



TOGETHER, FOR A BETTER TODAY.

3rd CONGRESS

ON PAEDIATRIC PALLIATIVE CARE
A GLOBAL GATHERING



Rome • 16th - 19th November 2016
Auditorium Antonianum

maruzza.org/congress-2016/

WITH ENDORSEMENT OF

The Italian Ministry of Health

With the patronage of the Italian Committee for UNICEF

Istituto Superiore di Sanità



PARTNERS



The aim of the 3rd Congress on Paediatric Palliative Care: a Global Gathering is to engage professionals working with seriously ill children worldwide by providing an international forum for interdisciplinary knowledge sharing where experiences, current topics and new perspectives on key issues regarding palliative care for children and their families can be debated, compared and discussed.

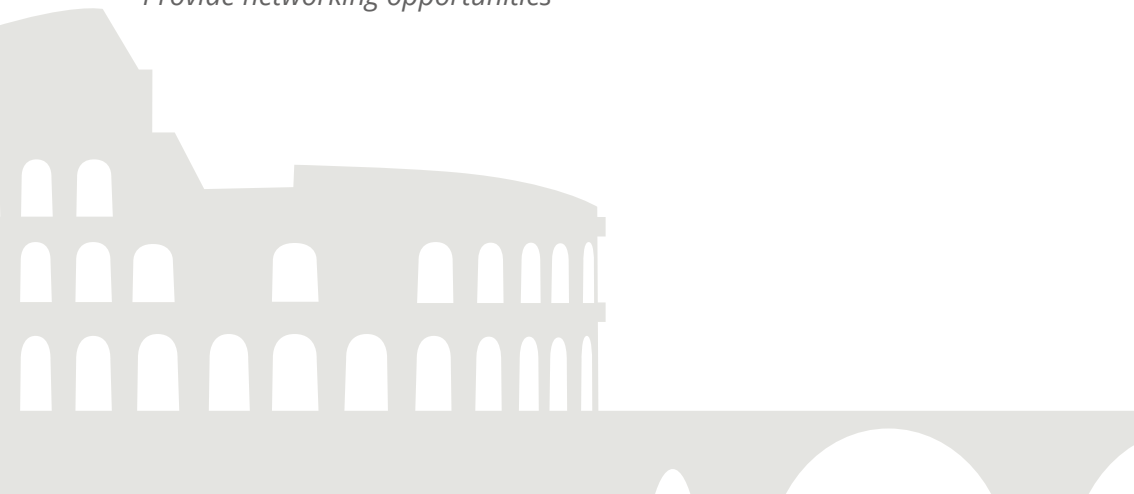
The congress programme foresees numerous opportunities for professional development and networking: from pre-congress courses, keynote lectures, plenary symposia, focus sessions and abstract-driven presentations.

Theme:

'Quality Through Integrated Care'

Objectives:

- *Advance paediatric palliative sciences*
- *Enhance professional development*
- *Provide networking opportunities*



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.

Promoter/Coordinator

Maruzza Lefebvre D'Ovidio Foundation

Scientific Committee

Franca Benini - Chair (*Italy*)

Ann Goldman - Honorary President (*UK*)

Ross Drake - Co-chair (*New Zealand*)

Margaret Al-Sayer (*Kuwait*)

Myra Bluebond-Langner (*USA/UK*)

Lizzie Chambers (*UK*)

Julia Downing (*Uganda/UK*)

Rut Kiman (*Argentina*)

Malin Lövgren (*Sweden*)

Danai Papadatou (*Greece*)

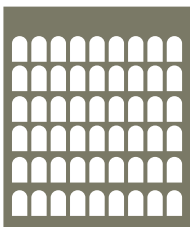
Joanne Wolfe (*USA*)

Boris Zernikow (*Germany*)



Timetable

November 2016
16th Wednesday
17th Thursday
18th Friday
19th Saturday



WEDNESDAY 16TH NOVEMBER

	Auditorium (Basement level)	Room S. Francesco (Ground Floor)	Room S. Bernardino da Siena (Ground Floor)	Room A (1 st Floor)	Room Jacopone da Todi (Ground Floor)
08.30 12.00		Pre-congress workshop <i>Treating distressing symptoms in children with serious illnesses</i>	Pre-congress workshop <i>Setting up research in children's palliative care</i>	Pre-congress workshop <i>Decision making about care and treatment</i>	Pre-congress workshop <i>End-of-life care: a taste of the EPEC-paediatrics curriculum</i>
13.00 16.30		Pre-congress workshop <i>Treating distressing symptoms in children with serious illnesses</i>	Pre-congress workshop <i>Setting up research in children's palliative care</i>	Pre-congress workshop <i>Decision making about care and treatment</i>	Pre-congress workshop <i>End-of-life care: a taste of the EPEC-paediatrics curriculum</i>
18.00 19.30	Opening ceremony				
19.30 21.00	Icebreaker – Welcome cocktail and buffet				

THURSDAY 17TH NOVEMBER

	Auditorium (Basement level)	Room S. Francesco (Ground Floor)	Room S. Bernardino da Siena (Ground Floor)	Room A (1 st Floor)	Room Jacopone da Todi (Ground Floor)
08.30 09.00	Gaining Insight				
09.00 13.00	Plenary Session <i>Symptom Management: The Benefits of Integrated Care</i>				
11.00 12.00	Working session I	Working session II		Working session III	
13.30 14.30	Working session IV	Working session V		Working session VI	
14.30 15.30	Poster Visit				
15.30 15.45	No Pain for Children Award 1st Prize				
15.45 17.15	Plenary Session <i>Managing Distress Across Childhood</i>				
17.30 18.30		Networking Session <i>Home-based/Community-based PPC</i>	Networking Session <i>Antenatal care planning and pathways</i>	Networking Session <i>Guidance for parents (or other adult family members) about the psychological functioning of their children - both the child who is ill and the healthy siblings</i>	Networking Session <i>Children with reverse sleep cycle: discuss options to get back to a normal cycle</i>

