

## STEERING GROUP

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## LETTER FROM THE CEO

Dear Friends,

**G**reetings from a beautifully green and vibrant Malawi.

A wonderful aspect of my job is either actual or virtual meetings with many inspiring people around the world who are working tirelessly and passionately to ensure children have access to palliative care. The past two months I have had the privilege of visiting the project ICPCN is managing in both India and Malawi in order to observe the developments in palliative care for children in those countries, despite having areas of great poverty and many challenges. Two leading children's palliative care programmes – Tata Memorial Cancer Hospital Palliative Care team, in Mumbai, led by Dr Maryann Muckaden; and Umodzi Children's Palliative Care in Blantyre, with Mr Fed Chiputula at the helm - have each taken on the added responsibility of training and mentoring three new programmes in each country. They will be working together with the national associations, IAPC in India and PACAM in Malawi and with the country co-ordinators, Dr Raj Bhandari and Mr Sydney Kabambe. Despite very busy programmes themselves, the vision and actions that led to their own success, will generously be shared with others.

This generosity and willingness to share and help other organizations to reach more life-limited children, is a very special element of children's palliative care programmes and practitioners everywhere, and I would encourage those who have not yet signed up to be part of the ICPCN partnership project, to consider the impact your knowledge and experience could have on a new or developing programme; and how much you could learn from them, especially their resourcefulness despite being resource-limited.

We would also encourage you to support the relief

efforts in Japan where so many children have been left orphaned and homeless. On page 6 of this Newsletter you will find a list of organizations that would use your donations wisely, as well as a message of sympathy and encouragement from our organization. However, I remain convinced that as an organization we should be doing more than this, and would appreciate your thoughts and ideas on ways we could respond to these disasters around the world.

We supported a children's hospice in Haiti, and Colette Cunningham, who personally responded to that disaster, is looking for people to join her compassionate response group to plan ways we can respond. Should you wish to be part of this conversation, please feel free to email Colette at colette.cunningham@gmail.com

Palliative care for children is a movement that receives recognition in far too few areas of the world; we are moving forward, and governments, international organisations and donors are listening when we speak of the need; but this movement needs to increase and accelerate if our vision of palliative care for all children is to be achieved.

I am so thankful that we are all together on this journey and in this movement. With my very best wishes to all,

*Joan*

## WIN ONE OF TWO US\$50 VOUCHERS FOR AMAZON.COM BY TAKING PART IN OUR NEW ICPCN TRAINING & TRAINING NEEDS SURVEY

ICPCN is undertaking a survey of training needs and training programmes in children's palliative care. The aims of the survey are to:

- Understand the training needs around children's palliative care in order to help shape future training programmes on children's palliative care.
- Develop a comprehensive database of training programmes on children's palliative care from around the world.

The survey therefore includes questions on your training needs for children's palliative care, along with questions about what training programmes your

organisation administers on children's palliative care.

It should take about 10-15 minutes to complete, but may take longer depending on the speed of your internet connection. To access the survey please go to the ICPCN website [www.icpcn.org.uk](http://www.icpcn.org.uk) or click on the following link: [http://www.icpcn.org.uk/survey\\_page.asp?section=000100010042&sectionTitle=Training+and+Training+Needs+Survey](http://www.icpcn.org.uk/survey_page.asp?section=000100010042&sectionTitle=Training+and+Training+Needs+Survey)

We would very much appreciate it if you would be able to complete our survey, and as an incentive, we are able to offer respondents the opportunity to enter into

a draw to win one of two Amazon.com vouchers worth US\$50 each.

As this is an international survey we would like to get as many people as possible to respond and so we request that you forward this information on to others who you know are involved in children's palliative care.

Thank you and we look forward to feeding back the results of our survey.

**Dr Julia Downing**  
Research and Education Consultant for ICPCN  
E: [julia.downing792@btinternet.com](mailto:julia.downing792@btinternet.com)

## INTERNATIONAL EVENTS CALENDAR: APRIL - JUNE 2011

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)

### April

- 07 - 08 Early Childhood in Developing World Contexts - An International Conference
- 10 - 12 "One Vision One Voice" - 2011 Hospice Palliative Care Conference
- 13 Sibling Support - Study Day
- 14 - 17 14th ASEAN Paediatric Congress 2011

- University College, Cork, Ireland
- Sheraton Parkway, Toronto North, Canada
- Derian House Children's Hospice, Preston, Lancs UK
- Suntec International Convention & Exhibition Centre, Singapore

