



## STEERING GROUP

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## LETTER FROM THE CHAIR

Dear Friends,

There is a wise Chinese proverb: "When you drink the waters, remember the Spring" that came to mind when we opened the 20th World Congress of Children's Hospice International in Cape Town this month, which ICPCN and the Hospice Palliative Care Association of South Africa hosted in partnership with CHI and the Tutu Institute for Pilgrimage and Prayer.

I was on the stage with two of the "Springs" of the children's hospice and palliative care movement – Sister Frances Dominica who founded the first children's hospice, Helen House and then Douglas House, a "respite" for young adults, in Oxford, England, and Ann Armstrong-Daily, the founding CEO of Children's Hospice International, who has stimulated interest and development through the congresses she has arranged in many parts of the world and her advocacy with the US Government.

These two inspirational and energetic ladies shared their vision and influenced so much of what is happening in our field all over the world. We owe them both an enormous debt of gratitude, and I would like to acknowledge and thank them for all they are, all they have done and continue to do for children.

The Congress was a time of refreshment, collaboration and stimulation, and for many a reminder of why we do what we do – it was even described as "life-changing" by some delegates. From the congress and especially as a result of challenges to the present situation by Dr Gerri Frager from Canada and Dr Justin Amery from the UK, came what we have called the "ICPCN Declaration of Cape Town" – a commitment by delegates to work together to share our resources to bridge the gap between the resources for palliative care for children in developed and developing countries.

We plan to use the document to raise the voices of our children on World Hospice and Palliative Care Day, as well as writing this up for publication. This will be used as an advocacy tool and we urge all to strengthen the message by signing the Declaration, and to make use of it in your own countries. We welcome your ideas on ways to implement this effectively.

Dr Liz Gwyther impressed many with her comment that although the developing world does not have the material resources, we are very resource-FUL, and this resourcefulness can be shared with our colleagues in the developed world.

Presentations from 19 countries gave us a taste of the incredible programmes and developments around the world and we are surely getting to the stage of a "Tipping Point" in children's palliative care, where our numbers and the care we provide will in itself help to persuade governments of the importance of providing resources for palliative care for children, as part of their national health policies, and integrated into the undergraduate training of all health care professionals.

The ICPCN steering group is exploring setting up an Honorary Board of Ambassadors for Children's Hospice and Palliative Care, and we welcome suggestions as to who could be invited to become these Ambassadors.

May World Hospice and Palliative Care Day on the 10 October be a day of "Discovering your Voice" for life-limited Children, and may you continue to be resourceful champions for children's palliative care.

Many blessings on your work and good wishes always,

*Joan*

## MESSAGE OF SUPPORT FOR WORLD HOSPICE AND PALLIATIVE CARE DAY FROM SISTER FRANCES DOMINICA, FOUNDER OF THE WORLD'S FIRST CHILDREN'S HOSPICE, HELEN HOUSE

*“Children are our future, but for some children there is no future. They deserve the very best we can give them today – to live life fully until they die.”*

*Sister Frances shares a happy moment with Jordi, who visits Helen & Douglas House for respite care. Photo used with permission, & courtesy of Steve Wheeler*



WORLD  
HOSPICE &  
PALLIATIVE  
CARE DAY

10 OCTOBER 2009



More information and contact details for all these conferences, courses and events can be found on our website. Go to [www.icpcn.org.uk](http://www.icpcn.org.uk)

### October

1	Supporting the most vulnerable disabled young children & their families	Euston Rd, London, UK
10	World Hospice & Palliative Care Day: Discovering your voice	International see: <a href="http://www.worldday.org">www.worldday.org</a>
10	Sibling Group Leader Conference 2009 - Sharing the Learning	City of London School, London, UK
16-17	ELNEC Pediatric Palliative Care Training Program	St Jude Children's Research Hospital, Memphis, USA
18-21	Canadian Hospice Palliative Care Conference: Voyages in Care & Understanding	Winnipeg, Manitoba, Canada
20	Working with Children facing loss and bereavement	St Christopher's Hospice, London, UK
21-23	Spirituality in Pediatrics 2009: Transforming Care for Children	Houston, Texas, USA