FRIDAY 18TH NOVEMBER

	Auditorium (Basement level)	Room S. Francesco (Ground Floor)	Room S. Bernardino da Siena (Ground Floor)	Room A (1 st Floor)
08.30 09.00	Gaining Insight			
09.00 10.30	Plenary Session <i>Ensuring Quality Care</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>Support for the Child, Adolescent & Family</i>			
17.15 18.15		Networking Session <i>How to improve quality of life in the hospital setting?</i>	Networking Session <i>Place and role of spiritual care in the family. Respect for culture and religious practices when you work with family</i>	Networking Session <i>Living in the shade of death – how to ease the burden of the seriously ill child?</i>

SATURDAY 19TH NOVEMBER


	Auditorium (Basement level)
08.30 09.00	Gaining Insight
09.00 10.30	Plenary Session <i>Learning From Conflict and Adversity</i>
11.00 12.00	Roundtable discussion <i>Leadership of a CPC Service</i>
12.00 12.30	Closing Ceremony



Programme

16th 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 San Francesco (Ground Floor)

Treating distressing symptoms in children with serious illnesses

Coordinator: *Stefan J. Friedrichsdorf*

Co-presenters: *Wendy Cristhyna Gómez García - Barbara M. Sourkes*

Room A (1st Floor)

Decision making about care and treatment

Coordinator: *Myra Bluebond-Langner*

Co-presenters: *Maggie Comac - Dilini Rajapakse*

Room Jacopone da Todi (Ground Floor)

End-of-life care: a taste of the EPEC-paediatrics curriculum

Coordinator: *Joanne Wolfe*

Co-presenters: *Justin N. Baker - Angela Feraco - Barbara L. Jones - Kathleen Perko*

Room San Bernardino da Siena (Ground Floor)

Setting up research in children's palliative care

Coordinator: *Julia Downing*

Co-presenters: *Jayne Galinsky, Liz Grant*

CONGRESS



09.30 - 16.00 Registration



18.00 - 19.30 Auditorium (Basement Level)

Opening Ceremony

Greetings

Keynote Lecture: The Significance of Integrated Care

Joanne Wolfe

Presentation of *No Pain for Children Prizes*

for the Best Young Researchers' Abstracts

Keynote Lecture: "Religions of the World Charter" for Children's Palliative Care

Richard Hain

Presentation of *Vittorio Ventafridda Award*



19.30 - 21.00 Icebreaker - Welcome cocktail and buffet

LEGEND:



MORNING



AFTERNOON



17th Thursday

Reception opens at 08.00



08.30 - 09.00 Auditorium (Basement Level)
Gaining insights: Nourishing the senses
Massimiliano Alajmo, Defendente Mauro Febbrari
Introduced by *Momcilo Jankovic*



09.00 - 10.30 Auditorium (Basement Level)
Plenary session
Symptom Management: The Benefits of Integrated Care
Moderators: *Mercedes Bernad , Joanne Wolfe*

- Nausea and Vomiting - *Ren e McCulloch*
- Challenging Pain Syndromes - *Elliot J. Krane*
- Sleep Problems - *Ross Drake*

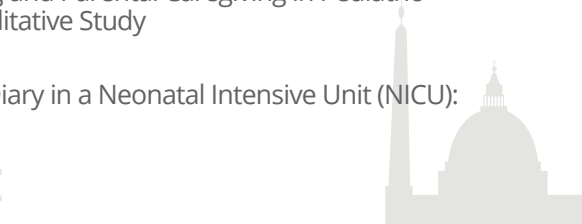
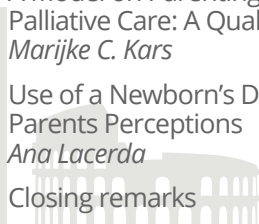
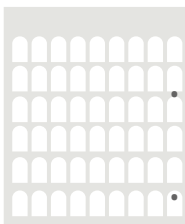


10.30 - 11.00 Coffee break



11.00 - 12.00 Oral presentation session (3 in parallel):
Auditorium (Basement Level)
Working session I: Parents, Siblings and Family
Moderators: *Margaret Al-Sayer, Myra Bluebond-Langner*

- The Emotional Worlds of Parents of Children with Life-limiting Conditions
Bryony Beresford
- Parent Perspectives after Receiving an Early Palliative and End-of-Life Care Communication Intervention
Joan Haase
- A Model on Parenting and Parental Caregiving in Pediatric Palliative Care: A Qualitative Study
Marijke C. Kars
- Use of a Newborn's Diary in a Neonatal Intensive Unit (NICU): Parents Perceptions
Ana Lacerda
- Closing remarks



Room S. Francesco/San Bernardino da Siena (Ground Floor)
Working Session II: Neurological Problems

Moderators: *Rut Kiman, Elliot J. Krane*

- A Pain Observed: A Phenomenological Study of Maltese Caregivers of Children with Severe to Profound Developmental Disability
Hermione Andrejevic
- Spinal Muscular Atrophy Type 1: Needs and Interventions from Diagnosis to Post-Mortem during a Pediatric Palliative Care Program
Chiara Di Pede
- Seizure Management in End-of-Life Care for Children
Nicky Harris
- Spinal Muscle Atrophy: The Spanish Pediatric Palliative Care App
Alvaro Navarro-Mingorance
- Closing remarks

