

## THE CHARTER PROJECT

The ***Religions of the World Charter for Children's Palliative Care*** originated from a profound reflection of the barriers prevent children patients with life-threatening and life-limiting illnesses from accessing care that is appropriate to their age and disease and that significantly improves their quality-of-life and promotes dignity. It is a universal obligation of all faiths to share the responsibility of caring for those who are suffering or vulnerable, therefore, we believe that the main religions can provide fundamental support for Children's Palliative Care provision through four actions:

- by affirming that all children with serious illness should have access to palliative care;
- by confirming that ameliorating pain is a moral and religious obligation;
- by convincing political leaders and policy makers that Children's Palliative Care should be integrated into every national healthcare system.
- by strengthening the movement for the global availability of Children's Palliative Care, through the involvement and endorsements of all religious leaders.

On the 10th of November 2015, during a historical gathering entitled '*Defining the Essence of Children's Palliative Care*' organized in the Vatican by the Maruzza Foundation at the Pontifical Academy for Life, representatives of the main world religious faiths, leading palliative care experts, preeminent human rights activists, and young patients and their families joined forces in support of Children's Palliative Care. Regardless of their backgrounds, participants upheld a common principle that all children are precious and the concept that children's palliative care offers the best solutions to the needs of children with serious illness and their families. The outcome of the meeting was the *Religions of the World Charter for Children's Palliative Care*, signed by all the participants.

The preparations for The Charter had begun three months previously, following a process overseen by the Project's Scientific Director, Dr. Franca Benini. Having received enthusiastic approval of the project and an offer to host the event from the Pontifical Academy for Life, a list of participants with a broad range of experiences and perspectives of Children's Palliative Care was compiled. For practical reasons, the final panel of contributors was divided into four different working groups: Clinical Voices; Children's Rights; the Patients' and Families' Perspective; Religions and Spirituality. For each group, a Preparatory Document, conceived to stimulate the participants' involvement and input, was devised and 4 Group Leaders appointed to coordinate the circulation and collection of material/feedback in preparation for the face-to-face roundtable discussion in Rome in November.

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In the morning the 10th of December workshop, the working groups met in 4 simultaneous roundtables. The 'Clinical Voices' working group, led by Prof. Joanne Wolfe, brought together some of the most prominent children's palliative care experts from around the world to define the fundamental aspects of effective palliative care delivery for children. The 'Children's Rights' working group, led by Prof. Kathleen Foley, examined the issue of Children's Palliative Care as a human right. The 'Patients' and Families' Perspective' group gave voice to a wide spectrum of issues regarding dignity and respect. The group Leader, Prof. Myra Bluebond-Langner, worked alongside families from different cultures and backgrounds with experience of children's palliative care and two 'Young Ambassadors' for children's palliative care: Sara Pavan (affected by SMA1) and Francesco Ostellari (affected by muscular dystrophy) who, the next day, met with Pope Francesco during the Papal Audience. The 'Religion and Spirituality' working group led by Prof. Richard Hain united voices from the main world faiths: Hinduism, Judaism, Buddhism, Islam, the Catholic, Lutheran, Anglican and Orthodox Churches. The roundtable highlighted how physical, psychological, and spiritual sufferings are intricately linked.

In the afternoon, a plenary session was devoted to the composing and signing of The Charter.