



## STEERING GROUP

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## LETTER FROM THE CHAIR

Dear Friends,

I know that you all join me in congratulating the Chief Executive of St Christopher's Hospice, Barbara Munroe, who has been

made a Dame of the British Empire by Her Majesty, Queen Elizabeth, in her birthday honours list. Dame Barbara has been an inspirational leader in palliative care and we know that this award is well-deserved.

### Visit to CHAS

Last week I was delighted to meet with staff of the Children's Hospice Association of Scotland (CHAS) and visit their two beautiful residential units for children and families, Rachel House and Robin House, and was not only very impressed by their excellent services, but most of all by the model that they have for a children's palliative care service for the whole of Scotland, that is well-supported by all of Scotland. Many countries that are starting out with children's palliative care services could be encouraged to assess whether a similar approach might be effective in their countries. CHAS has also hosted the children's team from the Neighbourhood Network for Palliative Care in Kerala, India, and they are working together on an evaluation of volunteerism in palliative care. Many lessons could be shared from this partnership, especially as so many hospices have felt the effect of the recession.

### New resource on Hospice Partnerships in Children's Palliative Care

To help us to implement the Declaration of Cape Town, Sue Boucher has produced an excellent document on children's hospice and palliative care partnerships in children's palliative care that will be launched at the Cardiff Paediatric Palliative Care Conference in July when it will become available for download from our website. Dr Rut Kiman and Colette Cunningham are helping to translate documents into Spanish, French and Portuguese, and we welcome any offers to translate the Declaration and other documents into other languages.

### Cardiff Conference

We look forward to meeting many of you in Cardiff and it would be good to know who will be attending the 5th International Cardiff Paediatric Palliative Care Conference, the International AIDS Conference and the CCABA Conference

in Vienna, and the UICC Conference in Shenzhen, China. We could then arrange a time and place to meet up with members.

### Human Rights Watch

Human Rights Watch has taken up the cause of palliative care for children, with their initial project in Kenya, and we are delighted to be working with this influential organization to continue to raise the voice of children with life-limiting and life-threatening conditions.

### Welcome

We would like to extend a very warm welcome to Fatia Kiyange onto the ICPCN Steering Group. Fatia will be replacing Dr Julia Downing as the representative for central Africa and for the African Palliative Care Association. Julia has left APCA and is presently taking a sabbatical in the UK. While we say goodbye and offer our very sincere thanks to Julia for her valued contribution to the Steering Group, we are very pleased that it is not the end of her association with the ICPCN as she remains as one of the Vice Chairs of our recently formed ICPCN Research & Scientific Committee.

### World Cup Fever

As you know, South Africa has been hosting the World Cup and the country is covered in flags and footballs against a noisy background of Vuvuzelas! With World Hospice and Palliative Care Day on the 9 October, and the theme "Sharing the Care", wouldn't it be wonderful if together we could raise the same level of awareness for the children we are privileged to care for.

With warmest greetings to all,

*Joan*



## A Two Day Seminar to take place before the 18th International Congress on Palliative Care in Montreal, Canada

Tues, Oct. 5, 9:00 - 17:30 & Wednesday, Oct. 6, 11:00 - 17:30

**PEDIATRIC PALLIATIVE CARE (Find out more at [www.palliativecare.ca/](http://www.palliativecare.ca/))**

### Organisers and Chairs:

STÉPHEN LIBEN, The Montreal Children's Hospital, Montréal, QC, Canada;

JOANNE WOLFE, Dana-Farber Cancer Institute, Children's Hospital Boston, Boston, MA, United States

**Day 1:** The theme for Day 1 will be "Easing Suffering in Pediatric Palliative Care" with a specific focus on therapeutic modalities aimed at reducing pain and suffering of the body (both allopathic and complementary approaches) and of the mind, soul and spirit. The day will include a combination of internationally renowned plenary speakers and those selected through abstract submission, with an emphasis on encouraging interactive presentations.

**Day 2:** The second day will focus on Research in Pediatric Palliative Care. The day will include oral and poster paper presentations selected through abstract submission, with an emphasis on state of the art pediatric palliative care research initiatives, and will conclude with two internationally distinguished plenary speakers.

## INTERNATIONAL EVENTS CALENDAR: JULY - SEPTEMBER 2010

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)

### July

06 - 08	5th International Cardiff Conference on Paediatric Palliative Care	Cardiff, Wales
18 - 23	18th International AIDS Conference	Vienna, Austria
23 - 24	2010 Pediatric Bioethics Conference	Seattle, Washington, USA

### August

04 - 09	26th IPA International Congress of Pediatrics 2010	Johannesburg, South Africa
29 - 2/9	13th World Congress on Pain	Montreal, Canada

### September

01 - 03	Hospice Palliative Care Association (South Africa) 2010 Congress "Sharing the Care"	Umhlanga Rocks, KZN, South Africa
11 - 15	11th Clinical Team Conference, Scientific Symposium and Pediatric Intensive	Nashville, TN, USA
14 - 17	Austrian and New Zealand Society of Palliative Medicine Conference	Adelaide, Australia
15 - 17	3rd APCA (African Palliative Care Association) Conference	Windhoek, Namibia
23 - 25	3rd Annual International Hospice & Palliative Care in Developing Countries Conference	Fresno, CA, USA

## DATES FOR YOUR DIARY

ICPCN is proud to partner with Cardiff University for the 5TH INTERNATIONAL CARDIFF PAEDIATRIC PALLIATIVE CARE CONFERENCE to take place at Cardiff University, Wales.