### November

4	Tools of the Trade 2009: Children's Hospices UK National Conference for fundraisers and communications staff	Aston Conference Centre, Birmingham, UK
12	Trans-Pennine Palliative Care Research Meeting	Sheffield, UK
17	Just too many practitioners - Peter Limbrick	Cedar Court Hotel, Wakefield, UK
24-26	Help the Hospices Multi-Disciplinary Conference	Harrowgate International Conference Centre, UK
30-3/12	5th SAHARA Conference (Social Aspects of HIV/AIDS Research Alliance)	Gallagher Estate, Midrand, South Africa

### December

4	Inclusion and Exclusion in Palliative and End of Life Care: Who's In, Who's Out?	Kingston upon Hull, UK
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## What's Happening in Australia and New Zealand?

### Report by Dr Ross Drake

An Australia and New Zealand Paediatric Palliative Care Reference Group has been functioning for the past 3 years and fosters a collegial, collaborative approach to progressing PPC in the region. The group have an annual meeting but in 2009 were moving to meet twice a year. This forum has been invaluable to making PPC more visible to the wider PC community and lead to three important and exciting developments for PPC.

- Dr Jenny Hynson, the current chair of the reference group has gained a seat on the executive of Palliative Care Australia (PCA) as an "observer" to represent paediatric issues.
- A PPC Symposium has been attached to the annual PCA meeting from 2009 with this being held in Perth on September 24th. This will also act as one of the reference group's meeting times.
- The effectiveness of the collaboration and collegiality of the group is perhaps best exemplified by the development and trial of a National Standards Assessment Program for PPC by Dr John Collins and his team in Sydney with PCA. This has been so successful that all of the existing services in Australia and New Zealand have enrolled in the program and met on the 27th of July for training in their use and application.

based, care planning tool that covers 6 care plans (diagnosis of a life threatening condition, stable phase, deterioration [or crisis], transition between care settings, end of life and bereavement care and 5 tools (child and family information, assessment tool, pain and symptom management plan, referral template and documenting goals of care and treatment decisions). This is near the end of its evaluation phase although further research may delay its implementation. The intention is to allow for open access.

### New South Wales

A proposal has been submitted to NSW Dept Health for funding to write a plan for a NSW state-wide PPC service. This has been accepted by NSW Health and is in the final stages of sign-off.

The team at Children's Hospital at Westmead (CHW), Sydney run a high quality annual one-day PPC symposium that attracts paediatric healthcare workers from around Australia, New Zealand and further afield. In response to consistent feedback and requests from past symposiums a workshop day was added with great success. The reference group's AGM is held during the symposium.

The CHW team have two project trials in the pipeline that promise to be valuable for the ongoing care of children and their families in the community. An in-home volunteer program for families of children with life-limiting illness and a 6 module PPC education program across the Western Child Health Network (this area covers over 400,000 sq kms). If both projects are successful then there will be strong consideration for rolling them out across NSW.

A Policy, Form and Education Module for "Allow a Natural Death" are to be rolled out and trialled across CHW later in the year and discussions are being held with the NSW Ambulance Service on instructions for Ambulance Officers when called to the home of a child receiving palliative care. A form to be completed by the child's medical officer has been created and is due for a trial.

### Western Australia

The team in Perth have expanded to include a nurse specialist to establish and improve care for children/young people with life-limiting conditions of non malignant origin.

### Queensland

The service in Brisbane has expanded by appointing a specialist PPC paediatrician at Royal Children's Hospital, Brisbane.

### New Zealand

A PPC Special Interest Group (SIG) has been established under the auspices of the Paediatric Society of NZ. This group has a membership of around 40 paediatric and palliative care healthcare workers from all regions of NZ. The SIG is establishing a work stream to advance PPC in NZ with its first focus being to improve the information available to parents and/or caregivers through **Kidshhealth** - [www.kidshhealth.org.nz](http://www.kidshhealth.org.nz), a web-based information site.

### Auckland

The team at Starship Children's Hospital (SCH) support children/young people, their families/whanau with life-limiting illness and the community healthcare workers involved in their care in the greater Auckland region and provide support and advice to paediatric healthcare professionals nationally. The team have been instrumental in developing an "Allow Natural Death" policy and "End of Life Care Plan" for SCH. This is to be introduced in the near future with interest in adopting this already being shown by other paediatric services in New Zealand.