Room A (1st Floor)

Working Session III: Perinatal - Neonatal Problems

Moderators: *Marcello Orzalesi, Chakrapani Vasudevan*

- The Outcome of End-of-Life Care (EOLC) in a Tertiary Neonatal and Paediatric Intensive Care Unit in the UK
Abigail Callender-Iddon
- Development of a Multidisciplinary Regional Perinatal Palliative Care Pathway
Emily Harrop
- How do Neonatal Units Support Siblings Following Loss? A National Survey
Reyhana Henderson
- Decision-making on Withholding Treatment and Facilitating Choices in Neonates with Congenital Ultra-short Small Bowel: Clinical and Ethical Considerations
Michelle Koh
- Closing remarks



12.00 - 13.30 Poster visit and Lunch



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

Auditorium (Basement Level)

Working session IV: Parents, Siblings and Family

Moderators: *Maggie Comac, Ulrika Kreicbergs*

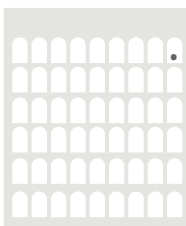
- Communication at Diagnosis and at End-of-Life (EOL) in Complex Congenital Heart Disease (CCHD): Fathers' and Mothers' Perceptions
Francesca Benedetti
- Socioeconomic Needs of Families with a Child with a Life Threatening Disease during the Economic Crisis in Greece
Alexandra Gerardi
- Growing Family Strengths: Parent Views on the Potential Benefits and Acceptability of a Structured Group Programme to Enhance Resilience and Well-being in Parents of Children with Life Limiting Conditions and Complex Health Needs
Sharon McCloskey
- Symptom Prevalence and Parental Distress in Paediatric End-of-Life Care
Karin Zimmermann
- Closing remarks

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

Working session V: Pain Assessment and Control

Moderators: *Eva Bergsträsser, Lucia De Zen*

- The Use of Rapid Onset Fentanyl in Children and Young People for Breakthrough Cancer Pain
Lucy Coombes
- Suitability, Feasibility, Utilisation and Acceptability of Patient Controlled Analgesia in the Community for Children with Life Limiting Conditions
Ellen M. Henderson
- Effectiveness of Innovative Non-pharmacological Therapy with Puppy Humanoid Robot: A Observational Study
Giovanni Poggi
- Identifying and Treating Pain in Children with Advanced Cancer. A Pediatric Palliative Care Perspective
Manuel Rigal Andrés
- Closing remarks



Room A (1st Floor)

Working session VI: Adolescents and Young Adults

Moderators: *Justin N. Baker, Luca Manfredini*

- Palliative Care Practices in Health Teams Supporting Young Adults with Non-malignant, Life-limiting Conditions
Bryony Beresford
- The Use from Cyberspace by Adolescents in Palliative Care - Their Social Networks
Camila Amaral Borghi
- Make IT Happen - A Project Supporting Young People with Life-limiting Illness Transition to Adulthood
Michelle Koh
- Are Adolescent and Young Adult Patients More Symptomatic at End of Life?
Victoria Hwei May Wong
- Closing remarks

 14.30 - 15.30 Poster visit (coffee station available)

 15.30 - 15.45 Auditorium (Basement Level)

No pain for Children Award -1st prize winning abstract

Effectiveness of Paediatric Palliative Homecare in Reducing the Need for Hospital Care

Saba Iordanishvili

 15.45 - 17.15 Auditorium (Basement Level)

Plenary Session

Managing Distress Across Childhood

Moderators: *Myra Bluebond-Langner, Marcello Orzalesi*

- Neonatal - *Chakrapani Vasudevan*
- Young Child - *Barbara M. Sourkes*
- Adolescent/Young Adult - *Justin N. Baker*

 17.15 - 17.30 Room Change

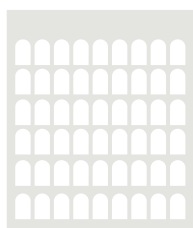
 17.30 – 18.30 Networking/Focus Sessions (4 in parallel)

Room S. Francesco (Ground Floor)
Home-based/Community-based PPC
Coordinator: *Justin N. Baker*

Room San Bernardino da Siena (Ground Floor)
Antenatal care planning and pathways
Coordinator: *Chakrapani Vasudevan*

Room Jacopone da Todi (Ground Floor)
Children with reverse sleep cycle: discuss options to get back to a normal cycle
Coordinator: *Ross Drake*

Room A (1st Floor)
Guidance for parents (or other adult family members) about the psychological functioning of their children - both the child who is ill and the healthy siblings
Coordinator: *Barbara M. Sourkes*