## 5TH INTERNATIONAL CARDIFF CONFERENCE PAEDIATRIC PALLIATIVE CARE 6 - 8 JULY 2010 "FACE TO FACE WITH INTERFACE"

*"No man is an island, entire of itself; every man is a piece of the continent, a part of the main... any man's death diminishes me, because I am involved in mankind." John Donne, 1618*



### Programme

To see the indicative programme and to learn more go to: [www.icpcn.org.uk](http://www.icpcn.org.uk) and follow the link to the 5th International Cardiff Conference on the home page.

### Registration

Registration costs £199 per delegate

If you have any queries please do not hesitate to e-mail Su Hayward-Lewis at: [PPC2010@cardiff.ac.uk](mailto:PPC2010@cardiff.ac.uk)

### Registration now open!

3rd APCA Conference,  
Windhoek, Namibia,  
15-17 September 2010



[www.apca-windhoek2010.com](http://www.apca-windhoek2010.com)

Visit the website for registration, bursary applications and sponsorship options for APCA's third triennial conference. Its theme, **Creativity in Practice**, reflects both the current reality of palliative care provision on the continent - which demands so much creativity from its practitioners - and the resourcefulness we'll all need to draw on in the future if we want to realise our shared vision of high-quality palliative care for all in Africa who need it.

Don't miss this rich opportunity to explore creative approaches to palliative care delivery.



## Children and HIV: Family Support First

Working Together to Achieve Universal Support and Access to Treatment

July 16th & 17th, 2010  
Vienna, Austria

An international symposium that will present the latest evidence and share the latest models on family-centered care and services for children affected by HIV and AIDS. The underlying theme for the symposium is based on the findings of The Joint Learning Initiative on Children and AIDS which demonstrated how central and under-supported families are in their care of children affected by HIV and AIDS.

The two-day symposium, jointly hosted by **The Teresa Group**, the **Coalition on Children Affected by AIDS (CCABA)**, and **World Vision Austria**, will be held on July 16th & 17th 2010 at the Austria Center in Vienna. The symposium will bring together close to 600 service providers, donors, researchers, advocates and policy leaders working within affected communities on national, regional and global platforms. It will promote opportunities for stronger linkages between program design and implementation, policy, research, and advocacy efforts.

This think-tank and networking opportunity is for anyone working on issues related to children and HIV/AIDS and is concerned about how to improve local, national and international responses.

Learn more and register at: <http://www.teresagroup.ca/vienna/>



ICPCN acknowledges with gratitude the funding received from The True Colours Trust for the furtherance of its work in promoting the development of paediatric palliative care worldwide.

[www.truecolourstrust.org.uk](http://www.truecolourstrust.org.uk)



ChinaKidz provide specialist children's palliative care services in Changsha and also offer palliative care services to families, aiming to support them and avoid the pressure to abandon their sick baby/child. This is an exciting and groundbreaking project in China. Lyn Gould, Director of Care at Chinakidz writes the following to any health professionals looking for an opportunity to do some volunteer work:

The Butterfly Home is the first of the organisation's children's hospices in China which opened in April 2010 in Changsha, Hunan Province.

In co-operation with the Changsha No.1 Children's Welfare Centre we are providing palliative care for the abandoned children in the orphanage and will extend the service to families in the community who have a sick baby/child, aiming to support them at home and avoid the pressures to abandon their child. This is an exciting and groundbreaking project in China; even in many other parts of the world children's hospice services are not available.

As in many countries palliative care is not a well understood specialty and we are privileged to be able to help establish this vital service for children. In order to ground the service into the area we employ and train Chinese staff to deliver the service, however we want to supplement the care given by local staff with that of overseas volunteers aiming to provide good education and role models.

There are a number of ways in which you can consider being part of this wonderful work, whatever your skills and experience. The main 'qualifications' are a desire to serve and an ability to be flexible,

### Medical/nursing

We have several opportunities for people with a medical/nursing professional background.

1. We need someone or a couple with a professional background in healthcare (medical, nursing, therapy) to provide the day to day care of the children's medical needs and running of the home. Ideally you will want to spend a year or so here after a short reconnaissance trip.
2. Are you a registered nurse with a good all round experience or even a paediatric nurse? We need nurses who will provide the day to day nursing care of the children, short or longer term. We particularly need cover from mid September 2010 - any periods of time from 3 weeks to 3 years will be considered.

The Chinakidz Directors (Alan & Lyn Gould) manage the service overall and will provide your induction and general support during your time in China. For those committing to periods of over 3 months you will be encouraged to learn Mandarin and given time to attend language classes.