### May

- 02 - 08 ICN Conference and CNR
- 15 - 17 Regional Forum on Psychosocial Support
- 18 - 21 12th Congress for EAPC
- 18 Supporting the Family of a Child with a Life Threatening Illness

- Malta
- Kopanong Hotel & Conference Centre, Johannesburg, South Africa
- Lisbon, Portugal
- Derian House

### June

- 01 - 02 10th Annual Kaleidoscope International Palliative Care Conference
- 11 - 13 1st International HIV Social Science and Humanities Conference,
- 11 - 17 Pediatric Pain Master Class
- 22 - 25 Making Connection: Dying, Death and Bereavement in the Global Community
- 22 - 24 International Society of Advance Care Planning and End of Life Care Conference 2011
- 22 Enhancing Communication through the use of Signalong

- Dublin Castle, Ireland
- Durban ICC, South Africa
- Marquette Hotel, Minneapolis, MN, USA
- Miami, Florida, USA
- QEII Conference Centre, London, UK
- Derian House, Preston, Lancs UK

## Save the Date

**Mark your Calendars**  
4th Annual  
**Pediatric Pain Master Class**  
June 11 - 17, 2011  
Marquette Hotel  
Minneapolis, MN, USA

Presented by  
Children's Institute for Pain and Palliative Care (CIPPC)  
Department of Pain Medicine,  
Palliative Care and Integrative Medicine  
Children's Hospitals and Clinics of Minnesota

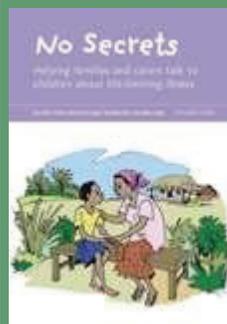
This seminar offers state of the art education in pain management for the pediatric patient from a holistic and multidisciplinary perspective. The program features a faculty of internationally recognized experts, who will cover pharmacological, medical, psychosocial, and integrative therapies in the management of children's acute and complex/chronic pain. Pain assessment and management of somatic, visceral, neuropathic, and psychosocial/spiritual pain, as well as end-of-life management of pain and distressing symptoms will be discussed in depth using lectures, workshops, and small-group approach.

The Master Class is primarily designed for physicians and advanced practice nurses to develop their expertise in the field of pain management in a highly interactive seminar format. Space is limited.

For more information, or to request a registration packet, please contact Children's Institute for Pain and Palliative Care (CIPPC) at (612) 813-6450, or e-mail at [cippc@childrensmn.org](mailto:cippc@childrensmn.org).

For more information about the program, visit the website at <http://www.childrensmn.org/Services/PainPalliativeCare/>.

## Publications and Resources



The Booklet NO SECRETS, based on a study conducted by Dr Mary Bunn at Umodzi in Malawi, which aimed to investigate attitudes towards talking to children about life-limiting illness. It summarises the findings of both international research and Dr Bunn's research in Malawi and provides a brief guide for healthcare workers who want to encourage families/carers to talk to their children.

Printed copies of the book are available now from the African Palliative Care Association.

For more information contact APCA at [info@africanpalliativecare.org](mailto:info@africanpalliativecare.org)

## Introducing Fatia Kiyange

Fatia is the Director of Programmes for the African Palliative Care Association (APCA), and the latest member of the ICPCN Steering Group. She holds a Masters Degree in Social Sector Planning and Management of Makerere University, Kampala and a Bachelor of Arts Degree in Social Work and Social Administration of the same University.

Fatia has 10 years experience working in the area of palliative care, previously as the Education Administrator of Hospice Africa Uganda and she also used this opportunity to provide advice and guidance on the Social Work role in palliative care. Her experience in palliative care cuts across core areas such as education and training; standards and wider programming. Before joining the APCA staff team, Fatia was involved with the initial stages of establishing APCA as well as the Palliative Care Association of Uganda (PCAU). She is currently the President of the Governing board of the Palliative Care Association of Uganda (PCAU), having previously been the Secretary of its founding steering committee.



## Congratulations to Dr John Collins



### Dr John Collins

*Head, Pain and Palliative Care Service The Children's Hospital at Westmead, Sydney, Australia*

We would like to congratulate Dr John Collins for the enormous honour of receiving the **Order of Australia** for service to medicine in the field of paediatric palliative care as a practitioner, academic and researcher, and to professional organisations. The Order of Australia, instituted by Her Majesty The Queen in 1975, was established as an Australian society of honour for the purpose of according recognition to Australian citizens and other persons for achievement or for meritorious service.