Poster exhibition

17th

Exhib N°	Title	Name
1	Normalization of Symptoms: A Leading Barrier to Symptom Management in Pediatric Advanced Cancer	<i>Veronica Dussel</i>
2	Developing Confidence in Pediatric Palliative Care: Building from the Evidence	<i>Deborah Lafond</i>
3	Open for Business	<i>Lee-anne Pedersen</i>
4	Breath Easy	<i>Lee-anne Pedersen</i>
5	WhatsApp, Doc? Use of Social Media to Facilitate Palliative Care for Children Residing in Remote Locations	<i>Yuriko Nakashima-Paniagua</i>
6	Hospitality: A Beginning of Paediatric Palliative Care for Children Affected by Cancer, in LMICs and in Italy	<i>Elisa Nicoletta Accornero</i>
7	Patient-centered Model of Care: Meeting the Patient´s Evolving Needs with a Transversal Team	<i>Manuel Rigal Andrés</i>
8	Patient-centered Model of Care: Meeting the Patient´s Evolving Needs with a Transversal Team. A Case Study	<i>Manuel Rigal Andrés</i>
9	Integrating Social and Medical Care – The Experience of a Paediatric Oncology Palliative Care Service	<i>Michelle Koh</i>
10	Helping the Helpers: Focus Groups in Pediatric Hematology/Oncology to Explore Factors Contributing to Burnout	<i>Deborah Kramer</i>
11	“The Nasty, Unpleasant Stuff”: Parents’ Experiences of Being Responsible for Carrying out Distressing Healthcare Procedures for their Child	<i>Gemma Spiers</i>
12	“I Guess we Don’t Do it very Often”: Health Care Professionals’ Views, Attitudes and Experiences Discussing Preferred Place of Death for Children and Young People with Life-limiting and Life-threatening Conditions	<i>Michelle Hills</i>
13	Palliative Care at a Cardiology Intensive Care Unit for Children: Indications and Interventions	<i>Carolina Vieira Campos</i>
14	Value of a Pediatric Palliative Care Team: The Parental Perspective	<i>Lisa Myrthe Verberne</i>
15	How Do French Psychiatrists and Psychologists Stand within Pediatric Palliative Care Team?	<i>Laurine Zerka</i>
16	Nosological Structure of the Patient Population, Receiving Pediatric Palliative Care in Hospital Setting in Russia	<i>Elena Polevichenko</i>
17	Understanding the Factors that Influence Parents as they Plan and Manage their Child’s End of Life Care	<i>Karen Brombley</i>

18	Pilot Study of a Paediatric Ambulance Care Directive	<i>Irene OBrien</i>
19	The Development of a Physician-led Pediatric Palliative Care Service in a Children ´s Hospital in Republic of Korea	<i>Min Sun Kim</i>
20	Pediatric Palliative Care: Evolution of a Pediatric Intensive Care-based Service in a Referral Cancer Center	<i>Regina Okhuysen-Cawley</i>
21	Changing Referral Patterns to an Evolving Children ´s Palliative Care Service in Ireland	<i>Elizabeth O'Donoghue</i>
22	A Review of the Impact of Caring for a Child with a Life Limiting Condition on Both Mothers and Nurses	<i>Cathy Keighery</i>
23	What to Study Next: Utilizing the Delphi Method to Prioritise Research Topics in Paediatric Palliative Care in Ireland	<i>Claire Quinn</i>
24	Checking in! The Development of the PaedPAL TASK Tool for Appraising Nursing Skill and Knowledge in Children's Palliative Care Nursing	<i>Claire Quinn</i>
25	Hidden Part of the Iceberg: Making Paediatric Palliative Care in Belgium Visible	<i>Marie Friedel</i>
26	Access to Palliative Care for Children in Ukraine – Challenges and Views	<i>Andriy Penkov</i>
27	Hospital: The Place where Patients with Muscular Dystrophy Meet Palliative Care Services	<i>Mirela Silvia Iancu</i>
28	Family Survey of 3 PPC Services in New South Wales, Australia	<i>Sharon Ryan</i>
29	"Living Despite the Pain" – The Perspective from Children and Adolescents in Palliative Care	<i>Camila Amaral Borghi</i>
30	Submission of Abstract for Consideration to Be Presented at the 3rd Congress on Paediatric Palliative Care in Rome, 16th-19th November 2016 Audit of Emergency Care Plan (ECP) Completion in a Cohort of Children Known to a UK Paediatric Hospice Palliative Care Team	<i>Sinead Summers</i>
31	Is Palliative Care Being Used for Children and Adolescents Living with Rheumatic Diseases? A Review	<i>Esther Angelica Luiz Ferreira</i>
32	Non-pharmacological Therapy for the Treatment of Newborn in Pain: An Alternative to Neonatal Palliative Care?	<i>Esther Angelica Luiz Ferreira</i>
33	Evaluation of Treated Patients in the Pediatric Palliative Care Team in Hamburg, Germany	<i>Maite Hartwig</i>
34	Early Introduction of Palliative Care for Children with CNS Tumor	<i>Carlota Moraes</i>
35	End of Life Decision Making in Families Receiving Paediatric Palliative Care at Home: How Much and What Happens?	<i>Hui Ren</i>
36	«Palliative Care Line»: Work of Help-line for Children and Young People in Need of Palliative Care in Ukraine	<i>Kateryna Burlak</i>
37	The Paediatric Palliative Care Team: The Case Manager of Integrated Paediatric Care	<i>Giovanna Visconti</i>



