



4<sup>TH</sup> GLOBAL GATHERING

# MARUZZA CONGRESS

ON PAEDIATRIC PALLIATIVE CARE  
ROME 24<sup>TH</sup>-27<sup>TH</sup> OCTOBER 2018

# 4<sup>TH</sup>

ROME 24<sup>TH</sup> - 27<sup>TH</sup> OCTOBER 2018 • *AUDITORIUM ANTONIANUM*

[www.childrenpalliativecarecongress.org/congress-2018/](http://www.childrenpalliativecarecongress.org/congress-2018/)

# PROGRAMME



**ENDORSED BY**  
The Italian Ministry of Health

**Società Italiana di Cure Palliative - SICP**  
**Patrocinio SICP n. 7 del 31.01.2018**

con il patrocinio



With the patronage of  
FIMP - Italian Federation of Pediatricians



**PARTNERS**



The purpose of the 4<sup>th</sup> Global Gathering - 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 scientific program provides many opportunities for professional development and networking: pre-congress workshops, keynote lectures, plenary symposia, focus sessions and abstract-driven presentations.

## **Theme**

'Thinking outside the box'

## **Objectives**

- To transfer experiences and encourage knowledge sharing
- To divulge innovative approaches and disclose cutting-edge technology
- To foster new synergies across diverse cultures and disciplines aimed at improved palliative care delivery to children with serious illness worldwide

## **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.



## Scientific Committee

Franca Benini - Chair (*Italy*)

Ann Goldman - Honorary President (*UK*)

Justin N. Baker - Co-chair (*USA*)

Jan Aldridge (*UK*)

Mercedes Bernad  (*Uruguay*)

Mary Devins (*Rep of Ireland*)

Ross Drake (*New Zealand*)

Stefan J. Friedrichsdorf (*USA*)

Julie Hauer (*USA*)

Pamela Hinds (*USA*)

Ulrika Kreicbergs (*Sweden*)

Joan Marston (*South Africa*)

Michelle Adrienne Meiring (*South Africa*)

Mary Ann Muckaden (*India*)

## Promoter/Coordinator

The Congress is devised and organised by **Maruzza Lefebvre D'Ovidio Foundation** an independent organization based in Rome, Italy that, since 1999, is engaged at a national and international level in activities aimed at disseminating the culture of palliative care, promoting research and providing specialised training for healthcare professionals.

In 2013 the Maruzza Foundation was awarded the Gold Medal of Merit for services rendered to public healthcare by the President of the Italian Republic.

TIMETABLE

24<sup>TH</sup>

WEDNESDAY

25<sup>TH</sup>

THURSDAY

26<sup>TH</sup>

FRIDAY

27<sup>TH</sup>

SATURDAY

OCTOBER 2018

## WEDNESDAY 24<sup>TH</sup> OCTOBER

	Auditorium (Basement level)	Room S. Francesco (Ground Floor)	Room S. Bernardino da Siena (Ground Floor)	Room A (1 <sup>st</sup> Floor)	Room Jacopone da Todi (Ground Floor)
08.30 12.00		<b>Pre-congress workshop</b> <i>Multimodal Treatment of Pain and Distressing Symptoms in Children with Intellectual and Physical Disabilities</i>	<b>Pre-congress workshop</b> <i>Team Building and Leadership in Paediatric Palliative Care</i>	<b>Pre-congress workshop</b> <i>Implementing Psychosocial Care, Including Sibling Engagement Care and Bereavement</i>	<b>Pre-congress workshop</b> <i>Advanced Care Planning in Children - When, Who, How?</i>
13.00 16.30		<b>Pre-congress workshop</b> <i>Multimodal Treatment of Pain and Distressing Symptoms in Children with Intellectual and Physical Disabilities</i>	<b>Pre-congress workshop</b> <i>Team Building and Leadership in Paediatric Palliative Care</i>	<b>Pre-congress workshop</b> <i>Implementing Psychosocial Care, Including Sibling Engagement Care and Bereavement</i>	<b>Pre-congress workshop</b> <i>Advanced Care Planning in Children - When, Who, How?</i>
17.30 19.45	<b>Opening ceremony</b>				
20.00 21.30	Icebreaker – Welcome cocktail and buffet				

## THURSDAY 25<sup>TH</sup> OCTOBER

	Auditorium (Basement level)	Room S. Francesco (Ground Floor)	Room S. Bernardino da Siena (Ground Floor)	Room A (1 <sup>st</sup> Floor)	Room Jacopone da Todi (Ground Floor)
08.30 09.00	<b>Gaining Insight</b>				
09.00 10.30	<b>Plenary Session</b> <i>Next Generation Approaches</i>				
11.00 12.00	<b>Working session I</b>	<b>Working session II</b>		<b>Working session III</b>	
13.30 14.30	<b>Working session IV</b>	<b>Working session V</b>		<b>Working session VI</b>	
14.30 15.30	Poster Visit				
15.30 15.45	<b>No Pain for Children Award</b> 1 <sup>st</sup> Prize				
15.45 17.15	<b>Plenary Session</b> <i>The Needs of Young Adults in PPC and Model Transitions in PPC</i>				
17.30 18.30		<b>Networking Session</b> <i>Preventing or Reducing Needle Pain for Hospitalized Children</i>	<b>Networking Session</b> <i>How to Assess and Manage the Distressed non Verbal Child in PPC</i>	<b>Networking Session</b> <i>Intractable Symptoms in Children with Severe Impairment of the Central Nervous System: What Defines Success when Elimination of Symptoms is not Possible?</i>	<b>Networking Session</b> <i>Parents' Time and Space when a Sick Twin Child is Surviving</i>

