

4th Maruzza Congress on Paediatric Palliative Care – A Global Gathering Rome, 24th- 27th October 2018 Congress report

The Maruzza Congress on Paediatric Palliative Care - Background

The Maruzza Congress on Paediatric Palliative Care, launched in 2012, is a biennial meeting devised and organised by the Maruzza Foundation, a family run non profit-organization based in Italy that has operated since 1994 at a National and international level in the palliative care sector. Sectors that, as technical and medical advancements improve and prolong the survival of babies, children and adolescents with serious and incurable illness, is in continuous evolution.

The intention is to engage with professionals working with critically 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, bringing together many of the world's leading authorities on children's palliative care and, drawing an eclectic audience of healthcare professionals from over 40 countries across 5 continents, is considered one of the most important dedicated global meetings of the sector.

The appointment for the Maruzza Congress on Paediatric Palliative Care - a Global Gathering, held in Rome, was renewed for the 4th edition from the 24th to the 27th of October 2018.

The Scientific Committee

An expert team of International children's palliative care specialists, representing a broad scope of disciplines and geographical areas, is united for each congress to develop the scientific programme. The decision process is overseen by the Congress Chair, the forerunner of child-specific palliative care in Italy, Franca Benini, who, for the fourth edition, was assisted by the 2018 congress Co-chair Justin Baker and the Honorary President Ann Goldman. The duties of the scientific committee include: the identification and approval of relevant topics and the identification of appropriate guest speakers, the peer-review of delegate abstracts, and, during the congress, the moderation of plenary and working sessions.

The main theme

The leitmotif designated for the 2018, 4th edition of the Congress was *'Thinking outside the box'*.

The scientific programme

The purpose of the scientific programme, developed by the Scientific Committee, is to transfer experiences and encourage knowledge sharing, to divulge fresh perspectives and innovative solutions, also to foster new synergies across disciplines and geographical regions aimed at improved palliative care delivery to children with serious illness worldwide. To this end, the congress programme provides many opportunities for professional development and networking: pre-congress workshops, keynote lectures, plenary sessions, abstract presentations and focus sessions.

For the 2018 congress programme 19 plenary lectures by international experts covering topics linked to the main theme of *'Thinking outside of the box'* were organised, ranging from global PPC access, integrated treatments, bereavement care, the use of social media, palliative care provision in low resource countries, across-discipline collaboration, perinatal care, training and education, spiritual care and future technologies.



Delegate participation

The target audience of the congress is 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. To foster participation from developing countries and render the congress as accessible as possible to all healthcare workers, 100 places were reserved at a reduced cost for delegates from low-income countries. At the 2108 Congress there were over 400 participants from 40 different nations. These were professionally distributed as follows: 36% doctors, 26% nurses, the remainder included researchers, students, volunteers, psychologists, sociologists, social workers etc. Of these 83% women and 17% men.



Abstract submission

To encourage the introduction of new ideas and/or concepts, new research findings and advances to the field of Paediatric Palliative Care, a large part of the congress programme is abstract-driven. All the submitted abstracts are peer reviewed by 3 members of the scientific committee. Based on the review score, abstracts are designated for oral presentation during the daily 'working sessions' or for the poster exhibition organized during the Congress.

For the 2018 edition, besides the foreseeable abstract submission from the European Regions and the USA, abstracts also were submitted from a vast scope of countries worldwide including: the Korean Republic, Thailand, India, Cameroon, South Africa, Israel, Kuwait, Brazil and Argentina.

- 158 abstracts were submitted for peer review;
- 150 abstracts were accepted for presentation;
- 49 abstracts were designated for oral presentations during the working sessions
- 101 were abstracts assigned for the poster presentation.

The No Pain For Children Awards for Excellence in Paediatric Palliative Care

Since the first edition of the congress in 2012, the No Pain For Children Association has encouraged the work of young researchers by presenting a series of awards to the best abstracts submitted by authors under the age of 35. For the 2018 edition, the 1st prize went to Cho Hee Kim of the Seoul University Paediatric Hospital in the Republic of Korea. The 2nd prize was awarded to Elin Hjorth from Stockholm, Sweden. The 3rd prize went to Marije A. Brouwer from Groningen in the Netherlands and the 4th prize was awarded jointly to Valentina Giardini from Monza, Italy and Kim Beernaert from Gent in Belgium. Furthermore, for the 4th Maruzza Congress, with the aim of creating a communication tool for raised awareness of palliative care for children, the Award was extended to a new category for the best short video (open to all registered delegates). The winning film was submitted by Nino Kiknadze from the 'Children's Hospice Firefly World' in Tbilisi, Georgia.