## Regional Reports and Updates

### AUSTRALIA & NEW ZEALAND

#### Establishment of a new service in NSW

It is with great pleasure that the first report from Australia and New Zealand for 2011 highlights the recent establishment of a new service in New South Wales (NSW), Australia.

John Hunter Children's Hospital in Newcastle, NSW was established in April 2010 with the intention of providing consultative paediatric palliative care support for northern and north-western NSW (an area of approximately 165,000 square kilometres). The service comprises of a specialist paediatric palliative care doctor, paediatric registrar, clinical nurse consultant, senior social worker, occupational therapist and an administrative assistant. Two special-purpose patient and family rooms have been created at the hospital for children with life-limiting conditions with these having been built with funds raised through the extraordinary efforts of a local trust, the Nicholas Trust.

The specific challenge this service has identified is how to provide adequate bereavement support services to a large geographical area.

#### Other Key Events

The National Standards Programme undertaken by Australian and New Zealand services just over one year ago continues to provide the impetus for

improvements in existing services.

The Royal Children's Hospital, Brisbane, Queensland has made considerable strides in service development with the commencement of a formal bereavement support program, developing brochures of the service to give to families and will run a palliative care education day twice a year. The service has also received funding, through the National Partnership Agreement, for a small number of inpatient sub-acute beds to be located at the hospital.

The Children's Hospital at Westmead in NSW, Sydney has taken a lead role in the development of the NSW PPC Planning Framework and this is in its final draft for submission to NSW Health. This documents a vision for PPC across NSW to allow for the development of the services on a state wide basis by articulating the activities required to develop paediatric palliative care over the next three years.

The service is at the start of developing a Bereavement Support Service. The initial stages of the program involve identification of referral criteria, program components, and the monitoring of support activities across hospital and hospice.

Starship Children's Hospital in Auckland, New Zealand has been closely involved with the Ministry of Health supporting a project on identifying models of PPC in one third of New Zealand's health districts. Key clinical and advocacy stakeholders were questioned, using a mixture of individual interviews and focus groups. The final report is due for release next month and a primary focus of the report is going to be on implementation of recommendations.

The beginnings of a collaborative transitioning model with adult hospices for adolescents with life-limiting illnesses are being developed.

#### In Progress

The Royal Children's Hospital continues with telehealth (videoconferencing) support of families. This is being evaluated by a case-control study of 30 families (ten currently enrolled) who have used the service.

The Children's Hospital at Westmead have been trialling their project with the Ambulance Service of NSW to allow paramedics to support end of life care at home without the need to commence CPR or transport the child to hospital. The early results are excellent.

*Dr Ross Drake*

### EXCITING DEVELOPMENTS IN INDIA

#### Achievements

Much has been achieved since the commencement of the DFID Children's Palliative Care (CPC) Project under the auspices of Help the Hospices and ICPCN and with mentoring by Tata Memorial Centre in Mumbai.

The CPC project began officially in November 2011 although preparation for it began six months prior after discussion with the Department of Paediatrics at Sion Hospital and the Maharashtra District AIDS Control Society along with many NGO's in the field of HIV in Mumbai. It was also originally conceived to work through the Maharashtra chapter of the Indian Association of Palliative Care.

To begin to identify gaps Dr Bhandari, the country coordinator visited the Regional Paediatric ART Centre at Sion Hospital, Mumbai as the first site for the development of CPC where detailed discussions were held.

#### Raising awareness of CPC

In order to bring about an awareness to the Paediatricians in India regarding palliative care and its impact on their practice, a questionnaire was chosen and permission to administer it was obtained. Dr Bhandari attended the Indian Association of Paediatrics (IAP) meeting hosted by IAP branch of Navi Mumbai, Issues relating to CPC were discussed and some questionnaires administered to IAP members. To complete this survey, please go to: <http://www.iapindia.org/>  
At the 85th National Conference of the Indian

Medical Association (IMA), Dr Bhandari chaired a session on Child and Adolescent Health. In order to have greater access to CPC and pain relieving medicines for children, meetings were held with office bearers of the Indian Medical Association at Tata Memorial Centre.