## FRIDAY 26<sup>TH</sup> OCTOBER

	Auditorium (Basement level)	Room S. Francesco (Ground Floor)	Room S. Bernardino da Siena (Ground Floor)	Room A (1 <sup>st</sup> Floor)	Room Jacopone da Todi (Ground Floor)
08.30 09.00	Gaining Insight				
09.00 10.30	Plenary Session <i>Breaking Walls: PPC and Paediatric Specialties - Part 1</i>				
11.00 12.00	Working session VII	Working session VIII		Working session IX	
13.30 14.30	Working session X	Working session XI		Working session XII	
14.30 15.30	Poster Visit				
15.30 17.00	Plenary Session <i>Breaking Walls: PPC and Paediatric Specialties - Part 2</i>				
17.15 18.15		Networking Session <i>Encounters at the Time of Death</i>	Networking Session <i>Prenatal Diagnosis of Life-Limiting Genetic Condition Complicated with Severe Cardiac Anomalies</i>	Networking Session <i>Preparing for The Withdrawal of Life Sustaining Therapy in Paediatric ICU in Diverse Cultural Contexts</i>	Networking Session <i>Paediatric Palliative Care in Acute Communicable Diseases</i>

## SATURDAY 27<sup>TH</sup> OCTOBER

	Auditorium (Basement level)
08.30 09.00	Gaining Insight
09.00 10.30	Plenary Session <i>From Denial to Palliative: Practical Steps for Developing a PPC Program</i>
11.00 12.45	Roundtable discussion <i>2018 - What News in PPC? What Does the Future Hold?</i>
12.45 13.15	Closing Ceremony



PROGRAMME

# 24<sup>TH</sup> WEDNESDAY

## PRE-CONGRESS WORKSHOPS

[ 08.00 - 08.30 Registration

[ 08.30 - 12.00 Pre-congress Workshops

[ 12.00 - 13.00 Lunch

[ 13.00 - 16.30 Pre-congress Workshops

Room Jacopone da Todi (Ground Floor)

**Advanced Care Planning in Children - When, Who, How?**

Coordinator: *Justin N. Baker*

Co-presenters: *Jennifer Snaman, Holly Spraker-Perlman*

Room S. Francesco (Ground Floor)

**Multimodal Treatment of Pain and Distressing Symptoms in Children with Intellectual and Physical Disabilities**

Coordinator: *Stefan J. Friedrichsdorf*

Co-presenters: *Kris Catrine, Julie Hauer*

Room San Bernardino da Siena (Ground Floor)

**Team Building and Leadership in Paediatric Palliative Care**

Coordinator: *Ann Goldman*

Co-presenters: *Jan Aldridge, Danai Papadatou*

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

**Implementing Psychosocial Care, Including Sibling Engagement Care and Bereavement**

Coordinator: *Lori Wiener*

Co-presenters: *Nancy F. Cincotta, Sokhna Ndiaye*



## CONGRESS

[ 09.30 - 16.00 Registration

[ 17.30 - 19.45 Auditorium (Basement Level)

**Opening Ceremony**

Welcomes of participants and presentation of Guest of Honour  
*Franca Benini, Silvia Lefebvre D'Ovidio*

Guest of Honour: *Her Highness Sheikha Jawaher bint Mohammed Bin Sultan Al Qasimi*

Double interview: 'The Importance/Meaning of Time'

Interviewer: *Ross Drake*

Interviewees: *Caterina Albertini, Stefano Spigler*

Presentation of *Vittorio Ventafridda Award*

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

*Joanne Wolfe*

Launch of a WHO Guide for Health Care Planners, Implementers  
and Managers "Integrating Palliative Care and Symptom Relief  
into Paediatrics"

*Marie-Charlotte Bouësseau*

Presentation of No Pain for Children Awards for the Best Abstracts

Projection of No Pain for Children Award for the Best Video  
Children's Hospice - Firefly World

*Nino Kiknadze*

[ 20.00 - 21.30 Icebreaker - Welcome cocktail and buffet

LEGEND:

[ MORNING

[ AFTERNOON

# 25<sup>TH</sup> THURSDAY

Reception opens at 08.00

**08.30 - 09.00** Auditorium (Basement Level)  
**Gaining insights: Galenic Medicine and Traditional Remedies Used in PPC**  
*David Steinhorn*

**09.00 - 10.30** Auditorium (Basement Level)  
**Plenary session**  
**Next Generation Approaches**  
Moderators: *Ross Drake, Joanne Wolfe*

- Innovative methods to providing PPC - *Stephen R. Connor*
- New drugs, routes and approaches in PPC - *Satbir Singh Jassal*
- Medical technology in PPC: an aid or a limit? - *Julie Hauer*

**10.30 - 11.00** Coffee break

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

Auditorium (Basement Level)

**Working session I - Rainbow Session: Tools**

Moderators: *Sokhna Ndiaye, Danai Papadatou*

- EMDR integration of non-pharmacological techniques for anxiety and trauma prevention in paediatric sedo-analgesia  
*Isabella Lucia Chiara Mariani Wigley*
- "Informed decision-making is a valuable notion but a faulty tool" - pediatric health care providers perspectives on adolescent and young adult advance care planning in bone marrow transplant  
*Jennifer Needle*
- Validation of the Spanish version for Argentina of the Memorial Symptom Assessment Scale (MSAS) in children from 2 to 20 years with cancer treated at two public hospitals in Buenos Aires city, Argentina  
*María Silvina Bevilacqua*

