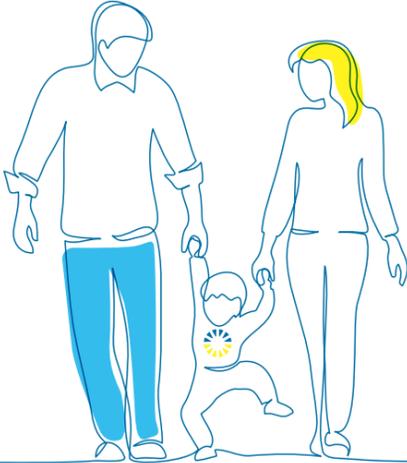


## Our mission

We aspire to a world in which every child living with serious illness can live to the best of their potential: to be free from pain and distressing symptoms, to receive the care they need in a setting of their choice surrounded by loved ones and supported by a caring and inclusive community.

Our goal is that global access to child-specific palliative care, the only appropriate solution to the needs of these children and their families, becomes a reality through the development of integrated, family-centred networks based on an interdisciplinary approach.

*"I want to live my life to its fullest"*  
Andrea, 15yrs



TOGETHER, FOR A BETTER TODAY.

## Promoting the culture of paediatric palliative care in Italy and beyond since 1999



## Our work in Italy

We have the immense pleasure and privilege of working in synergy with an ever-growing team of volunteers who choose to gift their time and competencies to help us to mobilize the Regional Maruzza Associations. The Associations, already active in several regions, work alongside the local healthcare authorities and institutions to support the development of regional paediatric palliative care and pain management networks as specified in national legislation (38/2010).

The Maruzza Associations also provide vital local support services for children with complex care needs and strive to raise public awareness of paediatric palliative care by highlighting the importance of these services for the families of children with serious illness.

For more information about the activities of the Regional Maruzza Associations please contact us at: [info@maruzza.org](mailto:info@maruzza.org)

## Paediatric Palliative Care

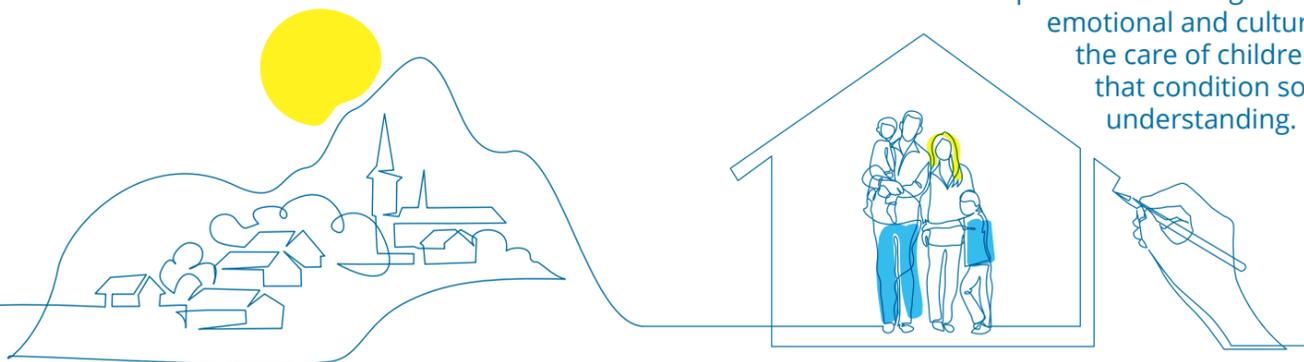
The World Health Organization defines palliative care for children as *"the active total care of the child's body, mind and spirit, and also involves giving support to the family."*

It is provided for a wide range of serious paediatric conditions many of which are rare or without a diagnosis.

Paediatric palliative care is delivered by a multidisciplinary care team comprised of doctors, nurses, physiotherapists, psychologists, social workers and pastors capable of delivering holistic care tailored to the specific needs of each child and family.

It is estimated that there are currently 31 million children worldwide with palliative care needs; only a small percentage have access to dedicated services.