#### First session dedicated to CPC

At the Annual conference of the Indian Association of Palliative care held in Lucknow Feb 2011, a full session was dedicated to Children's Palliative Care for the first time in the history of the conference.

#### Recruiting new champions

At a meeting with Dr. Vijay Kumar Gavit, Minister of Medical Education and Horticulture, Gov. of Maharashtra the following outcomes were achieved:

- The Minister has agreed to be a champion for Children's palliative care in Maharashtra.
- The minister supports the issue of palliative care in Maharashtra and has promised to include palliative medicine within the curricula for all post graduate specialities.
- He would also support the issue of wider availability of morphine and other opioids at secondary and tertiary health care facilities within the state.
- Support from the Ministry for starting an MD program in Palliative Medicine.

A meeting with the State Minister for Health and Family welfare, Mr. Suresh Shetty on 7th march 2011, led

to his agreeing to support the Children's Paediatric Palliative Care project and to be a champion for the cause within the existing healthcare frameworks, especially in rural Maharashtra.

#### Identification of the second site

The meeting with the Minister of Health and Family welfare led to the meeting with the Mission Director of the National Rural Health Mission Maharashtra on 11th March 2011. As a result of the meeting the second site for the project was identified as **Jawhar Cottage Hospital**, Thane District. The hospital is about 120 km from Mumbai in a tribal belt and has a well developed Pediatric Facility. The integration of Pediatric care would start at the primary healthcare level with referrals to a specialist team at the secondary or tertiary health care facility wherever necessary. The need for additional staff, training and other resources for the program were discussed in detail. Tata Memorial would be the training site for the program. The need for making morphine available at Jawhar Cottage hospital was recognized by the Mission Director.

*Dr Maryann Muckaden*



L to R: Dr M. Muckaden; Dr A. Paleri, Joan Marston (ICPCN CEO); Dr Manglani; Dr Raj Bahndari (Country Coordinator) meet at Sion Hospital, the first site for the rollout of the programme.

## Regional Reports and updates cont.

### UNITED KINGDOM

**£30 Million Children's Palliative Care Funding Programme**  
Activity remains focused on delivering the projects that were funded under the Coalition government's £30 million children's palliative care funding programme. In total there were 461 funded projects across England, all of which are due for completion by the end of March 2011.

ACT has also been awarded additional funding to carry out a national 'Review and Analysis' of the £30m Funding Programme and to develop an online resource hub to provide searchable and easy access to the many excellent new resources that have been developed, including new e-learning programmes, many of which will be transferrable to children's palliative care services across the globe. This online resource hub is to be launched in late summer 2011.

**Children's Hospices UK and ACT Square Table Programme**  
Grants were awarded within the £30 million children's palliative care funding programme in England for this exciting and ground breaking project which is enabling over 40 local Square Table events to take place between February and April this year in order to creatively discuss issues relating to children's palliative care. Each Square Table event creates a structured environment for up to 40 people including professional commissioners and providers and young people and families. In this way, the events provide the opportunity for the aspirations of children and young people with life limiting and life threatening conditions, together with the views and concerns of their parents and key carers to be heard and understood in a common forum with key representatives from the entire children's palliative care provider community.

By the middle of April this year, the Local Square Table programme will have heard the thoughts and aspirations of well over 1,500 individuals who care deeply about children's palliative care in England. We are certain that of the many new ideas which will emerge from this programme, any one of which will have the potential to transform how we do things and how we think about our services.

We are now planning regional events to take place in early summer. This will include Scotland, Wales and Northern Ireland and will be followed by a national event which will draw together all the learning to inform our vision for the future direction of children's palliative care and our messages for lobbying governments across all 4 UK nations.

#### Restructuring of the NHS

The proposed restructuring of the National Health Service is beginning to take shape. A government bill is passing through parliament which sets out how the restructuring is to take place. The proposed changes will have a huge impact on the structure of the health service, taking a less centralised approach with a greater focus on local decision making and user involvement. The concern for the children's palliative care sector is that low incidence high need services will fall through the net as the proposed smaller commissioning bodies will not have the necessary expertise and experience of children's palliative care and the needs of children and families.

**Lizzie Chambers, ACT**  
**Barbara Gelb, Children's Hospices UK**

### SOUTH AMERICA

#### Argentina

Significant advances have been made to ensure that palliative care is recognized as a medical specialty by the Ministry of Health.