- Digital tool for better communication in Children's Palliative Care (CPC)  
*Stephanie Vallianatos*

- Closing remarks

### Room S. Francesco/San Bernardino da Siena (Ground Floor)

#### Working Session II - Surveys and Systematic Reviews

Moderators: *Michelle Adrienne Meiring, Lori Wiener*

- Bereavement support for parents of children who have died: a systematic review  
*Tom Ainscough*
- The prevalence and incidence of anxiety and depression in children and young people (CYP) with life-limiting conditions (LLC): a systematic review and meta-analysis  
*Mary Barker*
- Parental preferences in decisional autonomy and values-guided approaches in tracheostomy decisions  
*Ken Pituch*
- Parents' awareness and perspectives on the pediatric palliative care in South Korea  
*In Gyu Song*
- Closing remarks

### Room A (1<sup>st</sup> Floor)

#### Working Session III - End of Life Care

Moderators: *Ana Lacerda, Mary Ann Muckaden*

- Autonomy of competent children about end-of-life decisions: attitudes of Italian healthcare professionals  
*Emanuele Castagno*
- Palliative sedation in the end of life: standard based evaluation of practice in a paediatric palliative care service  
*Iñigo de Noriega Echevarría*
- Where children die, a regional analysis of Child Death Overview Panel (CDOP) data  
*Davina Hartley*
- A workshop on how to recognise a dying child: uncovering the complexities and professionals' fears whilst helping to increase understanding  
*Michelle Hills*
- Closing remarks

**12.00 - 13.30** Lunch and Poster visit

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

**Auditorium (Basement Level)**

**Working session IV - No Pain for Children Awards**

Moderators: *Stephen R. Connor, Stefan J. Friedrichsdorf*

- Parents' experiences and wishes on information provision and decision-making in the care for their child with spinal muscular atrophy: a population survey  
*Kim Beernaert*
- Perinatal comfort care: implications for decision-making and perinatal outcomes in pregnant patients with complex fetal anomalies  
*Valentina Giardini*
- "Adding days to a life, or life to the days left". Parents' and physicians perspectives on decision-making in a Dutch interview study  
*Marije A. Brouwer*
- Bereaved parents are more likely to report that the health care did everything to support their child than non-bereaved - A two countries study of parents of children with severe SMA  
*Elin Hjorth*
- Closing remarks

**Room S. Francesco/San Bernardino da Siena (Ground Floor)**

**Working session V - Rainbow Session: Meeting Needs**

Moderators: *Lucia De Zen, Daniel Garros*

- Networking to increase access to children's palliative care: the ICPCN experience  
*Julia Downing*
- Pediatric palliative care in Sub-Saharan Africa. What "knowledge" to transmit and how?  
*Christine Edan*
- Building a paediatric hospice in the home (The Lego Project): how one health care region in Ireland co-ordinated existing child and family community services to ensure seamless, cost neutral community palliative care at the end of a child's life  
*Siobhan Gallagher*
- Meeting expectations: student feedback from Ireland's first masters programme for children's palliative and complex care nurses  
*Claire Quinn*
- Closing remarks

**Room A (1<sup>st</sup> Floor)****Working session VI - Parents and Siblings**Moderators: *Finella Craig, Federico Pellegatta*

- Parents' experiences of requests for organ and tissue donation: the value of asking  
*Anne-Sophie Darlington*
- An exploration of the experience of caring for a child with a non-malignant life-limiting condition from the perspective of parents  
*Fiona Hurley*
- Anxiety and depression in bereaved parents after losing a child due to life-limiting diagnoses  
*Camilla Lykke*
- An analysis of use of 'cool rooms' in two children's hospices in the UK  
*Kate Renton*
- Closing remarks

**[ 14.30 - 15.30** Poster visit - coffee station available

**[ 15.30 - 15.45** Auditorium (Basement Level)  
**No pain for Children Award - 1<sup>st</sup> prize winning abstract**  
Pediatric death attributed to life-limiting conditions in Republic of Korea: exploring the nation-wide pediatric palliative care needs  
*Cho Hee Kim*

**[ 15.45 - 17.15** Auditorium (Basement Level)  
**Plenary Session**  
**The Needs of Young Adults in PPC and Model Transitions in PPC**  
Moderators: *Mercedes Bernad, 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/Focus Sessions (4 in parallel)

Room S. Francesco (Ground Floor)

Preventing or Reducing Needle Pain for Hospitalized Children

Coordinator: *Stefan J. Friedrichsdorf*

Room San Bernardino da Siena (Ground Floor)

How to Assess and Manage the Distressed Non Verbal Child  
in PPC

Coordinator: *Satbir Singh Jassal*

Room Jacopone da Todi (Ground Floor)

Parents' Time and Space when a Sick Twin Child is Surviving

Coordinator: *Graziella Fava Vizziello*

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

Intractable Symptoms in Children with Severe Impairment of the  
Central Nervous System: What Defines Success when Elimination  
of Symptoms is not Possible?