For more information please see our website

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

To express interest or for more information please email Lyn Gould at [Lyn@chinakidz.co.uk](mailto:Lyn@chinakidz.co.uk)

## United Kingdom

Over the Easter Weekend there was an unexpected funding boost of £30 million for children's hospices and the National Health Service (NHS) for children's palliative care services. Half of the money is to help hospices extend their range of services to include more outreach, the other half is to help the NHS to continue to move palliative care services out of hospitals and into children's own homes. The announcement follows a commitment made by the Health Secretary earlier this year to have a more patient-centred care across the NHS including delivering many more services in patients' homes. It includes a commitment to help children and young people who have acute or long-term conditions, or disability or palliative care needs to spend less time in hospital and receive care at home or the community instead.

### News from ACT

ACT has developed a series of twelve training packages and has accredited 8 trainers to deliver these training programmes to a wide range of health and social care professionals. Marketing for this new training and consultancy programme will take place during June 2010.

ACT now has a very active ethics committee which has been involved in preparing a response to the End of Life Assistance (Scotland) Bill and we await the outcome of this Bill which has implications for young people with palliative care needs.

ACT's Transition Coordinators are working part-time across the UK to encourage the use of the Transition Care Pathway and are making great progress in raising the profile of the needs of young people who use palliative care services. The Transition Coordinator in Scotland has contributed to the Scottish national strategy for Living and Dying Well for Young Adults, which recognises the ACT Transition Care Pathway. A new Consultant in Transitional Palliative Medicine has been appointed in Wales and plans to link up with the ACT Transition Coordinator for Wales to ensure a joined-up approach. The Coordinator in Northern Ireland organised two events this Spring for policy makers and practitioners to develop a Northern Ireland-wide approach to transition based on the ACT Pathway. A Transition Champions Network is now operating in the South East Coast area of England and ACT has been involved in the development of a needs assessment for young people in North East London.

### News from Children's Hospices UK

Following receipt of a legacy, Children's Hospices UK has developed a research grant programme for children's hospices in the UK. It is expected that 2 grants of approx £60K each will be made for research. We have developed a User Participation Toolkit to influence the way that children's hospices engage users in influencing the development of children's hospice services, to be launched in June 2010.

Following an award of approximately £400K from the Big Lottery Fund, we are leading a research project to enable the development of a model of best practice in delivering transitional palliative care to young adults.

Report by Barbara Gelb & Lizzie Chambers

## AFRICA

### South and Central Africa Multi-Professional Curriculum

Excellent progress has been made with the piloting of the new multi-professional children's palliative care curriculum in Tanzania, Uganda and South Africa. The research on the development of a curriculum for community caregivers has been completed. Research into mapping children's palliative care in sub-Saharan Africa has been completed and the report is in draft form.

### Launch of a Virtual Resource Centre

A Virtual Resource Centre at [www.baobabppc.co.za](http://www.baobabppc.co.za) has been launched and is now live online. This website is a resource specifically for children's palliative care in South and Central Africa. People can enter questions regarding CPC.

### The Threat of TB

The incidence of TB, including multi-drug resistant and extreme drug resistant TB has increased and this challenges traditional infection control procedures in hospices. It has also led to a special ethics committee being set up to decide when to withdraw TB treatment.

Report by Joan Marston

### Visit to Ethiopia

Sue Huff, ICPCN Steering Group member and US representative reports on a highly successful visit made to Ethiopia with colleagues Drs Nancy Hutton and Ben Lee.

In May of this year, I had the honor of accompanying my physician colleagues Nancy Hutton and Ben Lee to Ethiopia as part of a PEPFAR Project. PEPFAR (President's Emergency Plan for AIDS Relief) is a program that was established by President George W. Bush. Johns Hopkins University partners with Ethiopia to provide expert advice, technical assistance, as well as structural and intellectual capacity building to Ethiopian Hospitals under the new Ethiopian ART program.

### Focus of the trip

The focus of our trip was to provide training in pain management and palliative care to physicians and nurses working at Black Lion Hospital and the surrounding medical facilities. In addition, I met with the Dean of the School of Nursing for Addis Abba University to discuss plans for nursing education in palliative care; both for under graduate and graduate study. The understanding and application of palliative care is a great need in this country, not only for their HIV population but there is a significant need to address the management of pain and symptoms in the oncology population, for adults and children.

### Site Visits

We did site visits for two days, to HIV clinics and hospital wards. We also made a visit to Hospice Ethiopia and accompanied their nurse on a home visit. I gave ICPCN information and resources out at every opportunity.

### Nurse Training

The training for nurses was very successful with over 150 nurses in attendance. Morphine is available and used, mostly in the ART clinics. It is not widely used in the hospital settings although it is available. Liquid morphine will soon be available, which would help for pediatric dosing. Access effects proper dosing of morphine for both adults and children and this was a hot topic. Another focus was on the assessment of pain, and incorporating assessment into nursing documentation.