Ventafridda Award

Created by the Maruzza Foundation in 2007 in honour of the pioneer of palliative care in Italy, Vittorio Ventafridda, this award is presented to those who have demonstrated outstanding initiative and enterprise in the palliative care sector.

In 2018 the prize was presented to Dr Joan Wolfe who is the Director of Pediatric Palliative Care at the Boston Children's Hospital, USA. Amongst her many achievements, she was recently nominated as one of the top 10 influential leaders in the palliative care field in North America. She is considered: *"the voice for children with serious illness and their families. She is a great visionary in developing, implementing, teaching and mentoring."*

Pre-congress workshops

Since the 2nd Maruzza Congress, in response to the need for Knowledge-sharing opportunities, a series of workshops on different themes of significant interest and lead by eminent, International paediatric palliative care experts have been organised to precede the congress.

In 2018, 148 participants attended 4 pre-congress workshops, which ran simultaneously on Wednesday the 24th October 2018 from 8.30 to 16.30:

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

Opening Ceremony

The inaugural ceremony was held in the afternoon of October 24th 2018 and was presided by Silvia Lefebvre D'Ovidio of the Maruzza Foundation. The Congress Chair, Franca Benini, assisted by Ann Goldman, the Congress' Honorary President, and the 2018 Co-Chair, Justin Baker, officially declared the Congress open.



The Opening Ceremony initiated with the intervention of the guest of Honour Her Royal Highness Sheika Jawaher bint Mohammed Bin Sultan Al Qasimi, the International Ambassador for Childhood Cancer of the Union for International

Cancer Control, Founder and Royal Patron of the Friends of Cancer Patients Organisation and wife of the ruler of Sharjah in the United Arab Emirates, who, during her intervention, undertook to promote access to paediatric palliative care in the areas where the above mentioned organizations operate.

The opening ceremony continued with a thought-provoking double-intervention entitled and regarding 'The importance and meaning of Time' an articulate comparison of the scientific and human perception of time moderated by Ross Drake. Subsequently, Joanne Wolfe, who received the Vittorio Ventfridda Award 2018, presented a keynote lecture entitled 'Children's Palliative Care - a Game Changer for Paediatrics?'

This was followed by the launch of the latest World Health Organisation 'Guidelines for Health Care Planners, Implementers and Managers - Integrating Palliative Care and Symptom Relief into Paediatrics' presented by one of the document's main contributors, Joan Marston. The ceremony concluded with the 2018 No Pain for Children Awards and the projection of the winning short-film before the invitation to the icebreaker cocktail and buffet, which completed the evening's proceedings.



Gaining insight sessions

The 'gaining insight' sessions are three 30-minute introductory in the morning before the main plenary session introducing a topic that is linked to PPC but is unusual and thought-provoking. The "Thinking outside the box" theme of this edition of the congress offered particularly stimulating presentations: David Steinhorn spoke about traditional/integrated treatments used in PPC; Federico Pellegatta, gave an engaging interactive talk on new methods of communication through social networks and Matteo Asti proposed an interesting intervention regarding the representation of the end of life care in films and the media.

Plenary Sessions

Over the 2 and a half days of the 2108 congress, 5 plenary sessions, each with 3 specialist lectures by Invited Speakers, leaders in their specific discipline, covering topics linked to the main theme of 'Thinking outside of the box', were programmed.

The range of topics included: global palliative care access, integrated treatments, bereavement care, palliative care provision in low resource countries, future technologies, new drugs, co-operation across disciplines, perinatal care, spiritual care, PPC training and education etc. Particularly appreciated were The Needs of Young Adults in PPC and Model Transitions in PPC and From Denial to 'Palliactive': Practical Steps for Developing a PPC Program. The plenary programme culminated in a roundtable discussion regarding the future of this growing sector, which provided the inspirational and constructive 'take-home message' for those attending the meeting. For the first time in Italy, the discussion, moderated by Justin Baker and



Ann Goldman, saw the presentation of the ANA AVATAR Initiative by two aerospace engineers, Kevin Kajitani & Akira Fukabori, from ANA Holdings Inc. who highlighted the potentiality of this cutting edge technology, developed by the Japanese airlines, in the palliative care sector.