In September 2011, the "Centennial Congress" of the Argentine Society of Pediatrics will take place in BA. Joan Marston has been invited as a plenary speaker to address the congress on Children's Palliative Care.

We are also organising national palliative care meetings in Mendoza in October where round table discussions about children's palliative care (CPC) are being proposed and leading CPC teams in Argentina will share their experiences. At least three CPC courses are available in the city of Buenos Aires.

#### Chile

PINDA, a Ministry of Health children's cancer programme coordinated by RN Cherry Palma are working on standards and improved reporting on symptoms other than pain.

In Hospital Del Río in Santiago, a Pediatric Palliative Care Committee of specialists, nurses and medical assistants which meets every 2 months was formed in October 2010. They aim to raise awareness of CPC, to define care according to the complexity of groups of patients, and education and training.

In the Chilean Society of Pediatrics a committee called NANEAS (Children and Adolescents with Special Needs in Health) was created. They have been participating in meetings to raise awareness about CPC.

In September 2011, Spring Conference will be held and one of the topics will be non-cancer patients.

#### Guatemala

They have recently finished the reconstruction of the children's hospice *Villa de la Esperanza* which was severely damaged by the volcano eruption and floods last year.

#### Venezuela

Dr. Carolina Kamel was honored with her appointment as president of the new committee on Pain and Palliative Care of the Venezuelan Society of Childcare and Pediatrics.

**Dr Rut Kiman**  
**Argentina**

## ACT chosen to benefit from the Royal Wedding Charitable Gift Fund

Prince William and Miss Catherine Middleton have set up a charitable gift fund for those who very generously may wish to donate to charity to help the couple celebrate their wedding. Having been touched by the goodwill shown them since the announcement of their engagement, Prince William and Miss Middleton have asked that anyone who might wish to give them a wedding gift consider giving instead to a charitable fund. Leading UK children's palliative care charity ACT is one of the charities chosen by the couple to benefit from the Fund. Prince William and Miss Middleton have personally selected ACT and 25 other charities as beneficiaries of this special fund.

ACT has welcomed this exciting news and the generosity of Prince William and Miss Middleton in providing an opportunity to raise awareness of the UK's 24,000 children who have a terminal or life-threatening health condition.

Welcoming the news, ACT's Chief Executive, Lizzie Chambers said: "This charitable gift fund is such a thoughtful and generous gesture from the couple and I am absolutely thrilled that ACT is one of the chosen charities. Prince William and Miss Middleton have provided us with a precious opportunity to raise

awareness of the needs of the 24,000 children and families in the UK living day-to-day with palliative care needs and facing the uncertainty of a premature death. I wish the couple all the very best for a long and happy marriage."

ACT hopes that Prince William's and Miss Middleton's interest and support will have a real impact on children's palliative care and lead to greater understanding and awareness of what life-limited children and their families need.

Donations to the Royal Wedding Charitable Gift Fund can be made through the website [www.royalweddingcharityfund.org](http://www.royalweddingcharityfund.org) which includes a full list of the charities to benefit, personally chosen by Prince William and Miss Middleton.

You can find out more about ACT's work via this special Royal Wedding Charity Fund website or by visiting ACT's website [www.act.org.uk](http://www.act.org.uk).

**Myra Johnson**  
**PR & Communications Manager**  
**ACT**





**A historic moment in the life of the Light of My Eyes Foundation**

Last week, at a press conference, Gyura Barbara, the president of the Light of My Eyes Foundation has announced, that the National Health Organisation has given an operating license to Dóri House, so the first children's hospice in Hungary can start operations. Dóri House will soon accommodate children with life-limiting illnesses and their families. There was a good turnout at the official opening, and the media eagerly inquired about the facility. With three bedrooms, enabling two families to live in the house at the same time the hospice looks forward to welcoming its first residents

The main function of the house is to provide support to the children and respite to their family in a homely environment in the period of time they are there.

For more information please contact them by phone: +36 72 526-658 or visit the website: [www.szememfenye.hu](http://www.szememfenye.hu)

**Lilla Erstagården  
 Sweden's first hospice  
 for children and adolescents  
 is opened by The Queen**



On Thursday 9 September 2010, Queen Silvia, The Queen of Sweden opened Lilla Erstagården, Sweden's first children's hospice. Lilla Erstagården will enhance healthcare for children and young people by providing advanced care during the final stages of life in a home-like environment and to offer support to the children and their families to ensure that life can continue as the child and the family desire.