## INDIA

### Report by Dr Maryann Muckaden

We are making progress towards inviting Sachin Tendulkar or Amitabh Bacchan to be ambassadors for Paediatric Palliative Care in India. Ms Priya Dutt, MP, has agreed to promote Paediatric Palliative Care, and the Nargis Dutt trust helps all children in any way possible. More trusts and donors are on the anvil to help children with outings, educational material and toys and aid such as wheel chairs, Narcotic drugs etc.,

### The DFID Project

The DFID project in conjunction with Help the Hospices and ICPN to bring palliative care to children living with HIV and AIDS in India has been a great boost to developing a relationship with the non cancer Hospital where there is a thriving Dept of Paediatrics with all the life limiting conditions. It is also helping us develop relations with MDACS and MSACS for the provision of palliative care work to children living with HIV and AIDS. This project will also help the Indian Palliative Care Association to strengthen it's Paediatric thrust.

We recently held a meeting with the Maharashtra University of Medical Science to ask that palliative care is taught to medical students. ICPN and Paediatric Palliative Care are now part of the curriculum. The Vice chancellor is actively considering this programme to be taken on by faculty.

At the Armed Forces Medical College, Pune, Head of the Dept of paediatrics is going to help promote Paed Palliative care with MUHS for post graduate students.

## LATIN AMERICA

### Report by Dr Rut Kiman

In March the "V LATIN AMERICAN CONGRESS" and "VIII ARGENTINIAN PALLIATIVE CARE CONGRESS" took place in Buenos Aires. It was an opportunity to meet and share experiences in the field of children's palliative care (CPC) and also to learn about the matters arising in adult palliative care. More than 750 participants and many qualified speakers from around the world attended. The Congress held many wonderful surprises that were greatly enjoyed, such as tango lessons, and an exhibition of photos and videos.

During informal talks it became clear that no matter where you are, in a developed or developing country, some problems are very similar - such as how to introduce CPC to Paediatricians (not as "terminal care"), accessibility to drugs in suitable pharmaceutical forms for children, lack of tools validated for children, training and sustainability of multi-professional teams and the provision of payment for necessary jobs and not just volunteer work.

During the Congress we attended the Paediatric committee's legal formation within the ALCP. Representatives from many Latin-American countries: Argentina, Brazil, Bolivia, Chile, Colombia, Costa Rica, Guatemala, Mexico, Paraguay, Uruguay and also Dr. Martino from Spain, were there. The new authorities elected were: Dr Lisbeth Quesada Tristan (Costa Rica), Dr. Hernán García (Argentina) and Dr. Yuriko Nakashima (México). **The Latin American Palliative Care Association now has a Paediatric Committee!**

The need for quality CPC information in Spanish was perceived as a matter of great importance.



## PAEDIATRIC PALLIATIVE CARE IS MOVING FORWARD IN GREECE!

Much progress has been made during the last two years towards the development of paediatric palliative care in Greece. Even though research on the needs of Greek families facing a child's serious illness and/or death and on the responses of Greek professionals who care for dying children and adolescents have been conducted over the past two decades, paediatric palliative services had not been developed.

However, in 2009 the Greek Society for Paediatric Palliative Care was founded, with the purpose to promote the philosophy of paediatric palliative care as well as to ensure the development of paediatric palliative care practices and services that are culturally sensitive and appropriate. The 24 founding members have extensive experience in the care of seriously ill children and include paediatricians and nurses who have specialised in oncology, neurology, critical care, and social paediatrics, psychologists, social workers, physiotherapists, sociologists as well as parents who actively advocate for the rights of children and families facing serious illness.

The Society co-organized the 1st Panhellenic Symposium on Paediatric Palliative Care, which was held in Athens (March 2009) and attended by health care professionals, educators, health managers and parents. Amongst the keynote speakers, Sister Frances Dominica presented her pioneer work in paediatric palliative care in the U.K., Prof. Myra Bluebond-Langner addressed communication issues, and Greek experts, amongst whom Dr H. Kosmidis, Dr S. Giouroukos, Dr H. Skouteli and Prof. D. Papadatou, described the obstacles and opportunities of implementing paediatric palliative care in Greece, while a panel of parents addressed the challenges encountered by families of children with various life-limiting conditions.

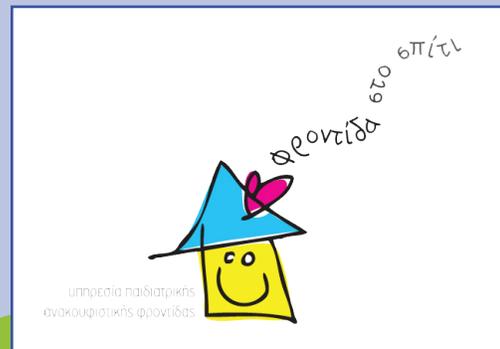
Through designated committees, the Society currently reviews the services that provide care to children and adolescents with life-limiting and life-threatening conditions in all parts of Greece, and concurrently has developed the Standards of Care and the Rights of Children with Life-Threatening Conditions, according to which the services to seriously ill children will be audited and evaluated. The Society also contributes to the sensitisation and training of the Greek health professionals on the principles of paediatric palliative care, by participating in postgraduate educational programs, seminars and conferences. Finally, it cultivates collaboration with international

organizations, groups, and services to promote paediatric palliative care across the world.