Working Sessions

During the 4th Maruzza Congress, 49 selected abstracts describing innovative research findings and specific case studies were presented orally during 12 working sessions. The elevated number of young researchers presenting valid scientific content was very fulfilling. Of particular interest were the Working Session VIII 'Neonatal and Perinatal Care' and Working Session X 'Ethics and Spirituality'.

Poster Exhibition

The 101 abstracts designated for the poster exhibition were displayed in 2 sessions during the two full days of the congress. The posters originated the majority of the countries represented at the congress and stimulated vigorous interest and discussion during the poster visits.

Networking Sessions

The aim of the afternoon networking/focus group sessions, led by an expert working in the palliative care sector, is to foster interactions and exchanges between delegates from different international cultures and backgrounds by bringing together smaller groups of participants with common interests to explore more challenging topics linked to the themes of the plenary presentations.

These sessions, covering a broad scope of topics and providing a platform for experience/knowledge sharing and valid networking opportunities, received elevated approval in the congress evaluation.

During the 4th Congress 8 (4+4) interactive focus sessions were scheduled 17:30-18:30 on the 25th and 26th of October.

Networking Sessions on the 25th October

- Intractable Symptoms in Children with Severe Impairment of the Central Nervous System: What Defines Success when Elimination of Symptoms is not Possible? – *Julie Hauer*
- Parents' Time and Space when a Sick Twin Child is Surviving – *Graziella Fava Vizziello*
- Preventing or Reducing Needle Pain for Hospitalized Children – *Stefan J. Friedrichsdorf*
- How to assess and manage the distressed non verbal child in PPC – *Satbir Singh Jassal*

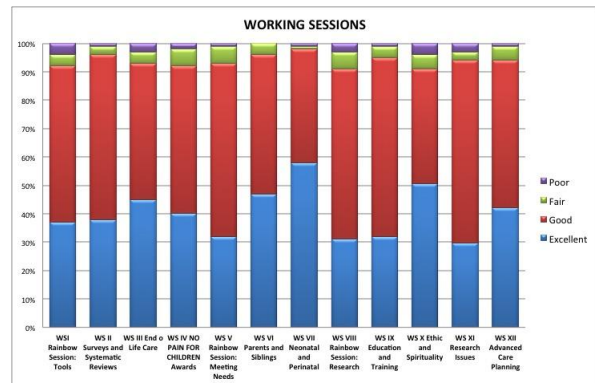
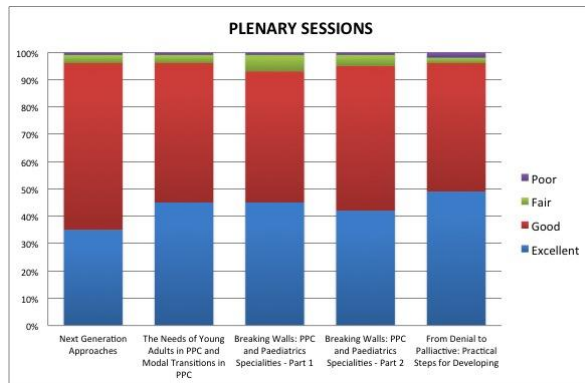
Networking Sessions on the 26th October

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

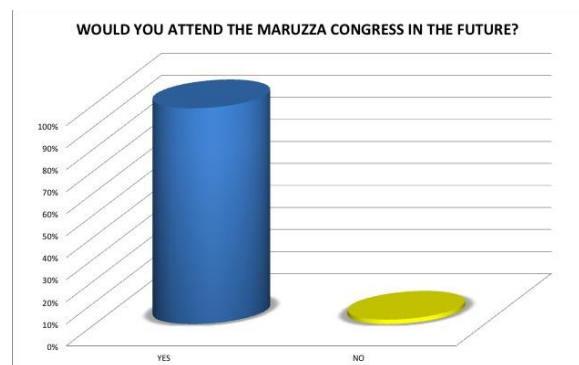
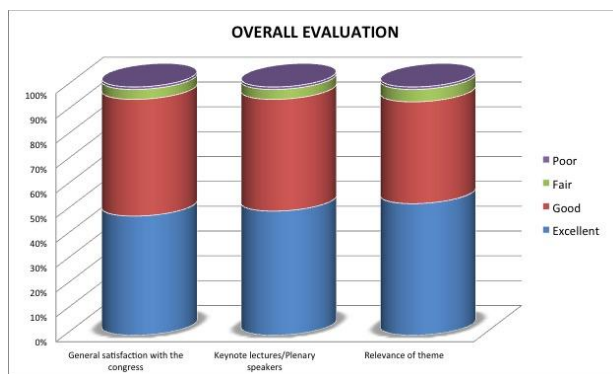
Congress Feedback Evaluation

