



**4th Global Gathering - The Maruzza Congress on Paediatric Palliative Care
Rome, 24th- 27th October 2018**

**Preliminary Congress Program-Day 0
Wednesday 24th October 2018**

Reception desk times:

Pre-Congress Workshops 08.00 - 08.30

Congress delegates 10.00 - 19.00

08.30 - 12.00 **Pre-congress Workshops**

12.00 - 13.00 **Lunch**

13.00 - 16.30 **Pre-congress Workshops**

Pre-congress Workshops (in Parallel):

- Course I: *Team Building and Leadership in Paediatric Palliative Care*
Coordinators: **Ann Goldman**, Jan Aldridge, Danai Papadatou
- Course II: *Implementing Psychosocial Care, Including Sibling Engagement Care and Bereavement*
Coordinators: **Lori Weiner**, Nancy F. Cincotta, Sokhna Ndiaye
- Course III: *Multimodal Treatment of Pain and Distressing Symptoms in Children with Intellectual and Physical Disabilities*
Coordinators: **Stefan J. Friedrichsdorf**, Kris Catrine, Julie Hauer
- Course IV: *Advanced Care Planning in Children - When, Who, How?*
Coordinators: **Justin N. Baker**, Jennifer Snaman, Holly Spraker-Perlman

Preliminary Congress Program

18.00 - 19.30

Opening ceremony

Welcome: Silvia Lefebvre D'Ovidio, Franca Benini

Institutional salutations:

Greetings: Ann Goldman, Justin N. Baker

Keynote Lecture: *The Importance/Meaning Of Time* (Double interview)

Interviewer: Ross Drake

Interviewee 1: Stefano Spigler

Interviewee 2: Caterina Albertini

Presentation: NPC prize for the Best Young Researchers' Abstracts

Keynote Lecture: Children's Palliative Care - a Game Changer for Paediatrics? - Joanne Wolfe

Presentation: *Vittorio Ventafridda Award*

19.30 - 21.00

Icebreaker - Welcome cocktail and buffet

PRELIMINARY CONGRESS PROGRAM-Day 1
Thursday 25th October 2018

Reception opens at 08.00 a.m.

- 08.30 - 09.00 **Plenary: Gaining insights**
Galenic Medicine and Traditional Remedies Used in PPC - David Steinhorn
- 09.00 - 10.30 **Plenary 1: Next Generation Approaches**
 Moderators: Ross Drake, Joanne Wolfe
- *Innovative Methods to Providing PPC* – Stephen Connor
 - *New Drugs and PPC* – Sebastiano Mercadante
 - *Medical Technology in PPC: an Aid or a Limit?* - Julie Hauer
- 10.30 - 11.00 **Coffee break**
- 11.00 - 12.00 **Oral Abstract presentation session (3 in parallel):**
 Moderators: (TBD)
 4 oral presentations each
- Closing remarks
- 12.00 - 13.30 **Lunch and Poster visit**
- 13.30 - 14.30 **Oral Abstract presentation session (3 in parallel):**
 Moderators: (TBD)
 4 oral presentations each
- Closing remarks
- 14.30 - 15.30 **Poster visit (coffee station available)**
- 15.30 - 15.45 **Plenary: No Pain for Children Award – 1st Prize winner**
- 15.45 – 17.15 **Plenary 2: The Needs of Young Adults in PPC and Model Transitions in PPC**
 Moderators: Mercedes Bernadà, Ulrika Kreicbergs
- *How Needs Change* - Graziella Fava Vizziello
 - *The Weaknesses and Strengths of Children's Palliative Care in the Age of Transition from Childhood to Adulthood*- Finella Craig
 - *Care Models* - Myra Bluebond-Langner
- 17.15 – 17.30 **Room Change**
- 17.30 – 18.30 **Networking Sessions (4 in parallel)**
- *Intractable Symptoms in Children with Severe Impairment of the Central Nervous System: What Defines Success when Elimination of Symptoms is not Possible?*
 - Julie Hauer
 - *Parents' Time and Space when a Sick Twin Child is Surviving*
 - Graziella Fava Vizziello
 - *Preventing or Reducing Needle Pain for Hospitalized Children*
 - Stefan Friedrichsdorf
 - *Opioid Metabolism in Children*
 - Sebastiano Mercadante

PRELIMINARY CONGRESS PROGRAM-Day 2
Friday 26th October 2018

Reception opens at 08.00 a.m.

08.30 - 09.00 **Plenary: Gaining insights**

New Methods of Communication: Social Networking and PPC - Federico Pellegatta

09.00 - 10.30 **Plenary 3: Breaking Walls: PPC and Paediatric Specialties: Part 1**

Moderators: Julie Hauer, Marcello Orzalesi

- *Neonatal/Perinatal PC* - Elvira Parravicini
- *PPC in PICU* - Daniel Garros
- *Inherited Metabolic Disease with Life-Limiting Consequences*- Carlo Dionisi Vici

10.30 - 11.00 **Coffee break**

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

Moderators: (TBD)

4 oral presentations each

- Closing remarks

12.00 - 13.30 **Lunch and Poster visit**

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

Moderators: (TBD)

4 oral presentations each

- Closing remarks

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

15.30 - 17.00 **Plenary 4: Breaking Walls: PPC and Paediatric Specialties: Part 2**

Moderators: Mary Devins, Lucia De Zen

- *PPC in Children Without a Diagnosis* - Richard Goldstein
- *Chronic Communicable Disorders* - Michelle Meiring
- *Oncology* - Ana Lacerda

17.00 - 17.15 **Room Change**

17.15 - 18.15 **Networking Sessions (4 in parallel)**

- *Prenatal diagnosis of Life-limiting Genetic Condition Complicated with Severe Cardiac Anomalies*
- Elvira Parravicini
- *Preparing For The Withdrawal Of Life Sustaining Therapy In Paediatric ICU in Diverse Cultural Contexts*
- Daniel Garros
- *Encounters at the Time of Death*
- Richard Goldstein
- *Paediatric Palliative Care in Acute Communicable Diseases*
- Michelle Meiring

PRELIMINARY CONGRESS PROGRAM-Day 3
Saturday 27th October 2018

Reception opens at 08.00 a.m.

08.30 - 09.00 **Plenary: Gaining insights**

The Representation Of End Of Life: Media And PPC - Matteo Asti

09.00 - 10.30 **Plenary 5: From Denial to Palliative: Practical Steps for Developing a PPC Program**

Moderators: Myra Bluebond Langner, Danai Papadatou

- *Training* - Stefan J. Friedrichsdorf
- *Awareness - Changing the Perception of PPC* - Jan Aldridge
- *Working with Policymakers* - Joan Marston

10.30 - 11.00 **Coffee break**

11.00 - 12.00 **Plenary Roundtable discussion: 2018 - What News in PPC? What Does the Future Hold?**

Moderators: Ann Goldman, Justin N. Baker

Panel of experts:

Philanthropist: Her Highness Sheikha Jawaher bint Mohammed Al Qasimi (emirate Sharja) (TBC)

World Health Organization NCD representative: Marie-Charlotte Bouésseau

Communicator: TBD

Physician/Nurse: Pamela Hinds

Parent: Omar Leone

Religious representative: Archbishop Vincenzo Paglia

12.00 - 12.30 **Closing Ceremony**

Conclusions - Ann Goldman, Justin N. Baker

Thanks & arrivederci! - Franca Benini

Preliminary programme