Dear ICPCN Members

The child’s voice: case studies from children’s palliative care

*World Hospice and Palliative Care Day* is a unified day of action to celebrate and support hospice and palliative care around the world. The theme for World Day 2011, which takes place on 8 October, is "Many diseases, many lives, many voices - palliative care for non-communicable conditions". *Voices for Hospices* takes place on World Hospice and Palliative Care Day every two years. The objective of the event is to raise awareness for hospice and palliative care around the world by using the voice.

The ICPCN would like to raise our voice for children with palliative care needs around the world on this day. To do so we are putting together a book on true stories, thoughts, poems and reflections of children and their family members from across the globe receiving palliative care. The focus of this book will not be academic, but will be the *lived experience* of children, siblings and family members from a variety of ages, diseases and nationalities.

If possible, we would like these stories, poems and reflections in the child’s own words but we do understand that it may be that the child is not well enough or able to write something down, in which case it would be great if they can tell you what they would like to say and you write it down – but in doing this please do not lose the child’s voice.

We want to hear their experience of receiving palliative care, how it has helped them, what they have found difficult or challenging, how the team has supported them, what is their favourite aspect of the palliative care service and how they think the service has helped their parents, brothers sisters etc. i.e. anything to do with their experience.

We do not want the book to be just words – pictures speak louder than words – so if the child would like to draw a picture to go in the book that would be great. We would also like to have some photographs in the book and would like at least one if not two or three photos for each case.

If the original language of the child is not English please also supply a direct translation of the text in English. Please also check both the translation and the original text for accuracy, if we cannot speak the language we cannot check it and so are relying on you. The text will appear in both the original language with the English translation alongside.
If you feel that you are working with a child or a family who would be interested in having their story told in this way, please send an email to Sue Boucher at sue@icpcn.co.za for further information on the project. Guidelines for authors can be downloaded from the ICPCN website under the heading World Hospice and Palliative Care Day.

Kind regards

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