Coordinator: *Julie Hauer*



# POSTER EXHIBITION

# 25<sup>TH</sup>

<i>Exhib N°</i>	<i>Title</i>	<i>Name</i>
1	Dynamics of quantitative indicators of pediatric palliative care in the Russian Federation	<i>Elena Plevichenko</i>
2	Sibling bereavement	<i>Silvia da Encarnação Barros Ramos</i>
3	Qualitative medical education for children's palliative care in Ukraine. Increasing demand	<i>Luidmila Andriishyn</i>
4	Advocacy for development of children's palliative care in Ukraine. Charter of the rights of the dying child	<i>Kseniia Shapoval-Deinega</i>
5	Sedation at the end of the life in a pediatric palliative care unit	<i>Maria José Peláez Cantero</i>
6	The role of the pediatric continuity nurse: there is no place like home	<i>Annarosa Bondioli</i>
7	Defining palliative opportunities in pediatric patients with solid tumors	<i>Katharine Brock</i>
8	Influenza strikes and ... costs	<i>Mirela Silvia Iancu</i>
9	Pediatric pain profile-cross cultural translation and adaptation to Italian	<i>Silvia Soffritti</i>
11	Implementation of a transition pathway in paediatric palliative care: a quality improvement approach	<i>Joanne Balfe</i>
13	Buccal opioid use for pain and dyspnoea for children with palliative care needs during end of life care	<i>Linda Maynard</i>
14	Quality of palliative care for paediatric patients in hospital stage in Latvia	<i>Sofja Tomase</i>
15	Caregiver burden, quality of life and their relationship to healthcare utilization in low-income parents of children with life-limiting conditions	<i>Andrea Postier</i>
16	Thinking outside the box: A new approach to handle patients with multidrug resistant bacteria on a paediatric palliative care unit	<i>Pia Schmidt</i>
17	Paediatric Advance Care Planning (PACP) and the Italian law: the outcome for children in a paediatric palliative care (PPC) programme	<i>Pierina Lazzarin</i>
19	Themes from the early days of children's palliative care	<i>Joan Marston</i>
20	The utilisation of hospice services following referral from malignancy tertiary team	<i>Fiona McElligott</i>

<b>21</b>	The experience of childhood cancer survival: reports of adolescents	<i>Carolliny Rossi de Faria Ichikawa</i>
<b>22</b>	Family impact on the diagnosis of autism spectrum disorder	<i>Carolliny Rossi de Faria Ichikawa</i>
<b>23</b>	To provide difficult information to parents when their children have a brain tumour	<i>Elisabeth Björn</i>
<b>24</b>	Spinal muscular atrophy type 1: an experience at a pediatric hospital	<i>Rodolfo Verna</i>
<b>25</b>	Cutting to the chase: when do severely ill children's sleep problems require clinical attention?	<i>Larissa Alice Dreier</i>
<b>26</b>	Continuous professional education in pediatric palliative care from recruitment stage	<i>Kateryna Burlak</i>
<b>27</b>	A systematic review of the impact of psychosocial interventions for siblings of children with life-limiting conditions	<i>Liam Robson</i>
<b>29</b>	Stepping up to integrate PPC in an intermediate care facility for children in Cape Town, South Africa	<i>Alex Daniels</i>
<b>30</b>	Psychological home assistance in the Paediatric Palliative Care: an operative model	<i>Arianna Pezzutto</i>
<b>31</b>	Medical marijuana use in pediatric oncology patients: single institution experience	<i>Ruth Ofir</i>
<b>32</b>	Improving medication safety in a children's hospice; a quality improvement project	<i>Joanne Balfe</i>
<b>33</b>	Caring for the team, caring for the child: developing a culture of staff support in a children's hospice	<i>Joanne Balfe</i>
<b>34</b>	Half-hourly buccal medications for end of life symptom management for infants too small for subcutaneous infusion	<i>Pat Sartori</i>
<b>35</b>	Options for management of pontocerebellar hypoplasia in light of a systematic review and patient cohort analysis	<i>Marinka Astrid Rachel de Groot</i>
<b>36</b>	Sustainable innovations in CPC, based on the real patient story!	<i>Carolien Huizinga</i>
<b>37</b>	Care analysis at a Pediatric Palliative Care Unit	<i>María Silvana Bevilacqua</i>
<b>38</b>	Perinatal Palliative Care: a protocol is enough?	<i>Francesca Rusalen</i>
<b>39</b>	How EPEC-p training changes PPC Ukraine	<i>Olena Riga</i>
<b>40</b>	Development and implementation of a community-based pediatric palliative care network in the presence of a well rooted adult network	<i>Marco Bolognani</i>
<b>41</b>	An assessment of the learning needs in Paediatric Palliative Care in Ireland	<i>Joanne Balfe</i>

42	Adaptation of infusion solutions for symptom relief and sedation for children in palliative care at home	<i>Marinka Astrid Rachel de Groot</i>
43	Ensuring their voice is heard: parental recruitment challenges in children's palliative care research	<i>Claire Quinn</i>
44	Pediatric palliative care service markedly reduce hospital resource use - a Southeast Asian experience	<i>Issarang Nuchprayoon</i>
45	Specialist paediatric palliative care for children and young people with cancer: a mixed methods systematic review	<i>Johanna Taylor</i>
46	Development of paediatric goals of patient care document	<i>Marianne Phillips</i>
47	"I didn't know a newborn could die!". Evaluating the impact of a new course in paediatric palliative care for midwife students in Belgium	<i>Marie Friedel</i>
48	A prospective study of preference in the place of death for children with life-limiting conditions cared for by a tertiary palliative care service	<i>Ellen M Henderson</i>
49	Anticipating the future in pediatric palliative care by parents and health care professionals: a qualitative study	<i>Marijke Kars</i>
50	"Capturing the voice of families". A service review of an Irish Children's Charity on its 20 <sup>th</sup> anniversary	<i>Sheila Hayes</i>

