time | |
|---------------------------|---|
| B14 12.15-12.25 | Anna Milani Quality of sleep in caregivers of children eligible for Pediatric Palliative Care |
| B15 12.25-12.35 | Reham Mohammed The effectiveness of a virtual physical therapy training program for carers with SMA at home |
| B16 12.35-12.45 | Karen Moody Enrollment Barriers on a Palliative Care Communication Trial for Parents of Children with Cancer |
| B17 12.45-12.55 | Valeria Moriconi Guilt in caregivers of pediatric cancer and its associations with meaning-making processes |

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| B18 | Vera Morsellino |
| 12.55-13.05 | Tracheostomy decision-making in pediatric palliative care: systematic review of qualitative research |
| B20 | Sergi Navarro Vilarrubi |
| 13.05-13.15 | Palliakid: Comprehensive Paediatric Palliative Care Approach |

Session 3 - Monitor C

N° - Time

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

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Friday, October 2024

Session 3 - Monitor D

N° - Time

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

Session 3 - Monitor E

N° - Time

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|---------------------------|---|
| E14 12.15-12.25 | Andrés Piolatti Luna Training Caregivers of Children with Home Invasive Mechanical Ventilation: From the ICU to Home |
| E15 12.25-12.35 | Andrés Piolatti Luna How acces to a pediatric palliative care unit influences on the choice of place of death |
| E16 12.35-12.45 | Andrés Piolatti Luna Complex pain case management in a 12-year old girl with a severe form of epidermolysis bullosae |
| E17 12.45-12.55 | Andreana Pipolo New strategies, old strategies: handling pain in an adolescent with cancer, a case report |

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| E18 12.55-13.05 | Andreana Pipolo Palliative sedation in pediatric patients: preliminary data from a retrospective study |
| E19 13.05-13.15 | Dimitrios Protogiros Epidemiological estimation for paediatric end-of-life and palliative care in Greece |
| E20 13.15-13.25 | Daniel Toro Pérez Comprehensive well-being, wish to change and concerns of children in palliative care: scale qESNA-14 |

Session 3 - Monitor F

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

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Friday, October 2024

Session 4 - Monitor A

N° - Time

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

Session 4 - Monitor B

N° - Time

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|---------------------------|--|
| B21 14.30-14.40 | Claudia Sansone Palliative Care in Children: Italian translation and validation of a questionnaire |
| B22 14.40-14.50 | Anna Santini School inclusion of children and youth in pediatric palliative care: a retrospective study |
| B23 14.50-15.00 | Pia Schmidt KoCoN: A new horizon for children with chronic complex neurological conditions |
| B24 15.00-15.10 | Amrita Shrestha "Your Presence Matters": A Journey of Pediatric Palliative Care in Nepal |

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| B25 | Emily Skinner |
| 15.10-15.20 | Syringe Driver Usage in Paediatric Oncology Patients at End of Life |
| B26 | Hilde Skrudland |
| 15.20-15.30 | FamilieFOKUS Psycho-social support to families |

Session 4 - Monitor C

N° - Time

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

18th

Friday, October 2024

Session 4 - Monitor D

N° - Time

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|---------------------------|--|
| D21 14.30-14.40 | Sofja Tomase End of life care utilization in pediatric oncology patients in Latvia: An observational study |
| D22 14.40-14.50 | Katerina Trkova Methodology of system integration of palliative care in pediatric patients with high-grade gliomas |
| D23 14.50-15.00 | Marie Nyström Psychosocial support in paediatric palliative care – a teamwork |
| D24 15.00-15.10 | Simona Ulrich Navigating Emotional Turmoil: A Case Study in Paediatric Palliative Care for a Boy with Brain Tumour |
| D25 15.10-15.20 | Michaela Váňová There's always a way... to play. Insight into the diary of a child life specialist in palliative care |
| D26 15.20-15.30 | Sid Vemuri Shepherding parents in end-of-life decision-making for children with life-limiting conditions |

Session 4 - Monitor E

N° - Time

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|---------------------------|---|
| E21 14.30-14.40 | Vita Voloshchuk The impact of the war in Ukraine on pediatric palliative care: a study from our center |
| E22 14.40-14.50 | Vita Voloshchuk The realities of children's hospice in Ukraine with challenges and opportunities |
| E23 14.50-15.00 | Fiona Woods Creation of an online GP referral app for inhouse requests within a Children's Hospice |
| E24 15.00-15.10 | Fiona Woods Ethnicity and Cultural Diversity in a Children's Hospice |

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| E25 | Joanna Woolley |
| 15.10-15.20 | Access to 24/7 telephone advice from specialist paediatric palliative care nurses improves choice |
| E26 | Joanna Woolley |
| 15.20-15.30 | A project to develop, implement and evaluate a blended learning model in paediatric palliative care |