The causes behind this situation are multiple and complex: gaps in organizational and managerial policy, a shortage of specialised training for healthcare staff, emotional and cultural issues related to the care of children with serious illness that condition social acceptance and understanding.



## Who we are

The Maruzza Foundation is an Italian registered non-profit organization established in 1999 by Antonio and Eugenia Lefebvre D'Ovidio to honour the final wishes of their late, beloved daughter Maruzza.

In 2013, the Foundation received *The Gold Medal Of Merit for services to public health* from the President of the Italian Republic.



TOGETHER, FOR A BETTER TODAY.

## Fondazione Maruzza Lefebvre D'Ovidio Onlus

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## Paediatric Palliative care is a basic human right

It is the only appropriate and effective care solution that a truly civil society can provide for babies, children and adolescents with serious illness and their families. To be able to achieve our mission, we need your help.



## You can donate by:

Credit card on our website:

[www.fondazionemaruzza.org](http://www.fondazionemaruzza.org)

Bank transfer

IBAN IT41V0321103200052807821020

5x1000 Italian tax gifting using our Italian tax code: 96399260585



## WHAT WE DO



### Advocacy and awareness

We lobby at an institutional level to stimulate the recognition of palliative care for children as an integral component of primary healthcare. We provide policy-makers and healthcare authorities with the know-how and skills necessary to define and develop efficient services based on established care models.

Together with leading scientific societies and professional associations, we develop projects and initiatives aimed at enhanced awareness and understanding of children's palliative care among healthcare workers.

The general public, families and students are at the centre of our public communication campaigns. We foster engagement with schools and key institutions; by proposing impactful awareness and educational projects which focus on palliative care for babies, children and adolescents, we aim to modify how serious childhood illness is represented and perceived in

the collective imagination and so contribute to shaping a truly open and democratic society that is respectful of every type of diversity.

*"As doctors, we can treat the physical symptoms of an illness but the well-being of children is only fully achieved when they are accepted and integrated into the places where sociality is cultivated. A friend can relieve the suffering that we cannot"*

**F. Benini**  
Head of the  
Veneto Regional PM and CPC Center  
Padua University Hospital

### Training and knowledge sharing

The quality of life of a child with serious illness is severely impacted by the proficiency of the team delivering care, which, in turn, is directly conditioned by the quality of training provided. Only a high level of competence, continuous learning and clinical assessment can prepare professionals working in paediatric palliative care with the broad range of skills and tools necessary to properly address the individual and complex care needs of each child and family and, at the same time, to be able to cope with the demands of working in a highly stressful environment, thus, safeguarding themselves and the performance of the entire team.

With the creation of the Maruzza Lyceum, the Maruzza Foundation has chosen to dedicate a part of its activities to providing cutting-edge training opportunities for healthcare professionals working with seriously ill children and their families.

The Maruzza Lyceum offers face-to-face courses and distance learning that is supplemented by a series of webinars devised to expand on specific topics and available to a wider audience of professional figures linked to the provision of palliative care to children. We also propose training programs organized in collaboration with international experts in paediatric palliative care.

*"The acquisition of a skill is a course of action that cannot be assimilated in a single episode but must be practised and repeated over time to be effective in producing significant and long-term changes in behaviour."*

**M. Orzalesi**  
Neonatologist  
Former President of the  
Italian Pediatrics Society's Bioethics Committee



### Research and divulgation

Recognizing the important role research plays in evidence-based practice, we devise and support research studies and generate publications, on both the epidemiological and clinical level, aimed at the development of efficient and sustainable organizational models for paediatric palliative care provision.

We organise the **Maruzza International Congress on Paediatric Palliative Care** as a networking platform where the global PPC community can share research and exchange experiences. The **Vittorio Ventafridda Award** was created by the Foundation to acknowledge the work of professionals who have excelled in the paediatric palliative care sector.

*"Being a child creates one of the greatest healthcare disparities in all countries; thus, the Maruzza Congress on Paediatric Palliative Care allows us to focus on this underserved, vulnerable population and gives a voice to children with incurable illness and their families."*

**D. Steinhorn**  
Professor of Pediatrics  
George Washington School of Medicine