# 26<sup>TH</sup> FRIDAY

Reception opens at 08.00

**08.30 - 09.00** Auditorium (Basement Level)  
**Gaining insights: New Methods of Communication:  
Social Networking and PPC**  
*Federico Pellegatta*

**09.00 - 10.30** Auditorium (Basement Level)  
**Plenary session**  
**Breaking Walls: PPC and Paediatric Specialties - Part 1**  
Moderators: *Julie Hauer, Marcello Orzalesi*

- Perinatal/Neonatal PC - *Elvira Parravicini*
- PPC in PICU: yes we can! - *Daniel Garros*
- Inherited metabolic disease with life-limiting consequences - *Carlo Dionisi Vici*

**10.30 - 11.00** Coffee break

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

Auditorium (Basement Level)  
**Working session VII - Neonatal and Perinatal**  
Moderators: *Richard Goldstein, Elvira Parravicini*

- Nursing recommendations to improve palliative care in neonatal intensive care  
*Joana Mendes*
- Outcomes of a high-risk cohort of infants with complex congenital heart disease referred to a perinatal palliative care service  
*Regina Okhuysen-Cawley*
- 'Juggling and struggling' - parent and professional experiences of accessing and providing neonatal palliative care within a children's hospice  
*Jayne Price*
- Challenges of perinatal hospice care in Hungary  
*Eva Zsak*
- Closing remarks

Room S. Francesco/San Bernardino da Siena  
(Ground Floor)

**Working Session VIII - Rainbow Session:  
Research**

Moderators: *Jan Aldridge, Holly Spraker-Perlman*

- Nusinersen and children with spinal muscular atrophy type 1 (SMA 1): do they still need pediatric palliative care (PPC)?  
*Caterina Agosto*
- Priorities for research on children and young people with life-limiting conditions: a systematic review and consultation exercise  
*Lorna Fraser*
- How much does a charitable hospice in the UK reduce admissions to NHS acute hospitals?  
*Michelle Hills*
- Home death for children - does inequality exist?  
*Mette Asbjørn Neergaard*
- Closing remarks

**Room A (1<sup>st</sup> Floor)**

**Working Session IX - Education and Training**

Moderators: *Myra Bluebond-Langner, Nancy F. Cincotta*

- A descriptive study of a simulation based palliative care communication curriculum for pediatric critical care fellows  
*Katharine Brock*
- Responding to global need for CPC education: an innovative multi-lingual approach  
*Alex Daniels*
- Project ECHO: creating a community of practice in children's palliative care  
*Sharon McCloskey*
- Continuous professional education of clinicians and raising patients'/families' awareness improves pediatric palliative care services quality  
*Tetyana Vilchynska*
- Closing remarks

**12.00 - 13.30 Lunch and Poster visit**

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

**Auditorium (Basement Level)**

**Working session X - Ethic and Spirituality**

Moderators: *Marcello Orzalesi, David Steinhorn*

- "I'm going to church anyway": the impact of spirituality on parental grief  
*Lindsay Blazin*
- Creating a safe environment for children and parents: how the concept of holding, applied to paediatric palliative care (PPC), collides with Belgian child euthanasia procedure  
*Marie Friedel*
- Non-religious arguments to discuss pediatric euthanasia: why should pediatric palliative care use them  
*Joana Mendes*
- Beliefs, luck, and oppression associated with paediatric palliative care in South Korea: implications for a model of anti-oppressive surrogate decision-making  
*Seunghoon Oh*
- Closing remarks

**Room S. Francesco/San Bernardino da Siena (Ground Floor)**

**Working session XI - Research Issues**

Moderators: *Ulrika Kreicbergs, Jennifer Snaman*

- Longitudinal and systematic screening for depression and anxiety in children and adolescents with cancer  
*Gadi Abebe Campino*
- The importance of cyberspace for adolescents in Palliative Care  
*Camila Amaral Borghi*
- Supporting the evolution of a programme of palliative care services for children: leadership lessons learnt  
*Sharon Foley*
- Regular GP consultations are associated with reduced rates of emergency care for children and young people with life limiting conditions  
*Stuart Jarvis*
- Closing remarks



**Room A (1<sup>st</sup> Floor)****Working session XII - Advanced Care Planning**Moderators: *Mercedes Bernadá, Julie Hauer*

- Pediatricians' experiences and attitudes regarding advance care planning  
*Jurriane C. Fahner*
- Enduring ambivalence: prepare - development of an advance care planning intervention in pediatric palliative care  
*Monika Führer*
- Training paediatricians to discuss advance care planning with families  
*Hannah Massey*
- Feasibility and acceptability of the Family Advance Care Planning (FACE) intervention for adolescent and young adult bone marrow transplant patients  
*Jennifer Needle*
- Closing remarks

**[ 14.30 - 15.30** Poster visit - coffee station available

**[ 15.30 - 17.00** Auditorium (Basement Level)  
Plenary session  
**Breaking Walls: PPC and Paediatric Specialties - Part 2**  
Moderators: *Finella Craig, 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):**