The congress feedback was gathered through an anonymous online questionnaire. The overall feedback for the congress was extremely positive.

All of the Plenary Sessions received an evaluation of 90% and over of 'Good' or 'Excellent', the same applied to the oral presentation of abstracts in the working sessions and the networking/focus groups.



The general organisational aspects, preceding and during the congress, also received a high percentage of approval and 98% of those who took part in the on-line survey indicated that they would participate in future Maruzza Congresses.



Many of the feedback comments were very positive and encouraging:

- *"The Maruzza Congress is the most important dedicated global meeting for children's palliative care"*
- *"I like the way the Maruzza Foundation dares to propose challenging thought-provoking topics...out of the usual comfort zone...Truly out of the box"*
- *"...Everyone has something to take home from the Maruzza Congress with them: the courage to take risks, creativity, humanity, and care"*
- *"... It has been the honour of my career to be asked to be part of the Maruzza Congress"*

Media coverage

The media coverage for the 4th Maruzza Congress has been somewhat prolific compared to previous congress. A series of articles were published in the Italian press directly regarding the Maruzza Congress or paediatric palliative care access and provision (or the lack of it). As a rather taboo subject, it is quite difficult to stimulate press interest in children's palliative care, however, the participation of HRH Sheika Jawaher bint Mohammed Bin Sultan Al Qasimi and the presentation of the Japanese ANA Avavar Initiative and other technological innovations instigated elevated press interest in the Maruzza Congress, resulting in some press coverage in the Middle East, India and Asia.

la Repubblica Salute

Di Rep. Mario Calabresi

Tiratura: 340.745 - Diffusione: 274.372 - Lettori: 216.200 - da essi certificati o autocertificati

L'associazione

Le cure palliative: a casa è "più meglio"

Il Sole a Mezzanotte è la luce di una vita che si spagna. Il riflesso di ciò che siamo stati e il calore di cui abbiamo bisogno. Questo è il significato del logo della Fondazione Maruzza Lefebvre D'Ovidio, che rappresenta l'energia e la vitalità di una donna che, da malata terminale, ha devoluto parte del suo patrimonio per aiutare persone in situazioni simili alla sua. Così la onlus è impegnata nel campo delle cure palliative che puntano al controllo dei sintomi di malattie croniche non curabili ma anche all'assistenza sociale, psicologica e spirituale con lo scopo di prendersi cura della persona nella sua totalità rispettandone qualità della vita, volontà e dignità. Assistenza da offrire in hospice o a domicilio, perché la casa è "più meglio" come disse un piccolo assistito. E proprio bambini, oltre agli anziani, sono i pazienti più sostenuti dalla onlus con iniziative come Parco Sole di Notte, un luogo dove i piccoli possono vivere momenti di divertimento e socialità.

— **giulia alice forzano**

The Gulf Today
Tuesday, December 4, 2018 | 04:59 p.m.
Last updated 8 minutes ago | TGT@Twitter

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Sheikha Jawaher establishes need for palliative care
BY A STAFF REPORTER | October 27, 2018

SHARJAH: Her Highness Sheikha Jawaher Bin Mohammed Al Qasbi, Wife of His Highness the Ruler of Sharjah and founder and Royal Patron of the Friends of Cancer Patients (FOCP) in the UAE, has highlighted the provision of palliative care to sick children facing an incurable disease, addresses an inherent human right; and is not a luxury.

Sheikha Jawaher called for promoting awareness of children's palliative care, lobbying global support for the development of palliative care services and sharing expertise, skills and knowledge between medical professionals and health experts to ensure the best quality of life for children with life-limiting diseases. Her Highness also stressed that without urgent and concerted action to make palliative care available for children, the suffering will continue.