The service continues to be very involved in a number of education initiatives including the running of a Postgraduate paper in PPC.

### Waikato

The Waikato hospice in developing its bed space for adults with palliative needs has made provision for a separate paediatric wing that will consist of 2 beds.

### Challenges and Barriers

The challenges and barriers remain fairly consistent and much of it has to do with PPC being invisible because of the relatively small population involved, the diversity of diagnoses, particularly the large non malignant element involved in PPC, the prognostic uncertainty that goes with the group of children with non malignant life-limiting illness and emotional responses to the dying child; most people just prefer not to think about it.

These factors are all contrary to what people perceive and hear about palliative care, including those in governmental positions. The thinking is very much swayed by the adult hospice movement and the care of terminal adult cancer patients. The broadening of care provision to adults with non malignant conditions (chronic lung and heart disease) is talked about but action is lacking. This has a direct impact on what people understand about paediatric palliative care as most of the children do not have cancer.

In many respects the way children's palliative care services operate should be the model for adult palliative care but declaring that sentiment is often met with glazed eyes.

Finally, palliative care for children/young people often has an uneasy interface with technological imperatives. That is the need for people to escalate medical intervention rather than take, the often harder step, of accepting the inevitable.

**Dr Ross Drake** currently holds the position of Clinical Director of the Paediatric Palliative Care (PPC) and Complex Pain Services at Starship Children's Hospital in Auckland, New Zealand. He is a member of the ANZ Society of Palliative Medicine, NZ Palliative Care Working Group, NZ Pain Society and International Association for the Study of Pain. He chairs the PPC Special Interest Group at the Paediatric Society of NZ and represents the ANZ PPC Reference Group on the International Children's Palliative Care Network Steering Group.

### Other initiatives occurring in Australia and New Zealand

#### Australia

##### Victoria

The Victorian state government has just released a policy on PPC called "Strengthening care for children with life-threatening conditions and their families", [www.health.vic.gov.au/palliativecare/strengthenncare-policy.pdf](http://www.health.vic.gov.au/palliativecare/strengthenncare-policy.pdf). This comes with an implementation committee so that the policy becomes a reality. A similar policy document is due out in the near future on respite care for children with life-limiting illnesses.

The team at Royal Children's Hospital Melbourne have been developing a web-



ICPCN, HPCA (SA) and the Tutu Institute for Prayer & Pilgrimage partnered with Children's Hospice International to bring the first congress on children's hospice and palliative care to the continent of Africa. The congress hosted the launch of the textbook for Children's Palliative Care in Africa, edited by Dr Justin Amery as well as an Awards Luncheon where "heroes" within the field were given well deserved recognition for their valuable contribution to the delivery and development of children's hospice and palliative care services worldwide. Born of a desire by delegates to find ways to narrow the gap between PPC provision in the developed and developing worlds, the "ICPCN Declaration of Cape Town" was conceived, to be used as an international advocacy tool.

## LAUNCH OF THE TEXTBOOK FOR CHILDREN'S PALLIATIVE CARE IN AFRICA

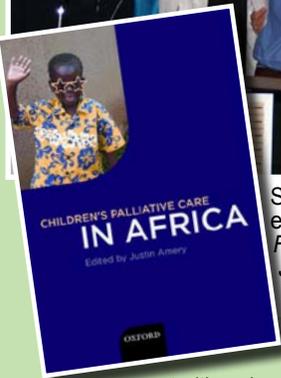


A new textbook for health and social care professionals was launched at the CHI 20th World Congress which will greatly improve and increase access to care for children with life-limiting illnesses in Africa.

Children's Palliative Care in Africa aims to respond to the enormous and growing need for children's palliative care services across the continent: About 90% of all HIV positive children of the world live in sub-Saharan Africa. In South Africa alone, about 100,000 infants contract HIV infection perinatally every year and mortality is 80% in children under 7 years of age. Out of the 166,000 children a year diagnosed with cancer, 84% of these are in the developing world. Despite the demand, provision of children's palliative care services is almost non-existent, with very few health workers trained and confident enough to care for children.

