

## 4<sup>th</sup> Global Gathering - The Maruzza Congress on Paediatric Palliative Care Rome, 24<sup>th</sup>- 27<sup>th</sup> October 2018

The purpose of the 4<sup>th</sup> **Maruzza Congress on Paediatric Palliative Care** is to engage professionals working with seriously ill children worldwide by providing a global forum where experiences, current topics and new perspectives on key issues regarding palliative care for children and their families can be debated, compared and discussed.

The congress programme foresees numerous opportunities for professional development and networking: from pre-congress courses, keynote lectures, plenary symposia, focus sessions and abstract-driven presentations.

During the congress, The No Pain For Children Award for Excellence in Paediatric Palliative Care will be awarded for the best presentations and posters by young researchers under the age of 35.

### Objectives:

- To transfer experiences and encourage interdisciplinary knowledge sharing
- To divulge fresh perspectives and innovative solutions
- To foster new synergies across disciplines and geographical regions aimed at promoting improved paediatric palliative care delivery globally

**The common thread for the 4<sup>th</sup> congress program is: 'Thinking outside the box'**

### Target audience:

All professionals involved in the scientific, clinical, organizational, ethical, legal, training and information sectors linked to the care of children affected by life-limiting and life-threatening illness and their families.

**Promoter/Coordinator: Maruzza Foundation** ([www.fondazionemaruzza.org/en/](http://www.fondazionemaruzza.org/en/))

### Scientific Committee:

**Ann Goldman** - Honorary President, Paediatrician, Editor Oxford Textbook of Palliative Care for Children, (retired) Consultant in Paediatric Palliative Care, Great Ormond Street Hospital for Children, London, UK

**Franca Benini** - Chair, Director of Paediatric Palliative Care - Pain Service Consultant in Paediatric Pain and Palliative Care, University of Padua, Italy

**Justin N. Baker** - Co-chair, Chief, Division of Quality of Life and Palliative Care, Attending Physician, Quality of Life Service Director, Hematology/Oncology Fellowship Program Associate Member, Department of Oncology St Jude Children's Research Hospital, Memphis, USA

**Jan Aldridge** - Consultant in Clinical Psychology, Martin House Children's Hospice, Leeds Teaching Hospitals and University, Leeds, UK

**Mercedes Bernadá** - Associate Professor of Paediatrics at School of Medicine, University of the Republic, Director of the Pediatric Palliative Care Unit, at Pereira Rossell Hospital Center, Montevideo, Uruguay

**Mary Devins** - Consultant Paediatrician s.i. Paediatric Palliative Medicine, Our Lady's Children's Hospital Crumlin and The Coombe Women & Infant's Maternity Hospital, Dublin, Rep of Ireland

**Ross Drake** - Clinical Lead PPC and Complex Pain Services Starship Children's Health, Auckland, New Zealand

**Stefan J. Friedrichsdorf** - MD, FAAPM, Department of Pain Medicine, Palliative Care & Integrative Medicine, Children's Hospitals and Clinics of Minnesota, Associate Professor of Pediatrics, University of Minnesota, Minneapolis, USA

**Julie Hauer** - Medical Director, Seven Hills Pediatric Center, Division of General Pediatrics, Boston Children's Hospital, USA

**Pamela Hinds** - Executive Director, Department of Nursing Science, Professional Practice, and Quality; William and Joanne Conway Endowed Chair, Children's National Health System, and Professor of Pediatrics, the George Washington University, Washington, DC, USA

**Ulrika Kreicbergs** - Professor, Head of the research group, The child and family in palliative care, at Ersta Sköndal Bräcke University College/Karolinska Institutet, Stockholm, Sweden

**Joan Marston** - Children's Palliative Care Development Consultant and Global Ambassador for ICPCN Chief, South Africa

**Michelle Adrienne Meiring** - Healthcare practitioner, specialising as a Paediatrician, in Pinelands, Cape Town, Western Cape, South Africa

**Mary Ann Muckaden** - Professor (Former Head), Department of Palliative Medicine, Tata Memorial Hospital, Mumbai, India. Past President, International Children's Palliative Care Network. President Indian Association of Palliative Care