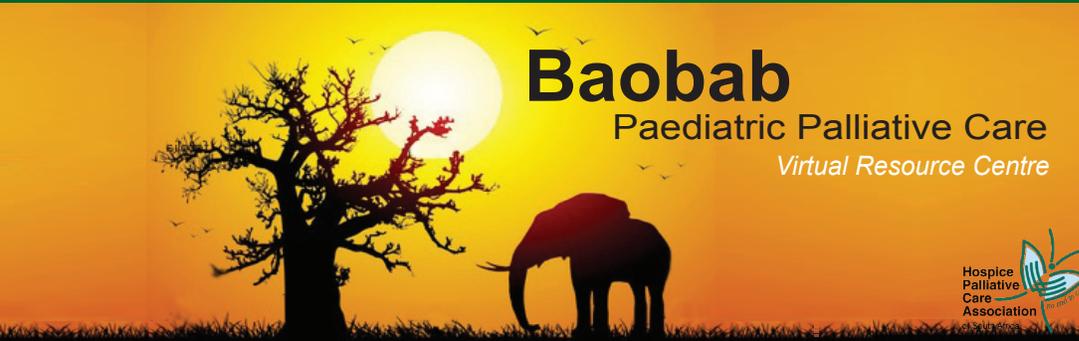
Paediatric palliative care in Greece has also been strongly advocated and promoted by Merimna (which means "Care"), the not-for-profit Society for the Care of Children and Families Facing Illness and Death, since its founding in 1995. Merimna has been providing psychological support to children and families facing serious illness, loss and death, through its Counseling Center since 1995 and has organized extensive training programs on paediatric palliative care for health professionals since 1997. On January 2010, Merimna founded the Paediatric Palliative Home Care Service, the first of its kind in Greece. This new Service provides palliative care to children and adolescents during the terminal stages of illness and supports family members. Services are offered by an interdisciplinary team, comprised by paediatricians, nurses, social workers and psychologists, as well as music therapists and chaplains, depending on families' needs. Merimna's Home Care Service collaborates closely with the "P. & A. Kyriakou" Children's Hospital, one of the largest children's hospitals in Greece, from which referrals are made, while collaboration with other paediatric hospitals is currently under development.

It should be noted that all palliative and bereavement services are free of charge, and Merimna relies solely on donations from individuals, companies and foundations.

**Report by Maria Bouri**  
**Medical Director**  
**Paediatric Palliative Home Care Service**  
**Merimna Society for the Care of Children and Families Facing Illness and Death**  
**Athens, Greece**  
**Email:merimnapalliativecare@gmail.com**



## The Baobab PPC Website - A brand new virtual Resource for Africa



### Baobab Paediatric Palliative Care Virtual Resource Centre



#### Why is it named after the Baobab Tree?

The Baobab is probably one of the most wonderful trees in the world. It is quintessentially African and an incredible resource in Africa. Baobabs can store up to 120 000 litres of water in their trunk and humans have been known to have survived off its water supply during droughts. Its leaves are used as vegetables and medicine and its fruit is very nutritious. It is hoped that this Virtual Resource Centre may become as useful to professionals as The Baobab tree is to Africa. Despite its usefulness there are many myths and legends about it...Unfortunately, like the Baobab tree, Paediatric Palliative Care is often misunderstood by professionals and lay persons alike and many myths and misconceptions around what it is and has to offer still exist.

#### What is the Baobab Website?

The Baobab Paediatric Palliative Care site is a web-based virtual resource for professionals caring for children with life-limiting and life-threatening illnesses in South Africa.

This resource has been developed by the Hospice Palliative Care Association of South Africa with the generous support of the Diana Princess of Wales Memorial Fund and the Open Society Institute.

#### Who can use the site?

The centre aims to provide multi-disciplinary professionals (doctors, nurses, social workers, educators, psychologists, counsellors, clergy and other spiritual workers) working in South Africa with useful resources and on-line clinical support to improve palliative care provided to children living with life limiting and life threatening illnesses.

The website offers clinical support, a forum, news on conferences and events and a regular

Newsletter, named for the most recent South African Celebrity Survivor series' form of communication: "Treemail"

While the website was created as a uniquely South African resource, practitioners from other African countries as well as the rest of the developing world are welcome and encouraged to make use of this new resource.

[www.baobabppc.org.za](http://www.baobabppc.org.za)

## ANIMAL ASSISTED THERAPY PROVIDED BY POPPY, THE NEWEST CARE TEAM MEMBER AT CANUCK PLACE IN BC, CANADA



2010 represents a milestone year in Canuck Place history. Not only are we celebrating 15 years helping of BC children and families embrace life, but we recently welcomed a new member to our care team. Poppy is a two-year-old female Golden Retriever, who has been trained by Pacific Assistance Dogs (PADS) to be a therapeutic companion and friend to

the children and families at the hospice. Poppy's official title is "therapy dog," a unique position that doesn't exist at any other hospice in the country.

Since joining the hospice, Poppy has become fully integrated in Canuck Place's comprehensive continuum of care to over 400 children and teens with life-threatening illnesses and their families. At the hospice, through all stages of a child's illness, an individual program is designed to meet the needs of each family. Canuck Place offers family support and respite care, expressive therapies, pain and symptom management, end-of-life care, grief and bereavement counselling, nursing and medical consultation.