Written by a group of experts with wide experience of caring for people with life-limiting illnesses and edited by Dr. Justin Amery, Children's Palliative Care in Africa addresses key palliative care themes, which are crucial to expanding the provision of children's palliative care.

The book provides practical action and guidance throughout, showing the reader what can be achieved in everyday practice in this demanding environment and has lessons applicable to other resource-poor settings.



Some of the contributing authors were there to share the excitement of the launch with Justin.

*From left to right: Colette Cunningham, Julia Downing, Justin Amery, Joan Marston, Sue Boucher, Michelle Meiring, Nkosazana Ngidi and Carla Horne*

In the foreword for the book, Sir Elton John, Founder of the Elton John AIDS Foundation, says: 'I applaud the publication of this book, which sets out with understanding and tenderness the specific palliative care needs of children. It can support thousands of health workers to better care for children for whom there is no immediate cure; can give them pride and clarity in their role and can make life better for millions of children around the world.'

Olivia Dix, Head of the Palliative Care Initiative (PCI) at The Diana, Princess of Wales Memorial Fund adds: 'We believe that children with life-limiting illnesses should receive the best possible care and treatment and not suffer unnecessary pain and symptoms. In resource-poor countries, the care and treatment of children with HIV/AIDS and other life-limiting illnesses has lagged behind that of adults and palliative care has been no exception. So a priority for the PCI is the needs of children. We are delighted that this vital book is now available to help health professionals address these needs.'

As part of its focus on children, PCI, in partnership with experts in providing palliative care for children, is developing centres of training and clinical excellence in children's palliative care in three African countries. In addition, PCI is commissioning extensive training resources. Through this work, it is hoped that the lives of thousands of children suffering from life-limiting illnesses will be dramatically improved.

**The textbook is available to download absolutely free from the ICPCN website. Go to: [www.icpcn.org.uk](http://www.icpcn.org.uk)**

Hard copies are available to purchase from Hospice Palliative Care Association of South Africa: [www.hospicepalliativecaresa.co.za](http://www.hospicepalliativecaresa.co.za) or directly through Oxford University Press: <http://ukcatalogue.oup.com/>

Children's Palliative Care in Africa is published by Oxford University Press and funded by The Diana, Princess of Wales Memorial Fund, represented at the launch by Laura Ross Gakava.

## SEEN AT THE CHI CONGRESS.....





## CHILDREN'S HOSPICE INTERNATIONAL ACHIEVEMENT AWARD WINNERS 2009



Three of the award winners pose with Ann Armstrong-Dailey, founder and CEO of Children's Hospice International, at the Awards Luncheon.  
From left to right: **Brother Francis Edwards, Joan Marston, Katrina McNamara-Goodger & Ann Armstrong-Dailey**

On Tuesday, September 15, 2009, Children's Hospice International (CHI) hosted the CHI Achievement Awards luncheon during the CHI 20th World Congress in Cape Town, South Africa. At each World Congress CHI presents these awards to recognize the accomplishments of individuals and organizations within the various specialties of children's hospice and palliative care. The awards are named in honour of renowned individuals who have greatly contributed to past advancements in the field. The 2009 CHI Achievement Awards winners, spanning the globe from England, Scotland, Germany, and South Africa, are as follows:

### ELISABETH KÜBLER-ROSS AWARD FOR OUTSTANDING CONTRIBUTION

The Elisabeth Kübler-Ross Award for Outstanding Contribution was presented to **Katrina McNamara-Goodger, RN** as representative of the ACT Care Pathway Development Team for her vision in commissioning ACT to develop the UK's first Integrated Care Pathway for children's palliative care. The breadth of Ms. McNamara-Goodger's influence throughout her career in program development and advocacy for children in the UK led to her selection.

### ROBERT A. MILCH AWARD FOR PALLIATIVE PAIN AND SYMPTOM MANAGEMENT

The Robert A. Milch Award for Palliative Pain and Symptom Management was presented to **Brother Francis Edwards, RN** in recognition of his incredible efforts to alleviate pain and to establish innovative programs to relieve suffering in children. Brother Francis' concept of managing "Soul Pain" alongside the more traditional pain and symptom management has maximized the child's comfort throughout their hospice and palliative care journey.