NAZIONE - Carino - GIORNO
Di Rep. Paola Girometta
www.nazione.it | Tiratura: 212.513 - Diffusione: 212.513 - da essi certificati o autocertificati | 05-OTT-2018 | Anno 4 | Foglio 1 / 2 | Impaginazione: S&S

Bimbi inguaribili, vergogna Italia
«Solo il 20% riceve cure palliative»
La denuncia dei pediatri in Parlamento: così non si rispetta la legge

IL PAESE SPACCATO
L'obiettivo: un hospice in ogni regione, supportato da una rete di servizi e cure

Quale Prospettiva?
ROMA

INGUARIBILI non significa non curabili. A ribellarsi sono gli esperti della Società Italiana di Pediatria (SIP) membri in Commissione Affari Sociali della Camera insieme ai rappresentanti dell'Associazione Culturale Pediatrici e della Federazione Italiana Medici Pediatrici, nell'aula del Parlamento convocata in materia di accesso alle cure palliative e alla terapia del dolore.

PEDIATRI hanno lanciato un appello affinché l'accesso alle cure palliative vada a coincidere con la qualità della vita dei malati e della loro famiglia, attraverso la creazione di un hospice in ogni regione, supportato da una rete di servizi e cure palliative che offrano cure palliative. Vi è inoltre, una richiesta di porre tra le Regioni che rende necessario - come ha sottolineato il responsabile dell'Unità operativa di oncologia ed ematologia pediatrica del Policlinico San Onofrio di Bologna, Andrea Pession - «garantire una migliore equità distributiva di queste assistenze. Tra gli hospice attivi vi è la Casa del Bambino dell'Ospedale di Padova, la struttura realizzata di fattivamente dall'ospedale Pediatrico

Per assicurare ai bambini malati la giusta assistenza, la Fondazione Maruzza Lefebvre D'Ovidio, punto di riferimento italiano per lo sviluppo della cultura delle cure palliative pediatriche, ha già da anni, finché sono obiettivi, quello di realizzare un hospice in ogni regione d'Italia supportato da una rete di servizi e cure palliative. Un servizio che possa accompagnare nel migliore dei modi bambini e familiari in questo percorso che, nella maggior parte dei casi, dura diversi anni. Se per gli adulti le cure palliative riguardano prevalentemente il fine vita, quest'eventualità riguarda solo il 2-30% per cento dei bambini. E restano 90 per cento più mantenere o creare condizioni di assistenza per anni. I piccoli bisognosi di cure palliative sono, infatti, per la maggior parte malati cronici (75 per cento) e solo nel 25 per cento

Partners

The Maruzza Congress is conceived and devised to be as accessible as possible to healthcare professionals working with seriously ill children worldwide, to be able to achieve this goal the Maruzza Foundation strives to maintain subscription fees as low as possible by containing costs and enlisting the support of corporate partners and funders who believe in our vision.

For their help in supporting the 2018 congress, our sincere thanks go to:
Fondazione Terzo Pilastro and Molteni Pharmaceuticals

Endorsements

The Maruzza congress is endorsed by a series of international organizations linked to PPC delivery that demonstrate their approval of the symposium by kindly permitting the use of their logo on all materials produced for the event and some promoted the congress on their institutional website. This year, we saw an increase of 20% in these endorsements. For their kind concession, we would like to thank:

- African Palliative Care Association
- Asia Pacific Hospice Palliative Care Network (APHN)
- Childhood Cancer International
- Courageous Parents Network
- European Association of Palliative Care
- International Association for Hospice & Palliative Care
- International Children's Palliative Care Network
- Paliativos Sin Fronteras
- Pallium India
- Together for Short Lives
- UNICEF ITALIA
- Associazione Culturale Pediatrici
- Consociazione Nazionale delle Associazioni Infermiere/i
- Famiglie SMA
- Federazione Cure Palliative Onlus
- FIMP - Federazione Italiana Medici Pediatrici
- FONDAZIONE NAZIONALE GIGI GHIROTTI
- IPASVI/FNOPI - Federazione Nazionale Ordini Professioni Infermieristiche
- Ministero della Salute
- Società Italiana di Cure Palliative
- Società Italiana di Neonatologia
- Società Italiana di Pediatria
- UNIAMO FIMR Onlus