**Room S. Francesco (Ground Floor)**

**Encounters at the Time of Death**

Coordinator: *Richard Goldstein*

**Room San Bernardino da Siena (Ground Floor)**

**Prenatal Diagnosis of Life-limiting Genetic Condition Complicated with Severe Cardiac Anomalies**

Coordinator: *Elvira Parravicini*

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

**Paediatric Palliative Care in Acute Communicable Diseases**

Coordinator: *Michelle Adrienne Meiring*

**Room A (1<sup>st</sup> Floor)**

**Preparing for the Withdrawal of Life Sustaining Therapy in Paediatric ICU in Diverse Cultural Contexts**

Coordinator: *Daniel Garros*



# POSTER EXHIBITION

# 26<sup>TH</sup>

<i>Exhib N°</i>	<i>Title</i>	<i>Name</i>
61	Paediatric palliative care without parents	<i>Emilie Leroy</i>
62	Osteosarcoma and severe treatment refractory cardiomyopathy: a case report	<i>María Silvana Bevilacqua</i>
63	The ethical challenge of providing Palliative Care when a parent refuses potentially curative treatment – a case study	<i>Manjiri Dighe</i>
64	Benefits of the use of upper limb orthoses in pediatric palliative patients with brain damage	<i>Inmaculada Diaz-Regañón</i>
65	Palliative care for children in Ukraine. Current state, problems and prospects of development	<i>Maryna Lobodina</i>
66	Fastening the integration of palliative care services, into the Cameroon national health system through trained community volunteers (adaptable model of hospice Africa Uganda)	<i>Bernard Pierre Messing</i>
67	A new period: a mutual help group for parents that lost a child	<i>Giulia Mariutti</i>
68	Barriers in providing pediatric palliative care in University Hospital in Prague – our first experience	<i>Lucie Hrdlickova</i>
69	Current bereavement services within paediatric palliative care services in Ireland: a review of the literature	<i>Aisling Devitt</i>
70	The seeds-of-silent words in prenatal palliative care - Prof. Luisella Magnani In Memory of Giampaolo Magnani born on 5th March 2009 died on 17 <sup>th</sup> October 2010	<i>Luisella Magnani</i>
71	Fetal echocardiography: what every paediatric palliative care provider should know	<i>Regina Okhuysen-Cawley</i>
72	Meaningful outcomes in pediatric palliative care	<i>Mandira Reuther</i>
73	'Cold bedrooms and cooling blankets' provided by children's hospices: mapping practice and exploring bereaved parents' experiences	<i>Julia Hackett</i>
74	The view from adolescents cancer survivors about family management	<i>Carolliny Rossi de Faria Ichikawa</i>
75	Motivation of voluntary works in pediatric oncology	<i>Carolliny Rossi de Faria Ichikawa</i>
76	Assessment of the needs for pediatric palliative care in our province	<i>Katia Rocchetti</i>
77	Telephone consultation to improve pediatric palliative care across regions	<i>Marinka Astrid Rachel de Groot</i>

<b>78</b>	Rapid access service for children with palliative care needs facilitated by clinical nurse coordinator for children with life limiting conditions at a regional paediatric centre	<i>Hilary Noonan</i>
<b>79</b>	The importance of a family foundation in the global development of Children's Palliative Care	<i>Joan Marston</i>
<b>80</b>	Survey of primary care nurses on pediatric palliative care	<i>Maria Jose Peláez Cantero</i>
<b>81</b>	Poor support to siblings of children with cancer: a Swedish and Finnish parental follow-up	<i>Malin Lövgren</i>
<b>82</b>	Perception of palliative care organizations in Republic of Korea toward providing pediatric palliative care	<i>Yi Ji Moon</i>
<b>83</b>	Mortality in a pediatric palliative care unit: who, how, where and why?	<i>Maria Jose Peláez Cantero</i>
<b>84</b>	Emergency care for patients followed up by a pediatric palliative care unit	<i>Maria Jose Peláez Cantero</i>
<b>85</b>	Tracheostomy care at home: yes we can. Caregivers' perceptions and concerns	<i>Lorenzo Giuntoli</i>
<b>86</b>	Thinking out of the box: non opioid rotation method for management of opioid induced neurotoxicity OIN in pediatric cancer patient case report	<i>Iman Aldiri</i>
<b>87</b>	The experience of losing a sibling in childhood or adolescence	<i>Silvia da Encarnação Barros Ramos</i>
<b>88</b>	PPC programmes and approaches in the biggest regions in Ukraine – questions or barriers?	<i>Olena Riga</i>
<b>89</b>	Children with extreme complexity: developing and maintaining nursing competency in a children's hospice	<i>Joanne Balfe</i>
<b>90</b>	A path to specialized pediatric palliative care. Screening tools for attending pediatricians and members of palliative care teams	<i>Merlin Deckers</i>
<b>91</b>	Predictors of place of death among terminally ill children: a systematic review with meta-analyses	<i>Sanne Wolff</i>
<b>92</b>	Polypharmacy in children with life-limiting conditions	<i>Joanne Balfe</i>
<b>94</b>	Initiating discussions with advanced care planning in children with severe neurological impairment; retrospective review to support quality improvement	<i>Joanne Balfe</i>
<b>95</b>	Models of pediatric palliative oncology outpatient care – benefits, challenges, and opportunities	<i>Katharine Brock</i>
<b>96</b>	Behind the scenes: care coordination and non-billable time associated with outpatient pediatric palliative oncology	<i>Katharine Brock</i>
<b>97</b>	On the road of pediatric palliative care...integrated care pathways (ICP) for children with complex chronic condition (CCC). AUSL Bologna experience	<i>Silvia Soffritti</i>
<b>98</b>	Ethical issues between life choice and palliative care: the experience of a SMA1 family	<i>Chiara Mastella</i>