#### Poppy's Activities

Poppy attends individual and group counselling sessions with our social worker to help foster a greater social and emotional connection with children and families on our program. She also accompanies children, along with their siblings and parents on visits to the garden and on special field trips led by the hospice's recreation therapy team. Poppy interacts with families every weekday with sympathetic visits and lots of one-on-one cuddles. Her gentle manner, warm smile and comforting nature helps ease distress and bring joy to everyone she meets. Poppy's visitation schedule is modified by her handlers to accommodate children and families who are allergic to dogs and they also ensure she maintains a healthy balance between work, rest and play.

can buy online Precious Gifts. \$15 helps make Poppy feel at home with pet supplies and accessories such as chew toys, dog dishes, treats and bedding, \$40 pays for an hour of counselling with Poppy's love and support and a gift of \$100 goes towards Poppy's health checks and any other costs associated with veterinary care that she may need throughout the year.

#### Poppy has her own blog

You can read all about Poppy's life at Canuck Place by reading her blog at [www.poppy.canuckplace.org](http://www.poppy.canuckplace.org)

With the help of her friends at the hospice, she provides regular updates of her day-to-day activities. She can also be reached through her very own email address at : [poppy@canuckplace.org](mailto:poppy@canuckplace.org)

Whether a life is measured in days, weeks, or months, children deserve the opportunity to learn, develop and grow. Canuck Place encourages each child to 'embrace life' and believes in enhancing the quality of whatever time a child may have left by empowering them to live fully and joyfully.

**Filomena Nalewajek  
CEO  
Canuck Place**



Poppy's specialty - bringing joy to children and young people at Canuck Place

## THEARA'S LIGHT - READ ABOUT ONE MAN'S DETERMINATION TO OPEN A HOSPICE FOR THE CHILDREN OF CAMBODIA

For the past 5 years, **Rick Peterson** has been a Board member, sponsor, fundraiser and volunteer with the Cambodian Children's Fund (CCF - [www.cambodianchildrensfund.org](http://www.cambodianchildrensfund.org)) which he describes as "...an amazing organization that has saved the lives of many of Cambodia's most destitute, abused, and poverty stricken children." His experience of the suffering of a young Cambodian girl, has led him to the realisation that the very least the children of Cambodia deserve is a dignified and pain-free death and so he is working tirelessly towards the opening of Cambodia's first children's hospice programme. This is his story...



*Theara Sok with her grandmother*

While in Cambodia volunteering for CCF, I became involved in a tragic situation around a 14 month old baby girl named Theara Sok. She was from Kompong Cham province and had been diagnosed with a kidney tumor at a free children's hospital in Phnom Penh.

### Theara's Diagnosis

Upon diagnosis, Theara was referred to another hospital in Phnom Penh which was the only hospital in Cambodia that treats cancer. Her mother took her to this hospital which confirmed Wilms cancer but would not treat her because of her young age. They do not treat any child under the age of 3 years - a fact which I have since verified via several other sources.

After being turned away by the hospital, we took Theara to a private clinic to get a further medical opinion and we were asked to provide CT scans from yet another hospital to better evaluate her condition. These scans sadly confirmed that her cancer was advanced and nothing that could be done for her in Cambodia.

*We were told that although treatment options may have been available at cancer treatment hospitals in the West, in Cambodia there was nothing more that could be done.*

### Accepting the Inevitable

A friend at CCF who has personally endured the losses of babies from various causes, told me; "Rick, no matter how determined you are, there comes a time when you have to accept that there is nothing more you can do." As painful as the decision was, I knew he was right. We took her home to her province to prepare for her inevitable passing, one of the most emotional experiences of my life.

On our arrival, we were greeted by her entire family on the road and invited into their small wooden home. As we all sat around her on the floor, my Cambodian friend explained the sad news to the family. The adults were tearful but held their composure for the sake of the children in the room.

After the head of the family expressed gratitude for what we had done to help Theara, he took my hand and put it on hers. She grabbed my finger with her tiny hand and as we sat there around her on the floor holding back the tears, the "oneness" that I felt with this family I had just met was unlike anything I have felt before. We all seemed to be connected by the love for this little girl on a level that was not of this world.

### Managing her pain

With no experience in the medical profession, via email I enlisted the help of a friend and volunteer who is a pediatric oncologist in America. I asked her to provide me with assistance for pain management to make Theara as comfortable as possible as this vicious disease attacked her tiny body. She gave me a list of several pain medications and dosages, including morphine for the final stages to help ease her suffering. I also enlisted the help of a certified nurse who would be able to properly administer these medications.

*In attempting to begin pain management, we were stunned and frustrated to learn that the only medication we could obtain was simple codeine syrup.*

We tried various pharmacies and even went back to the hospitals we first took Theara to, and were told that these items were not available in Cambodia....not even morphine.

### Theara's passing

For the next 4-5 weeks, I made regular trips to Theara's family's home in Kompong Cham to bring her the codeine syrup and other needs such as baby formula. With every trip, her condition worsened. On what turned out to be my last trip to her home to provide medication, she was a mere skeleton of the beautiful little girl I first met only several weeks earlier. She was having an extremely hard time breathing. I received a phone call about 3 days later from her family informing me of her death. While expected, it was still one of the most painful phone calls I ever received.