### SISTER FRANCES DOMINICA AWARD FOR INNOVATIVE PROGRAM DEVELOPMENT

The Sister Frances Dominica Award for Innovative Program Development was presented to **Professor Dr. Monika Führer** for her outstanding leadership, vision, and humanity as a physician and champion of pediatric palliative care. Dr. Führer created an innovative clinical program, Coordination Centre for Pediatric Palliative Care (CPPC) in 2004. The success of the CPPC led the Bavarian government to adopt a state-wide policy to install six pediatric CPPC teams to be funded by the public health insurance and to provide home based palliative care coverage for all Bavarian children. Unfortunately, Dr Führer's was unable to attend the congress but Sister Frances herself received the award on Dr Führer's behalf.

### MATTIE J.T. STEPANEK CHAMPION AWARD

The Mattie J.T. Stepanek Champion Award recognizes any individual with extraordinary commitment to the philosophy of the Children's Program for All-inclusive Coordinated Care (ChiPACC). This year's award was presented to **Joan Marston, RN** in recognition of her incredible leadership and commitment to the advancement in the children's hospice and palliative care community worldwide. Sr. Marston is a true ambassador for the field of children's hospice and palliative care, providing leadership and support to services throughout the world.

CHI is pleased to be able to recognize the incredible accomplishments of these outstanding individuals with the CHI Achievement Awards. We support their ongoing efforts in furthering our collective mission of providing better care and support for all children with life-threatening conditions and their families worldwide.

## THE ICPCN DECLARATION OF CAPE TOWN 2009

Palliative care for children is a basic human right.

We believe that all children with life-threatening and life-limiting conditions have the right to quality palliative care provided by trained health care practitioners. Holistic, family-centred children's palliative care encompasses individualised assessment, pain and symptom management, psychosocial, spiritual and bereavement support.

As a community of palliative care practitioners we recognise that disparities exist within and between countries and services but collectively we are a rich resource of knowledge, skill and judgement and we commit to share all that we can to achieve this joint vision.

We commit both individually and collectively to identify opportunities for collaboration.

At the CHI 20th World Congress held in Cape Town from 14 - 16 September 2009, the question was posed: "What can the developed countries do to support children's hospice and palliative care in developing countries?" Delegates were asked to think of ways to help bridge the gaps that exist between developed and developing countries. It was also acknowledged that resource poor countries often have much in the way of "resourcefulness" to teach their more affluent counterparts. After some discussion, and with valuable input from Lucy Sainsbury and Jo Ecclestone of *The True Colours Trust*, ICPCN Steering Group members created the **ICPCN Declaration of Cape Town**.

Once written, it was reviewed and approved by congress delegates.

Most delegates present signed this declaration both as individuals and on behalf of their organizations, and we would like to ask for your support in gathering even more signatures. A copy of the Declaration with sheets for gathering signatures can be downloaded directly from the ICPCN website: [www.icpcn.org.uk](http://www.icpcn.org.uk)

The Declaration will be used for advocacy purposes.

Please post signed forms to:

ICPCN Information Officer  
P.O. Box 38785  
Pinelands  
7430  
South Africa



**Neil Williamson**  
Team Leader  
Richard House Children's Hospice

I have always had an interest in working with adolescents and young adults; I suppose even though I have now turned 30, it is still the group of people that I feel I can relate to most comfortably. I remember only too well my first day at university, arriving at my accommodation and coming to the realisation that I was now an 'adult'. This was mainly due to the fact that I now knew I was responsible for navigating my own way and that everything I needed and wanted was now down to me to organise. I was in charge and was truly responsible for myself. I remember that being rather scary!

I now realise that one experience, whilst being significant, was only part of a long process of transition, which begins before we are even aware of it. Frankly I am not even sure today that the process is complete!

So what do I take from this into my work as the leader of developing transitional services in a hospice setting?