<b>99</b>	Teaching pediatricians the skill of shared decision making: a blinded, randomized, controlled pilot study utilizing a novel online curriculum	<i>Ken Pituch</i>
<b>100</b>	Parental experiences and perspectives of end-of-life decision-making in allogeneic paediatric stem cell transplant, a retrospective, multi-centre, grounded theory approach	<i>Hilda Mekelenkamp</i>
<b>101</b>	Palliative care for newborns with inoperable cardiac disease - the development of a hospice care pathway	<i>Michelle Koh</i>
<b>102</b>	Knowing the children's literature on death and grief: the possibility of interventions with families	<i>Carolliny Rossi de Faria Ichikawa</i>
<b>103</b>	Training in children's palliative care provided to postgraduates specializing in paediatric medicine in Italy - the evaluation of training programs and achieved levels of competency	<i>Sabrina Congedi</i>
<b>104</b>	Inhabiting the present: exploring the spirituality of children	<i>Jan Aldridge</i>
<b>105</b>	A case series exploring expected infant death - who, where and when?	<i>Charlotte Ashton</i>
<b>106</b>	The relationship between adolescents, in palliative care, and the cyberspace: an interaction model	<i>Camila Amaral Borghi</i>
<b>107</b>	Signs and symptoms experienced by children in the last 7 days of life	<i>Lucy Coombes</i>
<b>108</b>	Consistently seeing the same GP is associated with less emergency care for children and young people with life limiting conditions	<i>Stuart Jarvis</i>
<b>110</b>	How effective is the Paediatric Palliative Screening Scale (PaPas scale) in identifying children with cancer who may benefit from palliative care input?	<i>Jonathan Downie</i>

# 27<sup>TH</sup> SATURDAY

Reception opens at 08.00

[ 08.30 - 09.00 Auditorium (Basement Level)  
Gaining insights: The Representation of End of Life: Media and PPC  
*Matteo Asti*

[ 09.00 - 10.30 Auditorium (Basement Level)  
Plenary session  
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 to ensure palliative care for children  
*Joan Marston*

[ 10.30 - 11.00 Coffee break

[ 11.00 - 12.45 Auditorium (Basement Level)  
Roundtable discussion: 2018 - What News in PPC?  
What Does the Future Hold?  
Moderators: *Ann Goldman, Justin N. Baker*

- *Omar Leone*
- *Ross Drake*
- *Kevin Kajitani, Akira Fukabori*
- *Stefano Bellon*
- *Mark Brown*

[ 12.45 - 13.15 Auditorium (Basement Level)  
Closing Ceremony  
Conclusions - *Ann Goldman, Justin N. Baker, Franca Benini*  
Thanks & arrivederci! - *Silvia Lefebvre D'Ovidio*

## GUEST OF HONOR

**Her Highness Sheikha Jawaher** bint Mohammed Al Qasimi, Wife of His Highness the Ruler of Sharjah; Founder and Patron of the Friends of Cancer Patients; International Ambassador of the World Cancer Declaration for Union for International Cancer Control UICC; International Ambassador for Childhood Cancer for UICC; Patron of the Global NCD Alliance Forum – United Arab Emirates

## SPEAKERS AND MODERATORS

**Caterina Albertini** Postgraduate student (Master of Science in Marketing Management), President of the Students Marketing Society at the Bocconi University, Milan, Italy

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

**Matteo Asti** Lecturer in Film Criticism at Università Cattolica del Sacro Cuore, Brescia, Lecturer in Cinema & Media Communication at Accademia di Belle Arti, Santa Giulia, Teacher of Italian Language and Literature. Ministero dell'Istruzione, dell'Università e della Ricerca, Italy

**Justin N. Baker** 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

**Stefano Bellon** Physician, Co-Founder and President of Scientific Committee of the “City of Hope”, Padua, Italy

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

**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

**Myra Bluebond-Langner** Professor and True Colours Chair in Palliative Care for Children and Young People, Louis Dumas Centre for Children`s Palliative Care, UCL-Institute for Child Health, London England and Board of Governors Professor Anthropology, Rutgers University, Camden NJ, UK

**Marie-Charlotte Bouésseau** MD, Advisor, Service Delivery and Safety (SDS) World Health Organization Geneva, Switzerland

**Mark Brown** MDiv, BCC, Chaplain at St. Jude Children`s Hospital in Memphis, TN. Immediate Past President of the Pediatric Chaplains Network, USA

**Kris Catrine** MD, FAAP, Program Director Hospice & Palliative Medicine, Fellowship Site Director, Department of Pain Medicine, Palliative Care & Integrative Medicine, Children`s Hospitals and Clinics of Minnesota, University of Minnesota, Minneapolis, USA

**Nancy F. Cincotta** LCSW, MSW, MPhil, Psychosocial Director, Camp Sunshine, Casco, Maine, Faculty Icahn School of Medicine, Mount Sinai Medical Center, NY, Zelda Foster Mentor, NYU, Psychosocial Consultant, NYC, USA