*Through my tears, the only comfort I found was that she was no longer suffering.*

After Theara passed on, I vowed to do something in her name so that other Cambodian babies stricken with cancer or other terminal diseases do not die the same horrible and painful death as she did. Although sad, I am at peace in knowing that we did not walk away from Theara in her time of need and we exhausted all options.

Still, I am haunted by the fact that we could not do more, especially in comforting her when her passing was imminent.

### Theara's legacy

I do not know why, of all people, she was brought to me, but I will remember this little angel always as she has forever changed my life. I am a firm believer that everything that happens in a person's life is for a reason and I am determined to do all I can to ensure that as many Cambodian children as possible never have to suffer as Theara did.

Although I would ultimately like to see a pediatric cancer treatment facility in Cambodia, I have realised that the greatest need right now is the establishment of a hospice program. After further research I have discovered that Theara's suffering is commonplace in sick babies, especially the poor.

*My hope is that this hospice can eventually assist in giving the end-of-life quality and dignity that every person deserves.*

### Cultural Considerations

I know from my experience here that one of the most important details of such a program is the integration of Khmer/Buddhist beliefs with modern medical treatment. Cambodia is over 90% Buddhist, and many people, especially the poor, do not trust modern medical practices. However, I believe that with the collaboration of the Buddhist monks, they would welcome any relief for their dying child.

I have had several meetings with an American born doctor/Buddhist monk in Phnom Penh and he is very enthusiastic about such a program and has offered to help in any way he can.

**The ICPCN has been assisting Rick with information and networking partners but he would value any assistance possible to get this project off the ground. Should you be willing or able to help in any way, please contact him at: [Richard\\_Pete011@msn.com](mailto:Richard_Pete011@msn.com)**



*Living conditions for the poverty stricken people of Cambodia*



*Rick with a young girl found digging through waste at Stueng Meanchey*

### Poverty stricken Cambodians

Cambodia is ranked by WHO as one of the most impoverished countries in the world. The majority of people there literally survive day-to-day. The average Cambodian makes the equivalent of \$2 per day, and those are the fortunate ones able to find a means of income. It is also a country that is trying to find its footing after years of civil war. The true victims of this extreme poverty are almost always the children. The majority of CCF's children were found at one of the largest and most toxic landfills in all of Asia called Stueng Meanchey. This is where the poorest of Cambodia's poor call home. If there was ever a true hell on earth, Stueng Meanchey is it. No words or pictures can do justice to the horrific conditions and suffering inflicted upon those who have ever lived there.

### A living hell

Amid stifling heat, burning fires, nauseating stench, millions of flies and maggots, toxic chemicals, medical waste, (including bodies and body parts) and countless other hazards, the children who called this deplorable place "home" truly are in a living hell. To survive by themselves, or often to help provide their families with food, alcohol, or even drugs, children of all ages are forced to dig through the mountains of trash looking for anything of recyclable value.

*Because of these horrendous conditions, many children suffer from life threatening diseases such as AIDS, tuberculosis, hepatitis, lung disease from the toxic smoke and countless others.*

Some of these children are abandoned there to survive on their own by families who cannot support them, or worse, just do not care. On most days, these desperate kids work countless back breaking hours in the scorching Cambodian sun, and earn only around US 25 cents per day or less. We found one baby girl only 3 years old abandoned at the dump.

### Poor Medical Care

Although Stueng Meanchey is one of the most horrific places in all of Asia itself, most people in Cambodia are realistically one illness, injury, or debt away from this hell regardless of where they live in the country. This is why many children (and adults) go without medical care and other basic human essentials. This poverty also leads to the horrible end-of-life suffering like Theara endured. If it was not for our help, this beautiful little girl would not even have had the codeine syrup as her family was not able to afford any medicine for her at all.



**Dr. Huda Abu-Saad Huijer RN, PhD, FEANS** is a Professor of Nursing Science and the Director of Hariri School of Nursing at the American University of Beirut. On 26 March 2010 she was honoured with a Lifetime Achievement Award sponsored by Macmillan Cancer Support, in collaboration with the International Journal of Palliative Nursing (IJPN) in London. The award was granted in recognition of her truly remarkable work in palliative nursing both in the UK, Europe, and overseas. Dr Huijer is a leading pioneer in paediatric pain management and palliative care.

Huda's career span includes professorial positions at the University of California San Francisco, University of Maastricht, the Netherlands, University of Surrey & University of Manchester, the UK, and the American University of Beirut in Lebanon. She was a consultant to the Aga Khan Foundation in Kenya, Tanzania, India, and Pakistan. During her tenure in the Netherlands she was instrumental in developing the Masters in Nursing Science which was offered at three sites; Maastricht, Utrecht, and Groningen and the Red Cross School of Nursing in Switzerland. She was also instrumental in developing the PhD program and establishing the Centre for Nursing Research. Her consultancy with the Aga Khan Foundation led to the establishment of the Institute for Advanced Nursing Studies in East Africa. Since her appointment at AUB in 2003, the Masters of Science in Nursing and RN-BSN programs were launched. The BSN and MSN programs received unconditional accreditation by Commission on Collegiate Nursing Education in USA in 2007 and they are preparing to launch a collaborative PhD program with Johns Hopkins University SON. She is also involved in the development of the College of Health Sciences in Al-Khobar Saudi Arabia.