38	A New Danish Regional Outgoing Palliative Care Team for Children Based on Existing Cooperation between Paediatrics and Specialised Palliative Care	<i>Mette Asbjoern Neergaard</i>
39	Advance Care Planning in the Paediatric Population - Development of the 'Thinking Ahead' Framework	<i>Jenny Hynson</i>
40	Development of a Telemedicine Platform for Pediatric Home Care Assistance	<i>Lucia De Zen</i>
41	The Memorial Day	<i>Suzanne Runesson</i>
42	Development Integrated Pediatric Palliative Care (PPC): A Model for a Local Network that Supports Families with a Child in the Palliative Phase at Home	<i>Stephanie Vallianatos</i>
43	A Prospective Study on the Characteristics and Subjects of Pediatric Palliative Care Case Management Provided by a Hospital Based Palliative Care Team	<i>Antoinette Yvonne Narda Schouten-van Meeteren</i>
44	X-linked Adrenoleukodystrophy - A Challenge for a Palliative Approach from Diagnosis	<i>Estera Boeriu</i>
45	Flexibly Evolving a Hospice Model of Care to Fit the Needs of Babies, Children and Young People with Palliative and End of Life Care Needs - Is this Necessary?	<i>Patrick Carragher</i>
46	"Growing up with Ricky at Home" School Action in the Course of Treatment of Serious Pediatric Diseases. A Pilot Project	<i>Marilena Banfi</i>
47	School and Children Affected by Life-limiting or Life-threatening Conditions: The Experience of Veneto	<i>Alessandra De Gregorio</i>
48	A Summer Camp with CCHS Patients and their Families: An Experience to Improve Sense of Safeness and QOL	<i>Alessandra De Gregorio</i>
49	Role of Palliative Care in Children with Epidermolysis Bullosa: A Case Report	<i>Felipe Yu Matsushita</i>
50	Belgian Pediatric Palliative Care: Spreading the Ideas of Pediatric Palliative Care in the Different Fields of Pediatric Medicine	<i>Marleen Renard</i>
51	The Quality of an Integrated Treatment in an Epidermolysis Bullosa Pediatric Case Assumed by the Palliative Care and the Pediatric Home Care	<i>Francesca Fantin</i>
52	The Best of the Best for the Baby in the Womb the Urgent Need of Prenatal Palliative Care in Memory of Giampaolo Magnani Born on 5 th March 2009 Died on 17 th October 2010, at 19 Months	<i>Luisella Magnani</i>
53	Home Psychologist Assistance: A New Model for Children and Families in Pediatric Palliative Care	<i>Monica Minetto</i>
54	Pediatric Palliative Care Knowledge and Attitude: A National Survey to Healthcare Professionals	<i>Ana Lacerda</i>
55	Complicated Grief in Children after Parental Loss: A Longitudinal and Prospective Study	<i>Agnès Suc</i>
56	Through my Pain	<i>Martín Mindeguía</i>
57	Care Needs and Referral Patterns of Adolescent and Young Adult Cancer Patients Referred to a Palliative Medicine Service	<i>Janice Jie Er Soo</i>

18th Friday

Reception opens at 08.00



08.30 - 09.00 Auditorium (Basement Level)
Gaining insights: Children's Palliative Care Delivery
Across The Spectrum of Available Resources
Joan Marston



09.00 - 10.30 Auditorium (Basement Level)
Plenary session
Ensuring Quality Care
Moderators: *Caterina Agosto, Margaret Al-Sayer*

- Does Quality Care Ensure Quality of Life? - *Eva Bergsträsser*
- Standards to Ensure Quality Care - *Mercedes Bernadá*
- Outcome Measures to Improve Quality Care
Maria Laura Chiozza

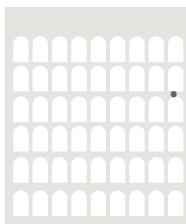


10.30 - 11.00 Coffee break



11.00 - 12.00 Oral presentation session (3 in parallel):
Auditorium (Basement Level)
Working session VII: Education and Training
Moderators: *Stefan J. Friedrichsdorf, Dilini Rajapakse*

- Improving the Nation-wide Outcomes for Children and Families Supported by Paediatric Palliative Care: Phase 1 Learning Needs and Capability, a National Quality of Care Collaborative
Angela Delaney
- "It Changed my View of Medicine" - Implementing a Multidisciplinary Undergraduate Course on Pediatric Palliative Care for Medical Students
Ana Lacerda
- Evaluating the Impact of Ireland's Only Nodule on Children's Palliative Care within an Irish Postgraduate Diploma in Palliative Care
Claire Quinn



- My Neighborhood: An Innovative Education Tool to Optimize the Opportunity for Palliative Care Patients to Stay at Home
Marsha Smith
- Closing remarks

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

Working session VIII: Epidemiology and Surveys

Moderators: *Delia Birtar, Daniel Garros*

- Children in Scotland Requiring Palliative Care: Identifying Numbers and Needs (The ChiSP Study)
Lorna Fraser
- Needs Assessment in Pediatric Palliative Care amongst Nurses and Doctors in the Netherlands
Erna Michiels
- Introducing Multi Disciplinary Reflective Practice Groups into Paediatric Palliative Care Services: An evaluation
Victoria Montgomery
- Recuppera, a Palliative Care Patient Registry: Results from a Pilot Study in Three Argentinean Public Hospitals
Luciano Gabriel Uzal
- Closing remarks

Room A (1st Floor)

Working session IX: Grief and Bereavement

Moderators: *Angela Feraco, Danaï Papadatou*

- Defining Good Death and Dying Well - What Does the Literature Say
Chris Barton
- Healing the Wounds: Setting up a Grief Centre
Ivan Gomez Garcia
- The Challenges and Ethics of Inviting Bereaved Parents to Participate in Research
Fiona McElligott
- Availability of Debriefing Sessions to Nursing Staff Following their Provision of Paediatric Palliative Care in an NHS Trust
Danielle Lewis
- Closing remarks



12.00 - 13.30 Poster visit and Lunch



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

Auditorium (Basement Level)