**Stephen R. Connor** PhD, Executive Director, Worldwide Hospice Palliative Care Alliance (WHPCA), UK/USA

**Finella Craig** Consultant, Great Ormond Street Hospital Oncology Outreach and Palliative Care Team, Louis Dumas Centre, London, UK

**Lucia De Zen** PhD, Home Assistance and Paediatric Palliative Care Service, AAS5 West Friuli, Pordenone, Italy

**Carlo Dionisi Vici** Division of Metabolic Diseases, Department of Pediatric Medicine, Bambino Gesù Hospital, Rome, Italy

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

**Graziella Fava Vizziello** Full Professor of Psychopathology Padua University, Pastpresident of AEPEA (Ass. Europ.Enfant.Ado), President AEPEAsi, Italy

**Stefan J. Friedrichsdorf** Medical Director, Department of Pain Medicine, Palliative Care & Integrative Medicine, Children`s Hospitals and Clinics of Minnesota, Department of Paediatrics, University of Minnesota, Minneapolis, USA

**Akira Fukabori** Co-Director, ANA AVATAR Program, ANA Holdings Inc., Tokyo, Japan

**Daniel Garros** Paediatric Intensivist, Stollery Children's Hospital Edmonton and Clinical Professor of Pediatrics, Department of Paediatrics, John Dossetor Health Ethics Centre, University of Alberta, Canada

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

**Richard Goldstein** MD, Director, Robert's Program on Sudden Unexpected Death in Pediatrics and Palliative Care Physician, Division of General Pediatrics, Boston Children's Hospital; Assistant Professor of Pediatrics, Harvard Medical School, Boston, Massachusetts, USA

**Satbir Singh Jassal** MBE, Medical Director Rainbows Hospice for Children and Young People, Loughborough, Leicestershire, UK

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

**Kevin Kajitani** Co-Director, ANA AVATAR Program, ANA Holdings Inc., Tokyo, Japan

**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

**Ana Lacerda** Paediatric Oncologist, Department of Child and Adolescent Oncology Portuguese Oncology Institute of Lisbon, Portugal

**Omar Leone** Head of Maruzza Regional Associations, Pordenone, Italy

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

**Michelle Adrienne Meiring** Paediatric Palliative Care Consultant - Paedspal, Cape Town, Chairperson PatchSA and Senior lecturer in Paediatric Palliative Medicine at the University of Cape Town, South Africa

**Sokhna Ndiaye** Psychologist, Pediatric Oncology Department, University Hospital A. Le Dantec, Dakar, Senegal

**Marcello Orzalesi** Director of Training School in PPC – Maruzza Foundation, Italy

**Danai Papadatou** Professor of Clinical Psychology, Nursing Dept, National and Kapodistrian University of Athens, President of "Merimna", Board of Directors, Association for the Care of Children and Families Facing Illness and Death, Greece

**Elvira Parravicini** Associate Professor of Pediatrics, Director, Perinatal/Neonatal Palliative Care Program, Department of Pediatrics, Division of Neonatology at CUMC, New York, USA

**Federico Pellegatta** Pediatric Clinic, University of Milano-Bicocca, MBBM Foundation, Monza Hospital, Italy

**Jennifer Snaman** Psychosocial Oncology & Palliative Care and Pediatric Oncology, Dana-Farber Cancer Institute, Boston, Massachusetts, USA

**Stefano Spigler** Postdoc Researcher in Machine Learning, Ecole Polytechnique Fédérale de Lausanne, Lausanne, Switzerland

**Holly Spraker-Perlman** Assistant Member, St. Jude Children's Research Hospital, Quality of Life & Palliative Care, Memphis, Tennessee, USA

**David Steinhorn** MD, PANDA Palliative Care Program, Division of Critical Care Medicine, Children's National Medical Center, Professor of Pediatrics, George Washington School of Medicine, Washington DC, USA

**Lori Wiener** PhD, Co-Director, Behavioral Health Core Head, Psychosocial Support and Research Program, Pediatric Oncology Branch, Center for Cancer Research, NIH, USA

**Joanne Wolfe** Director, Pediatric Palliative Care, Boston Children's Hospital, Division Chief, Pediatric Palliative Care Service, Department of Psychosocial Oncology and Palliative Care, Dana-Farber Cancer Institute Boston, Massachusetts, USA

### **Abstract book**

The abstract book is available for download at the following link:  
[www.childrenpalliativecarecongress.org/congress-2018/abstract/](http://www.childrenpalliativecarecongress.org/congress-2018/abstract/)

### **Certificates of participation**

The delegates' certificates of participation will be available for download after the Congress following the completion of the feedback/evaluation questionnaire.  
You will receive an email with the link.



TOGETHER, FOR A BETTER TODAY.

**CONGRESS VENUE**

Auditorium Antonianum  
Viale Manzoni 1 - 00185 Rome  
[www.auditoriumantonianum.it](http://www.auditoriumantonianum.it)

**CONGRESS**

**SECRETARIAT AND ORGANIZERS**

Fondazione Maruzza  
Lefebvre D'Ovidio Onlus  
Via del Nuoto 11 - 00135 Rome  
Tel: (+39) 06 3290609  
Fax: (+39) 06 36292743  
[icppc@maruzza.org](mailto:icppc@maruzza.org)  
[www.fondazionemaruzza.org](http://www.fondazionemaruzza.org)