The Queen is the patron of Ersta Diakoni. In her speech, she said: "Today, most seriously ill children are cared for at home during their final days, and

that is how things should remain. But for some children who cannot be cared for at home, a hospice environment is a better alternative than a hospital — both for the children and for their families."

An estimated 100 children in Stockholm County suffer from a life-limiting illness and are in need of palliative care. Lilla Erstagården, Sweden's first hospice for children was opened in the beautiful garden park in the paddock in Nacka at Järla Sea.

"It is with great satisfaction and humility that we've taken on the task of creating Sweden's first hospice for children and adolescents. This will be a place that is as much about life as death," said Georg Engel, Director of Ersta hospice clinic.

Also in attendance at the opening ceremony was Livia the labradoodle, a therapy and assistance trained dog, with her handler, Senior Physician Anne Edner. Livia will be a source of comfort and joy for the children and their families attending Lilla Erstagården.



**The ICPCN Partnership Initiative - Requests for partners**

Euripides, the Greek poet of ancient times wisely said, "Joint undertakings stand a better chance when they benefit both sides."

With the ICPCN Partnership Initiative, we are sure that any partnership we facilitate will be of benefit to both sides. We are not proposing partnerships where one programme supports another, but where both partners can learn from one another, support one another and be inspired by one another.

We are excited at the number and quality of partnership requests so far received, but all of these are from programmes that are in the early stages of development, looking for more established partners.

Sadly, we have had no requests at all from more established partners and would like to challenge those of you out there who have a firmer footing and a great deal more experience to make the effort and take the time to reach out to these infant programmes.

We are convinced that you will find it worth the effort. Programmes looking for partners include:

**RWANDA HOSPICE PALLIATIVE CARE CENTRE**

This centre in Kigali, offers palliative care to patients with HIV/AIDS, cancer and other life-limiting illnesses through an outpatient clinic and home

based care. They provide bereavement support, financial assistance and provide for the basic needs of their patients. They are looking to expand their paediatric case load as resources allow, and look forward to engaging in the partnership project as a means to exchange information and resources on children's palliative care. They are keen to develop their programme as a model within Rwanda and in neighbouring French-speaking countries. To find out more, please feel free to contact Kate Doyle and should you wish to partner with this organisation to contact the ICPCN on [info@icpcn.co.za](mailto:info@icpcn.co.za)

Contact person: Kate Doyle  
 Email: [kate.etta.doyle@gmail.com](mailto:kate.etta.doyle@gmail.com)

**ONGATA NGONG PALLIATIVE CARE COMMUNITY BASED ORGANISATION**

This young organisation working in both rural and urban Kenya in the area of Kiserian, hopes to share their knowledge and skills in looking after children and hope to find a partner who will provide support and expertise and be willing to share experiences. They offer training for community health workers and volunteers, including the parents of children. To find out more, please feel free to contact Stella Rithara and should you wish to partner with this organisation to contact the ICPCN on [info@icpcn.co.za](mailto:info@icpcn.co.za)

Contact person: Stella Mwari Rithara  
 R/N, Dip HE Pallcare U.K.  
 OPCCBO, Project coordinator  
 Email: [mwaris48@gmail.com](mailto:mwaris48@gmail.com)

**CHRIST'S AMBASSADORS**

This organisation offers Home based care, spiritual care and counselling services for adults and children living with HIV and AIDS and also care for malnourished children born from infected mothers. They are looking for a partner who would offer technical assistance related to the care and support of children living with AIDS and improving their services around spiritual care. They look forward to the possibility of exchange visits.

Find out more at [www.camzambia.com](http://www.camzambia.com)  
 Contact person: Leah Mwanza  
 Email: [info@camzambia.com](mailto:info@camzambia.com)



The ICPCN Guide to  
 Children's Hospice  
 & Palliative Care  
 Partnerships





Dr Hans-Joerg Lang with staff and patients in the Paediatric Ward at the Queen Elizabeth Central Hospital (QECH) in Blantyre, Malawi.

Starting 20 March 2011, Mark Jones, Terry Bishop and Hans-Joerg Lang, a paediatric critical care physician at Queen Elizabeth Central Hospital, Blantyre (QECH), are planning to cycle the length of Malawi, aiming to complete the 1,050 km within one week. They will start at the northern border of Malawi with Tanzania and ride to the one in the far south with Mozambique. Their effort has already raised nearly MKW 1.5 million for sick children in QECH. The money will go to the Friends of Sick Children charity, where it will be used to buy new oxygen concentrators and pay for nurses' salaries. The three strong and well motivated men hope to improve the lives of the sick children in Malawi.