Huda's research focuses on pain management and palliative care in children and adults and her contributions to the field of Nursing at the national and international levels have been significant. In the USA, she was one of the first nurse researchers investigating the phenomenon of pain in children. Her publications in the 1980's were seminal. She has been actively involved in a number of research projects in the Netherlands and in Lebanon on pain management and palliative care and has been instrumental in impacting policy in both fields. She has

supervised a large number of PhD dissertations in the field and published more than 300 articles including two books; one being "Evidence-based Palliative Care across the Life Span"; and has given a large number of keynote addresses.

Huda has also been actively involved in a number of organizations namely the International Association for the Study of Pain (IASP), European Association for Palliative Care on which she served as co-chair of the Task Force on Pediatric Palliative Care and a member of the Research Network, European Academy of Nursing Science (founding member), Dutch Foundation for Scientific Research, Lebanese Cancer Society of which she is chair of the workgroup on pain and palliative care, and Lebanese Society for the Study of Pain of which she is president elect. She was instrumental in developing the first course on PPC in Europe and in organizing international conferences in the field. She currently serves on editorial boards of a number of scientific journals.

Regionally, Huda has been involved in developing the College of Health Sciences in Saudi Arabia and in providing advisory assistance to a number of academic and health care institutions in the fields of nursing, pain management and palliative care. She currently serves on the International Scientific Advisory Board, Centre of Excellence in Pediatric Pain Management and Palliative Care, Faculty of Medicine, Kuwait University and is a member of WHO Expanded Review Panel on Pain Guidelines.

## PAEDIATRIC PALLIATIVE HOME CARE BY GENERAL PAEDIATRICIANS: A MULTIMETHOD STUDY ON PERCEIVED BARRIERS AND INCENTIVES

This research article appeared in the BMC Palliative Care which was published on 4 June 2010. The full report can be downloaded at: <http://www.biomedcentral.com/content/pdf/1472-684x-9-11.pdf>

**Authors:** Saskia Junger; Andrea E. Vedder; Sigurd Milde; Thomas Fischbach Boris Zernikow; Lukas Radbruch

The research examines potential barriers, incentives, and the professional self-image of general paediatricians with regard to paediatric palliative care in Germany.

### Methods:

Based on qualitative expert interviews, a questionnaire was designed and a survey among general paediatricians in their own practice (n=293) was undertaken. The survey was developed and performed in close cooperation with the regional professional association of paediatricians.

### Results:

Six main categories emerged from the data:

1. Prior experiences with palliative care
2. Emotional attitude towards palliative care
3. Barriers (emotional, professional, structural)
4. Facilitations, and the paediatricians' role
5. Professional self-image.
6. Prior experiences with palliative care

It became clear from the interviews that the need for palliative care in the paediatricians' daily practice occurs only rarely. The interview partners on average reported 1 case per year or less. During the interviews, the paediatricians reflected their emotional attitude towards

the care for a dying child, as the following quote illustrates.

*"And then, at a certain point, I have to take the decision: what can I do as a physician for this person? instead of talking about dosage, the drip, or whatever, these whole medical bells and whistles. At a point when death is approaching, all of this is pretty relative. And either I decide to remain reachable for this patient – also in a metaphoric sense – or internally I have already logged out."*

The lack of experience and routine was described as the major reason for professional barriers. Structural barriers mainly originated from the general conditions of the health care system, for example, inadequate remuneration, organisational obstacles such as long distances, as well as questions of responsibility, referral, and the interface between inpatient and outpatient care.

Confidence on part of the patient and the family was seen as an important facilitation for the paediatrician's work. The paediatricians mentioned the burden of the confrontation with a dying child but at the same time were confident that they will be able to care for a child with a life-limiting disease in an intuitive and natural way. The most important facilitations were seen in an adequate remuneration, as well as in a simplification of organisational procedures. The prominent incentive was

the possibility to collaborate with a specialist centre and to consult a palliative care specialist.

The results showed a high disposition on part of the paediatricians to engage in palliative care, and the majority of respondents regarded palliative care as part of their profile. Main barriers for the implementation were time restrictions (40.7%) and financial burden (31.6%), sole responsibility without team support (31.1%), as well as formal requirements such as forms and prescriptions (26.6%). Major facilitations were support by local specialist services such as home care nursing service (83.0%), access to a specialist paediatric palliative care consultation team (82.4%), as well as an option of exchange with colleagues (60.1%).

### Conclusions:

Altogether, the high commitment to this survey reflects the relevance of the issue for paediatricians working in general practice.

Education in basic palliative care competence and communication skills was seen as an important prerequisite for the engagement in paediatric palliative home care. A local network of specialist support on site and a 24/7 on-call service are necessary in order to facilitate the implementation of basic palliative care by paediatricians in their own practice.

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