## PRELIMINARY CONGRESS PROGRAM-Day 0

Wednesday 24<sup>th</sup> 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:**

- Course I: *Team Building and Leadership in Paediatric Palliative Care*  
Coordinator: Ann Goldman
- Course II: *Implementing Psychosocial Care, Including Sibling Engagement Care and Bereavement*  
Coordinator: Lori Wiener
- Course III: *Multimodal Treatment of Pain and Distressing Symptoms in Children with Intellectual and Physical Disabilities*  
Coordinator: Stefan J. Friedrichsdorf
- Course IV: *Advanced Care Planning in Children - When, Who, How?*  
Coordinator: Justin N. Baker

## 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 25<sup>th</sup> 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):**
- Working session I**  
 Moderators: 2 (TBD)  
 4 oral presentations
- Closing remarks
- Working session II**  
 Moderators: 2 (TBD)  
 4 oral presentations
- Closing remarks
- Working session III**  
 Moderators: 2 (TBD)  
 4 oral presentations
- Closing remarks
- 12.00 - 13.30 **Lunch and Poster visit**
- 13.30 - 14.30 **Oral Abstract presentation session (3 in parallel):**
- Working session IV**  
 Moderators: 2 (TBD)  
 4 oral presentations
- Closing remarks
- Working session V**  
 Moderators: 2 (TBD)  
 4 oral presentations
- Closing remarks
- Working session VI**  
 Moderators: 2 (TBD)  
 4 oral presentations
- Closing remarks
- 14.30 - 15.30 **Poster visit (coffee station available)**
- 15.30 - 15.45 **Plenary: No Pain for Children Award – 1<sup>st</sup> 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)**
1. *Intractable symptoms in children with severe impairment of the central nervous system: What defines success when elimination of symptoms is not possible?* - Julie Hauer
  2. *Parents' time and space when a twin child sick is surviving* - Graziella Fava Vizziello
  3. *Preventing or reducing needle pain for hospitalized children*- Stefan Friedlrichsdorf
  4. *Methadone in Paediatric Palliative Care* – Sebastiano Mercadante

## PRELIMINARY CONGRESS PROGRAM-Day 2

Friday 26<sup>th</sup> 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
  - *Metabolic and Genetic 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):**
- Working session VII**  
 Moderators: 2 (TBD)  
 4 oral presentations
- Closing remarks
- Working session VIII**  
 Moderators: 2 (TBD)
- 4 oral presentations
  - Closing remarks
- Working session IX**  
 Moderators: 2 (TBD)
- 4 oral presentations
  - Closing remarks
- 12.00 - 13.30 **Lunch and Poster visit**
- 13.30 - 14.30 **Oral Abstract presentation session (2 in parallel):**
- Working session X**  
 Moderators: 2 (TBD)  
 4 oral presentations
- Closing remarks
- Working session XI**  
 Moderators: 2 (TBD)  
 4 oral presentations
- Closing remarks
- Working session XII**  
 Moderators: 2 (TBD)  
 4 oral presentations
- 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: Marie Devins & Lucia De Zen
- *PPC in Children Without a Diagnosis* - Richard Goldstein
  - *Chronic Communicable Disorders* - Michelle Adrienne Meiring
  - *Oncology* - Ana Lacerda
- 17.00 - 17.15 **Room Change**
- 17.15 - 18.15 **Networking Sessions (4 in parallel)** Topics & Coordinator TBD
1. *Prenatal diagnosis of life-limiting genetic condition complicated with severe cardiac anomalies*  
 - Elvira Parravicini
  2. *Preparing For The Withdrawal Of Life Sustaining Therapy In Paediatric ICU In Diverse Cultural Contexts*  
 - Daniel Garros
  3. *Encounters at the time of death* - Richard Goldstein
  4. *Paediatric Palliative Care in Acute Communicable diseases* - Michelle Meiring

## PRELIMINARY CONGRESS PROGRAM-Day 3

Saturday 27<sup>th</sup> 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 - Whats 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 (Vatican Academy for Life (PAV) President

12.00 - 12.30 **Closing Ceremony**

*Conclusions* - Ann Goldman, Justin N. Baker

*Thanks & arrivederci!* - Franca Benini

preliminary program