**First off I try to remember that all the young people I meet are very different, regardless of whether they share a diagnosis or not. Second to this they do all share one common thread; they all want to be included, whatever their level of ability and whether or not they can take part in a specific activity. They just want to belong and be part of something and not feel like the outsider.**

This desire to belong is common to most people, whether you have a life threatening or complex healthcare condition or not - but if you have one of these conditions it can make it a lot harder to achieve. If the young adult group at Richard House Children's Hospice has done anything, I feel it has created a group where everyone belongs and that, to me, is core for young adult care. This gives them a sense of security and the knowledge that they are not alone as they develop their autonomy and move into adulthood.

The young adult group began in November 2007 when I began working for

Richard House as a care team leader. We were discussing the issue of transition and the idea of how to form a group to allow young people to meet with their peers, be supported by staff and be totally independent of their families and carers.

The decision to start the group for young people from the age of 17 was taken to ensure that those most in need of this type of service were prioritised, as they would be the first to lose the children's hospice service. Many were not connecting with adult services and it was evident their transition to adult services was inadequate, with most of them losing out on services such as therapy, community nursing input and respite services.

After two years I have seen the group, which runs once a month for six hours, start to fulfill its purpose in allowing these young adults to meet with their peers and to speak to various agencies and commissioning bodies about services. It has also given them a voice as to how services can be improved. However, it still falls short of providing everything these young adults need to ensure their transition process is successful for them as individuals.

**In my discussions with the group the main needs that have been identified are around the provision of social respite, employment and education services, and services around independent living.**

**So what is the answer? How do we meet these needs?**

The subject of transition has of late come increasingly under the spotlight and there are already some amazing services in Great Britain which are real flagships for how young adult palliative services should be run. However, young adult palliative care is a national issue and these young people form a patient group all of their own.

**Geriatric care, as an example of a client group, has had real focus in the National Health Service because there is the understanding that the elderly have specific needs. Now it is time for young adults' services to get the same kind of focus.**

Hospice services are key to the success of getting that focus right in every area of the United Kingdom. The local health services will have to assess the needs of the community and ensure **all** patients are able to access services they need. Due to the growth of children's hospice services in particular, both adult and child centered services are able to play a key role in this process.

Hospice teams, as experts in palliative care for both children and adults, need to feed into one another as well as the National Health Service. They must ensure that all young adults with palliative care and complex medical needs have the opportunity to have their needs assessed, individualised, with expert support to help guide them and their family through the process of transition.

The client group is changing for adult services. The increase in young people living into adulthood with neurological and metabolic conditions is increasing and as a client group they have a high nursing dependency. This will have a huge impact on adult services who must learn how to meet the needs of these young people.

**Too often these young people seem to fall through the cracks in services or hit a wall with particular services. This is also true for other aspects such as the referral process, or even what services are out there for them to access.**

We need to work in true partnership, communicate effectively and learn from one another to meet the changing needs of our patients as they switch services. They need to be empowered and prepared for the massive change ahead, both as individuals and in how the hospice services are tailored and delivered within the continuation of their care. We must ensure that we work in a way which will not only develop their autonomy but will support them to make decisions and ensure that they are able to be assertive in voicing their needs to new services.

Working with adolescents and young adults really captures my passion for my work in palliative care. Bringing a sense of belonging to the young adults who are able to meet together and share their experiences and friendship makes me feel I too belong to something.

**It gives me purpose in my work to look towards helping them to improve and enjoy their lives and create positive memories for the road ahead.**



## MOTIVATION FOR THE DEVELOPMENT OF A SPECIAL INTEREST GROUP (SIG) FOR PAEDIATRIC PAIN MANAGEMENT IN THE DEVELOPING WORLD



I had a conversation with a mother, many years ago. I was trying to comfort her, for you see, this mother had just lost her baby – and while the baby was no more than 48 hours old when she died, the pain on the mothers' face, touched my soul. I was at a loss for words. She had carried this child for almost nine months, and for almost nine months she spoke to her little daughter, sang to her and like many other mothers, had dreams for the future of her precious little baby. But 48 hours after giving birth she'd had to say goodbye.

### *What this mother told me shaped my life, and stayed with me forever.*

She said that when a wife or husband dies, they leave behind a widower or a widow. When parents die, what is left behind is an orphan, or orphans. But when a child dies, there are no words in any language to describe those "left behind", because, she said, there is nothing left behind. There are no words to describe the pain that is felt, and then she said: "No mother should ever bury a child, for a part of you dies with the child and this part

will remain forever dead." I was touched by her words and touched by her wisdom. But while sitting there, I became aware of my own inadequacies, my inability to heal her pain, and my lack of knowledge when it came to managing the baby's pain and my own fear.