Working session X: Education and Training

Moderators: *Caterina Agosto, Ann Goldman*

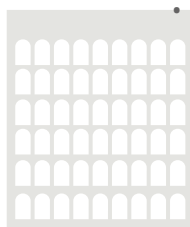
- Ensuring the Quality of Life of Children with Incurable Diseases: Education for Health Care Providers in Ukraine
Lyudmyla Andriyishyn
- Training Pediatric Oncology Providers in Palliative Care Communication: Communication Plan, Early through End-of-Life, version 2 (COMPLETE II)
Joan Haase
- Integrated Learning Supports Integrated High Quality Care: A Regional Model of Neonatal Training and Education for Healthcare Professionals
Alexandra Mancini
- Introducing the Trieste Charter to the Russian Audience
Karina Vartanova
- Closing remarks

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

Working session XI: Epidemiology and Surveys

Moderators: *Lizzie Chambers, Momcilo Jankovic*

- A Retrospective Review of the Timing, Duration and Characteristics of Children Accessing Paediatric Palliative Care in Kuwait
Saima Ali
- Outcomes for Children with Life-limiting Conditions in and after Paediatric Intensive Care Units: A National Data Linkage Study
Lorna Fraser
- The Need of Pediatric End-of-Life Care in the Czech Republic
Lucie Hrdličková
- Using Internet Search-query Analysis to Evaluate Public Awareness of Pediatric Palliative Care
Laura Whitla
- Closing remarks



Room A (1st Floor)**Working session XII: Home vs. Hospital CPC**Moderators: *Maria Laura Chiozza, Manuel Rigal Andrés*

- Place of Death: Report of Patients Receiving Paediatric Palliative Care in Kuwait
Manjiri Dighe
- Children's Palliative Home Care Programme Prevents and Reduces Unnecessary Hospitalizations
Anda Jansone
- Home or Hospital? How Parents Decide about the Site of the Dying Child's Care and Death
Danai Papadatou
- An Analysis of Trends in Place of Death Following Establishment of a Regional Paediatric Palliative Service and Opening of Children's Hospice in the UK
Kate Renton
- Closing remarks

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

 **15.30 - 17.00** Auditorium (Basement Level)
Plenary session
Support for the Child, Adolescent and Family
Moderators: *Justin N. Baker, Danai Papadatou*

- Support for the Child and Adolescent - *Ulrika Kreicbergs*
- Support for the Siblings - *Barbara L. Jones*
- Support for the Parents and Grandparents - *Anna Gorchakova*

 **17.00 - 17.15** Room Change

 **17.15 - 18.15** Networking/Focus Sessions (3 in parallel)
Room S. Francesco (Ground Floor)**How to improve quality of life in the hospital setting?**Coordinator: *Eva Bergsträsser***Room San Bernardino da Siena (Ground Floor)****Place and role of spiritual care in the family. Respect for culture and religious practices when you work with family**Coordinator: *Anna Gorchakova***Room A (1st Floor)****Living in the shade of death – how to ease the burden of the seriously ill child?**Coordinator: *Ulrika Kreicbergs*

Poster exhibition

<i>Exhib N°</i>	<i>Title</i>	<i>Name</i>
61	Managing Uncertainty in Non-malignant, Life-threatening Conditions: The Experiences of Young Adults and their Parents	<i>Bryony Beresford</i>
62	Provision of Multi-disciplinary End of Life Care for Children and Young Adults with Cancer: A Nationwide Survey	<i>Caroline Porter</i>
63	Nutrition and Hydration at the End of Life in Children Referred to a Tertiary Palliative Care Service: A Case Series Review	<i>Rachel Halpin-Evans</i>
64	Place of Death in Children Discharged from PICU: The Importance of Palliative Care	<i>Lorna Fraser</i>
65	Pediatric Palliative Care in a Multi-religious Society	<i>Alexander Tkachenko</i>
66	Pediatric Deaths Attributable to Complex Chronic Conditions in Republic of Korea, 2005-2014	<i>Min Sun Kim</i>
67	Evaluation and Management of Delirium in Seriously and Terminally-ill Children: A Review of the Literature and Contemporary Best Practices	<i>Regina Okhuysen-Cawley</i>
68	An Individual Care Plan to Stimulate Advanced Care Planning in Palliative Care for Children	<i>Erik A H Loeffen</i>
69	Narrative Medicine and Palliative Care: Proposals from a Peripheral Center	<i>Lucia Calajiore</i>
70	Best Practice of Provider/Parent Interactions when Children Are Seriously Ill	<i>Betty Davies</i>
71	End-of-Life (EOL) in Children with Congenital Heart Disease (CHD) who Died in Hospital: Parental, Physicians' and Psychologists' Perspectives on Suffering and Quality of Life	<i>Francesca Benedetti</i>
72	The Development of an Integrated Respiratory-palliative Care Service Supporting Patients Requiring Long Term Tracheostomy-ventilation	<i>Michelle Koh</i>
73	Complex Symptom Management in Advanced Pelvic Cancer: An Integrated Approach	<i>Michelle Koh</i>
74	Predictors of Quality of Life in Children with Cancer at the End-of-Life	<i>Katharina Maaßen</i>
75	Our Living Wall: Art, Fun, Stories and Feeling Connected	<i>Amanda Mingard</i>
76	Comparing the Prognostic Accuracy of the 'Surprise' Question Across Paediatric Diagnostic Categories	<i>Anna-Karenia Anderson</i>
77	Pediatric Pain Management Evaluation in Healthcare Providers	<i>Aurora Madrid Rodriguez</i>