### What is their motivation?

Every year, 28,000 children are admitted from the Children's Accident and Emergency Department at the Queen Elizabeth Central Hospital (QECH) in Blantyre, which sees and treats about 100,000 children each year. QECH is the largest hospital in Malawi, with 1,400 beds, and it provides medical, surgical, obstetric and paediatric care free of charge. It is also the site for the UMODZI children's palliative care programme.

### Children die from malaria, malnutrition, TB, respiratory infections and gastroenteritis

The children's unit of QECH has 320 beds, but on average 200 to 380 children are in-patients. During the rainy malaria season, from December to April, it's not uncommon for this number to increase to 450 or more, with two or three children sharing a bed and relatives sleeping outside or on the floor. Medical and nursing staff struggle to cope, shelves are often empty of essential medicines, the blood bank is unable to keep up with the constant demand for life-saving transfusions, and three or more children may have to share an oxygen supply intended for just one. Each morning the deaths are detailed, with malaria, malnutrition,

tuberculosis, respiratory infections and gastroenteritis the most common causes.

### Unacceptably high under-five mortality rate

An important part of the trip will be to remind people in Malawi and elsewhere about the unacceptably high under-five and maternal mortality rates in Malawi, and the need to invest in child and maternal health from community level to local health facilities and hospitals.

"We really appreciate this effort for the sick children in Malawi we daily care for, and hope that by touring Malawi from North to South Hans, Mark and Terry will raise not only money to help us care for the children but also the interest of the public, civic society, government and non-governmental organizations for the fate of sick children in Malawi and why they fall ill from (preventable) disease, accidents or even abuse," said a spokesperson for the QECH in Blantyre.

### The Riders



#### Mark Jones

Mark is a photographer and film maker who has close contacts with the sick children at the Queen Elizabeth Central Hospital (QECH) in Blantyre.



#### Hans-Joerg Lang

Hans is paediatrician with an interest in paediatric critical care medicine in low-resource settings. He is currently working as a lecturer and paediatric consultant at the College of Medicine, Queen Elizabeth Central Hospital in Blantyre, Malawi.



#### Terry Bishop

Terry manages the databases for a study in Malawi and Cape Town on the development of new methods of detecting TB, as well as designing web sites for local charities and organisations.

Mark, Terry and Hans aim to ride the length of the country, a distance of not less than 1,050 km. They plan to take the minimum of kit: a spare set of clothing for when they're off the bike, some flip-flops, a basic tool kit including puncture repair, several extra inner tubes and an assortment of essential spares. They will also need some medical supplies (Hans is Team Doctor), sun cream and water purification tablets. All this will fit in three small backpacks, and they will have water bottles on the bikes. "We think we can pick up all the food and water we need locally each day, and we're using lodges along the route to provide beds, evening meals and a big breakfast." See also : <http://design-edge.co.uk/mwe2e>

You can help by donating locally in Malawian kwacha to the FOSC National Bank, Chichiri, Blantyre. Account number 01 41120556200

## DONATIONS FOR RELIEF EFFORTS IN JAPAN

On March 11 a massive 9.0-magnitude earthquake shook the northeastern coast of Japan, creating extremely destructive tsunami waves which hit Japan a few minutes later. The earthquake and tsunami have caused extensive and severe damage in Northeastern Japan, leaving in excess of 16 thousand people dead, missing or injured and millions more affected by lack of electricity, water and transportation. And now freezing rain and snow is slowing Japan's relief efforts.

Our thoughts are with all those who are suffering from shock, loss and bereavement in the aftermath of the earthquake and tsunami. Should our members wish to contribute towards rescue and salvage efforts in this devastated region, what follows is a list of trusted organisations working towards this end:

### American Red Cross

Donations will be sent to the Japanese Red Cross Society: [www.redcross.org](http://www.redcross.org)

### Shelter Box

ShelterBox is an international disaster relief charity that delivers emergency shelter, warmth and dignity to people affected by disaster worldwide [www.shelterbox.org](http://www.shelterbox.org)

### Doctors without borders

Doctors without borders has sent medical teams to support the government-led earthquake and tsunami response in Japan. Their teams are running mobile clinics and conducting needs assessments. [www.doctorswithoutborders.org](http://www.doctorswithoutborders.org)

### Google Crisis Response

This page is being updated continuously to provide the latest information about this crisis, resources for those affected, and ways to contribute to relief efforts in Japan. <http://www.google.com>



## Healing with horses in South Africa - horse wisdom for the bereaved heart



By Liesl Jewitt, Social Worker & Equine Facilitated Psychotherapist



There is a mountain in a green valley in KwaZulu-Natal that is said to look like a lion lying in peaceful watch over all who reside there. Loskop mountain dominates your view when you stand anywhere on the soils of *Mizpah Farm Retreat* in the Karkloof.