The story stayed with me during the following weeks, and made me more sensitive to pain and to those around me who were suffering. I suddenly became acutely aware of my own "aloneness" in providing for the pain needs of an overwhelming number of children. How little I knew, and how big was this responsibility, placed upon my shoulders.

*I had to deal with the pain needs of, on average, 1000 burned children each year.*

In addition to that was the pain of many other desperately sick and dying children. Twenty years and thousands of children later, I still feel that things could have been different for me, if only I'd had an opportunity to talk to others in a similar situation. For years it felt like I was the only one dealing with so much pain, and that nobody else could help me.

The idea of developing a special interest group (SIG) for paediatric pain management in the developing world came from those years of "working in perceived isolation" and trying to find answers and solutions on my own. Of course this is not true, there are many like me who are faced with

the same problems, the same sick children, and who are feeling perhaps the same loneliness and despair I felt so many years ago.

So it is for us that the SIG needs to develop. It is for us who do not always have adequate access to the internet, or text books or peers who can provide answers to the unique problems we have to face in the developing world. The rationale behind this is to bring people together, to provide an opportunity where we can not only learn from each other, but where we can support each other.

I believe that together we have the answers and solutions to the problems with which we are faced. I hope that the SIG will create the opportunity for us to meet and communicate with each other, no matter where in the world we are.

**Dr Rene Albertyn**  
**Red Cross Children's Hospital**  
**Cape Town, South Africa**

ICPCN members interested in joining this SIG are asked to send an email entitled: PAIN SIG to the ICPCN Information Officer at:

sue@icpcn.co.za

Please supply the following details in your email:

Name, Profession, Job Description,  
Country, town and place of work,  
E-mail address and a contact telephone number

### SPIRITUALITY IN PEDIATRICS 2009: TRANSFORMING CARE FOR CHILDREN

21 - 23 October 2009



You have less than a week left to take advantage of the \$295 early registration rate for Spirituality in Pediatrics 2009. Don't miss your opportunity to learn best practices for meeting children's spiritual needs, in an interdisciplinary setting.

Through October 4, register for \$295.

Beginning Oct. 5, the full conference price is \$325.

Register here:

<http://ennect.com/e594/register>

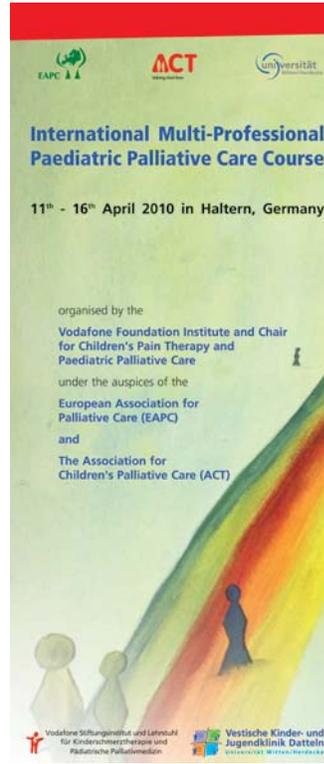
For more information visit the Spirituality In Pediatrics 2009 website or call 832-824-2514.

Texas Children's Hospital, 6621 Fannin, Suite A125, Houston, TX 77030

### International Multi-Professional Paediatric Palliative Care Course

Care structures for Paediatric Palliative Care are rapidly progressing throughout Europe. Recent changes in education and laws have led to profound improvements in the care of the children and their families. However, the structures of PPC differ between and within the European countries. It is therefore the aim of the first International Course to learn from each other. This entails learning from the very advanced European countries as well as learning from those countries that have just started to introduce PPC in their country.

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The ICPCN is administered from the offices of the Hospice Palliative Care Association of South Africa (HPCA) in Cape Town.

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The ICPCN is part of the Worldwide Palliative Care Alliance



Membership of the ICPCN is free and open to all who work in the field of palliative care for children. To join go to [www.icpcn.org.uk](http://www.icpcn.org.uk)