78	Analysis of Out-of-Ours Needs in Patients under Direct Care by a Palliative Pediatric Care Unit. An On-call 24/7 Service	<i>Manuel Rigal Andrés</i>
79	Improving Nation-wide Outcomes for Children and Families Supported by Paediatric Palliative Care. A National Quality of Care Collaborative	<i>Lee-anne Pedersen</i>
80	Complementary and Alternative Medicine Usage: A Source of Hope for Asian Families with Children in Palliative Care	<i>Issarang Nuchprayoon</i>
81	Preventing Acute Hospital Admissions through Specialist Palliative Care Intervention	<i>Claire Wastakaran</i>
82	A Descriptive Narrative of the Journey to Establish a Fully Comprehensive Paediatric Palliative Care Service	<i>Rasha Al-Hamad</i>
83	Hospital-based Pediatric Palliative Care Programs – A National Survey	<i>Ana Lacerda</i>
84	Using the “Surprise Question”: Who Could Benefit from a Palliative Care Approach in a Secondary Hospital Paediatric Ward?	<i>Ana Cardoso</i>
85	Mind-body Approaches Can Facilitate Parental End-of-Life Decision Making and Life Closure Activities	<i>Deborah Lafond</i>
86	Parental Coping in the Context of Having a Child who is Facing Death: A theoretical Framework	<i>Anne-Sophie Darlington</i>
87	Ensuring their Voice is Heard: Recruitment Challenges in Children’s Palliative Care Research	<i>Claire Quinn</i>
88	Eleonora’s Dream: A Project for Normal Life	<i>Chiara Di Pede</i>
89	A Small Palliative Care Team for Children in Japan	<i>Myoung-Ja Park</i>
90	Developing a Resilient Workforce	<i>Arlene Honeyman</i>
91	Survey on Palliative Care to Primary Care Pediatricians	<i>Aurora Madrid Rodriguez</i>
92	What Is the Correct Dose?	<i>Silvia Spolverato</i>
93	Fighting the Threat of Multidrug-resistant Strains: Hygiene Guidelines on a Paediatric Palliative Care Ward	<i>Boris Zernikow</i>
94	The Challenge of Accurate National Data Requires an Organisation’s Strategic Response	<i>Patrick Carragher</i>
95	Evaluation of Advance Symptom Management Plans (ASMPs) in Paediatric Palliative Care	<i>Pat Sartori</i>
96	Development of a System for Pain Monitoring and Evaluation at Home by a Platform of Telemedicine	<i>Lucia De Zen</i>
97	Decision Making for Children with Life-limiting Illnesses: The Different Guises of ‘Convincing’ and ‘Compromising’	<i>Emma Popejoy</i>


98	A Randomized Trial of Yoga for Children Hospitalized with Sickle Cell Vaso-occlusive Crisis	<i>Karen Moody</i>
99	Music Therapy and Paediatric Palliative Care: Translating Research into Clinical Practice to Improve the Effect of Music Therapy on Perceived Pain for Children with Life Limiting Conditions and their Families	<i>Angela Delaney</i>
100	Development and Use of Advance Symptom Management Plans (ASMPs) for Children with Palliative Care Needs	<i>Linda Maynard</i>
101	Home care and Pediatric Palliative Care: Needs Fulfillment for Families Involved in Pediatric Palliative Care Program and Home Assistance in Pordenone – A Cross-sectional Observational Pilot Study	<i>Anna Luchini</i>
102	“What Can We Do Better?” Analyzing Responses from Parents of Children Who Died of Complex Congenital Heart Disease (CCHD) in Pediatric Intensive Care Unit (PICU)	<i>Caterina Agosto</i>
103	Nutrition and Pediatric Palliative Care: Questions and Challenges	<i>Matheus Jordão Danza Silva</i>
104	Sharing the Learning from an Innovative Perinatal Hospice Service in the UK- An Integrative Approach Ensuring Quality Palliative Care from inside the Womb	<i>Emma Bleasdale</i>
105	Evaluation of the Need for a Paediatric Palliative Care Service in the West of Scotland: A Mixed Methods Analysis	<i>Jonathan Downie</i>
106	First Steps on Development of Pediatric PC in Tajikistan	<i>Zarina Kurbonbekova</i>
107	Dressing Material in Children and Adolescents with Epidermolysis Bullosa: Experiences of Families	<i>Almut Hartenstein-Pinter</i>
108	The Importance of Training in the Communication of Bad News to Parents	<i>Esther Angelica Luiz Ferreira</i>
109	Treatment of Cancer Pain in Pediatric Palliative and End-of-Life care: A Reflection	<i>Esther Angelica Luiz Ferreira</i>
110	The Introduction of a Pediatric Palliative Care Service in a Medium-sized City in the Interior of Brazil: A Challenge	<i>Esther Angelica Luiz Ferreira</i>
111	Leigh's Syndrome: Simultaneous Palliative Care to Improve Quality of Life	<i>Giovanna Visconti</i>
112	Use of Methylphenidate in a Pediatric Oncology Patient with Fatigue	<i>Jacqueline Duc</i>
113	Born and Raised in the Hospital - A Clinical Case	<i>Mariana Adrião</i>
114	Where Is the Line: The Art of Companionship	<i>Jiri Kralovec</i>
115	National Art-project “Oscar and the Lady in Pink”: Drawing Attention to Palliative Care for Children in Ukraine	<i>Kseniia Shapoval-Deinega</i>
116	Uncertainty: A Blessing and a Curse in Progressive Childhood Cancer the Illness Stories of Children, Parents and Physicians	<i>Eva De Clercq</i>

19th Saturday

19th


Reception opens at 08.00

 **08.30 - 09.00** Auditorium (Basement Level)
Gaining insights: Music cares about you
Paolo Petrocelli


 **09.00 - 10.30** Auditorium (Basement Level)
Plenary session
Learning from Conflict and Adversity
Moderators: *Stefan J. Friedrichsdorf, Ann Goldman*