Speakers and Moderators

- **AMMON ESTHER H**, LCSW, APHSW-C, Director of Palliative Care & Family Guidance, Stanford Medicine Children's Health, Palo Alto, USA
- **AVILÉS MARTÍNEZ MARÍA**, RN, PhD, Comprehensive Paediatric Palliative Care Unit, Hospital Universitario Infantil Niño Jesús, Madrid, Spain
- **ANANTH PRASANNA**, MD, MPH, Associate Professor of Pediatrics, Section of Pediatric Hematology/Oncology, Department of Pediatrics, Yale School of Medicine, New Haven, CT, USA
- **ABU-SAAD HUIJER HUDA**, RN, PhD, FEANS, FAAN, Professor of Nursing Science, Dean Faculty of Health Sciences University of Balamand, Founding Dean, School of Nursing, American University of Beirut, Lebanon
- **BENIN FRANCA**, Director of Paediatric Palliative Care – Pain Service Department of Women's and Children's Health, University of Padua, Professor of Pediatrics – Pediatric Palliative Care, University of Padua, Italy
- **BROWN MICHELLE R**, PhD, Division of Quality of Life and Pediatric Palliative Care. Clinical Professor of Psychiatry, Stanford University School of Medicine and Stanford Medicine Children's Health, USA
- **BOLOGNANI MARCO**, Medical Director at Neonatology and Neonatal Intensive Care Unit, Trento, Italy
- **BERTAUD SOPHIE**, Pediatrician, Consultant in Paediatric Palliative Medicine at Great Ormond Street Hospital for Children, London, UK
- **BERNADÀ MERCEDES**, Associate Professor of Pediatrics at the Faculty of Medicine, University of the Republic, Montevideo, Uruguay
- **BAKER JUSTIN N.**, MD, FAAP, FAAHPM, Chief, Division of Quality of Life and Pediatric Palliative Care Director, QoLA Program (Quality of Life for All), Attending Physician – QoLA Pediatric Palliative Care Team, Associate Chief Quality Officer for Patient Experience and Holistic Care Deborah E. Addicott – John A. Kriewall and Elizabeth A. Haehl Family, Professor, Department of Pediatrics Stanford School of Medicine and Stanford Medicine Children's Health, USA
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- **FRIEDEL MARIE**, RN, PNP, MPH, Dipl PPC, PhD, Full Professor in Nursing Science, Faculty of Science, Technology and Medicine, University of Luxembourg, Grand-Duchy of Luxembourg
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- **FRASER LORNA**, Professor of Palliative Care and Child Health – Cicely Saunders Institute and School of Life Sciences and Population Health, Associate Dean for People and Talent – Faculty of Nursing, Midwifery and Palliative Care, King's College London, UK
- **GOLDMAN ANN**, Paediatrician, Editor Oxford Textbook of Palliative Care for Children, (retired) Consultant in Paediatric Palliative Care, Great Ormond Street Hospital for Children, London, UK
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- **GARCHAKOVA ANNA**, Director of the Belarusian Children's Hospice, and palliative medicine course leader at the Belarusian Medical Postgraduate Academy – Belarus
- **HARDING RICHARD**, PhD, Herbert Dunhill Professor of Palliative Care & Rehabilitation, Vice Dean (International), Director and Global Lead, Cicely Saunders Institute of Palliative Care, Policy & Rehabilitation, King's College London, UK
- **KOH MICHELLE**, MD, Senior Consultant, Paediatric Palliative Care Service KK Women's and Children's Hospital, Singapore
- **KOFFMAN JONATHAN**, BA (Hons), MSc, PhD, Professor of Palliative Care and Associate Director of the Wolfson Palliative Care Research Centre. Programme Co-Director, MSc in Palliative Care: Implementing Best Practice. Chair of HYMS Research Ethics Committee. Visiting Professor of Palliative Care at King's College London, Cicely Saunders Institute, UK
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Speakers and Moderators

turer, UCL Great Ormond Street Institute of Child Health, UK

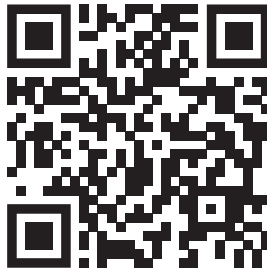
- **MASSERDOTTI ALESSANDRO**, Philosopher and Interaction Designer. Professor of User Experience Design, Domus Academy and Professor of interaction design, Politecnico di Milano. Digital Director of Dotdotdot Agency: Active in Creating a Bridge Between Healthcare and Design, Italy
- **MARTINO ALBA RICARDO**, MD, PhD, Head of Pediatric Comprehensive Palliative Care Unit at Niño Jesús University Children's Hospital, Madrid , Spain
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