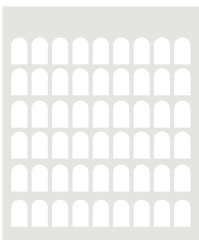
- Conflict Within and Between Teams - *Jan Aldridge*
- The Value of Team Supervision - *Daniel Garros*
- Managing Adversity in Times of Economic Hardship
Danaï Papadatou

 **10.30 - 11.00** Coffee break

 **11.00 - 12.00** Auditorium (Basement Level)
Roundtable discussion: Leadership of a CPC Service
Moderators: *Lizzie Chambers, Joan Marston*

Panel of experts:
Margaret Al-Sayer
Justin N. Baker
Rut Kiman
Mary Ann Muckaden

 **12.00 - 12.30** Auditorium (Basement Level)
Closing Ceremony
Conclusions - *Ross Drake & Ann Goldman*
Thanks & arrivederci! - *Franca Benini*



SPEAKERS AND MODERATORS

Caterina Agosto Physician, Paediatric Palliative Care and Pain Service, Department of Women's and Children's Health, University of Padua, Italy

Margaret Al-Sayer Managing Director of Bayt Abdullah Children's Hospice in Kuwait City, Kuwait

Massimiliano Alajmo Chef, Padua, Italy

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

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

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

Eva Bergsträsser Consultant in Paediatric Oncology and Palliative Care, University/Children's Hospital – Eleonore Foundation Europe, Zurich, Switzerland

Mercedes Bernadá Associate Professor of Paediatrics at Faculty of Medicine University of the Republic, Uruguay

Delia Birtar Paediatric Oncologist, Paediatric Programmes Coordinator, Hospice Casa Sperantei, Brasov, Rumania

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

Lizzie Chambers Deputy Chief Executive, Together for Short Lives Bristol, UK

Maria Laura Chiozza Director Of Operational Project And Clinical Research Unit at Padua Hospital, Italy

Maggie Comac Clinical Nurse Specialist, Great Ormond Street Hospital Oncology Outreach and Palliative Care Team, Louis Dundas Centre, London, UK

Lucia De Zen Paediatrician, In-Home Paediatric Palliative Care and Pain Management Service, Paediatric SOC, Western Friuli Regional Healthcare Agency, Pordenone, Italy

Julia Downing Honorary Professor at Makerere University, Kampala, Vice Chair of the Scientific Committee for ICPCN, Honorary Research Fellow, Department of Palliative Care, Policy and Rehabilitation, King's College London, UK

Ross Drake Clinical Director PPC and Complex Pain Services Starship Children's Hospital and Starship Children's Hospital, Auckland, New Zealand

Defendente Mauro Febrari Endocrinologist, Bergamo, Italy

Angela Feraco Paediatric Haematologist-Oncologist, Dana-Farber Cancer Institute and Clinical Fellow in Paediatrics, Boston Children's Hospital, Massachusetts, USA

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



Jayne Galinsky Health Services Researcher for Myeloma UK, formerly worked with the children's charity Dreams Come True and Richard House Children's Hospice in London, UK

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

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

Wendy Cristhyna Gómez García Paediatric Haematologist - Oncologist, Clinic Coordinator, LMA and Palliative Care, Dr Robert Reid Cabral Children's Hospital, Collaborator for International Outreach Program, St. Jude Children's Research Hospital, Haiti & Dominican Republic

Anna Gorchakova Director of the Belarusian Children's Hospice, Minsk, Belarus

Liz Grant Director of the Global Health Academy and Assistant Principal for Global Health in Edinburgh and Senior Lecturer in Global Health and Development, Usher Institute, University of Edinburgh, Scotland, UK

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Ulrika Kreicbergs Ersta Sköndal University College/Karolinska Institutet, Stockholm, Sweden

Luca Manfredini Paediatric Haematologist-Oncologist – Paediatric Palliative Care – Chronic Pain Service, Gaslini Children's Hospital, Genoa, Italy

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Mary Ann Muckaden Head of Palliative Department, Tata Memorial Hospital, Mumbai, India

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Danai Papadatou Professor of Clinical Psychology, Faculty of Nursing, University of Athens, Greece

Kathleen Perko Program Director Bridges Palliative Care Doernbecher Children's Hospital, Portland, California, USA

Paolo Petrocelli Founder & President, EMMA for Peace (Euro-Mediterranean Music Academy), Italy

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Manuel Rigal Andrés Paediatrician, Paediatric Palliative Care Team, Hospital Niño Jesus in Madrid, Spain

Barbara M. Sourkes Professor of Paediatrics (Critical Care), Psychiatry and Behavioural Sciences, Lucile Salter Packard Children's Hospital, Stanford University, California, USA

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



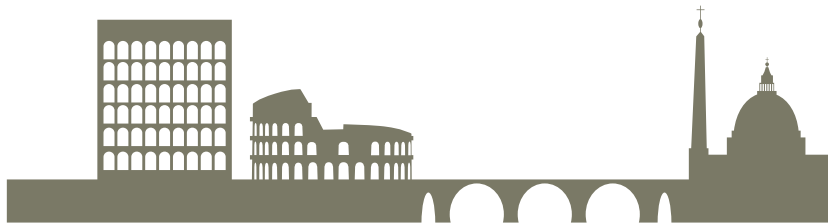
Abstract book

The abstract book is available for download at the following link:
maruzza.org/congress-2016/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.



3rd CONGRESS ON PAEDIATRIC PALLIATIVE CARE - A GLOBAL GATHERING
Rome, 16th - 19th November 2016

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