Twilight, Scully, Dancer, Silver, Isra, Lady, and Blue stretch their horse bodies in paddocks and gaze reflectively at Loskop. In between eating, sleeping and their internal chatter, these horses are waiting to introduce humans to things inside themselves they have never thought of exploring.

In 'healing with horses' we often work with bereaved children and adults in need of counselling and therapy. During different phases of the grief process, horses are able to offer humans new and innovative ways of healing the hurts, calming the emotional storms and above all being present in the here-and-now. They are masterful teachers of stress management, healthy communication, co-operative relationships, personal awareness and emotional understanding and integration.

*They are masterful teachers of stress management, healthy communication, co-operative relationships, personal awareness and emotional understanding and integration.*

Equine Facilitated Psychotherapy (EFP) focuses on the emotional content of the interaction and usually there is no riding. The simple physical proximity to the horses encourages the human to develop awareness and insight about their innermost feelings and thoughts. Once children or adults have worked with the horses, they are better able to digest and work through their grief and bereavement. Safely guided interactions with the horses offer space to consider feelings, coping skills and what other support they might need to deal with the loss. The experience is often intense and brief but it works!

### The story of a young, grieving boy

A young eleven year old client had never been around horses before. But the way he looked at their size and beauty showed his immediate admiration. He stood there and looked up at Twilight, leader of our small herd of horses. Twilight looked back at this small person, openly curious. No fear crossed this open boy-face as he measured the tall muscled gelding, and started firing away with questions about how old Twilight was, who his favourite friend was

in the herd, why he preferred the grass on one side of the paddock to the other and a myriad other little details that seemed to fascinate his developing mind.

In my notes I wrote: *'We chat as we walk the horses down to the shed for their dinner, this slight boy and I, with the horses listening in on our conversation. Slowly but surely he starts to tell me about himself, what he likes and dislikes, who his friends are, what upsets him and makes him happy.'* This small human had been a client for a few weeks. His foster family brought him for play therapy because he simply wasn't opening up and letting anyone in. An older sister, who had been his main caregiver, had died and his mother was refusing treatment for a life-limiting illness. He refused to acknowledge his feelings about any aspects of his life. He was often in trouble at school for being 'aggressive' and getting into fights with school mates. He had remained quite uncommunicative until the day after meeting the horses. His foster mother phoned in tears. The night before he had hugged her at bedtime – a first – and told her that he knows how much she loves him. A real breakthrough! It wasn't long before we ended the therapeutic relationship, as the issues which brought him to therapy had been resolved.



### A hospice carers 'destressing day' with the horses

The clinical team from a local Hospice come for a 'destressing' day. The horses wait eagerly from early in the morning to help these valuable individuals carry some of the emotional burden of their workload. The humans spend time letting go of concerns and the daily drama of the work, while creating emotional space, destressing and taking deep relaxing breaths throughout the day. The horses yawn and sigh in each interaction, helping release the tension and encouraging freedom and fun. The horses share messages of support and encouragement, the humans reflect deeply. Everyone greets farewell with a sense of knowing they serve the highest good.

Horses remind us to stay mindful in the moment, they help ground us, encouraging emotional awareness and honesty. Their wisdom opens our hearts. They ask only that we remain real, have empathy for ourselves and others. This is a win-win situation. The humans gain an opportunity to develop greater awareness and insight into their issues, selves and relationships, creating more connectedness and love. The horses gain humans who have more empathy and love for themselves and the world.

### Equine Assisted Growth & Learning Association USA

Those who are familiar with horses recognise and understand the power of horses to influence people in incredibly powerful ways. Developing relationships, training, horsemanship instruction, and caring for the horses naturally affects the people involved in a positive manner.

The benefits of work ethic, responsibility, assertiveness, communication, and healthy relationships has long been recognised. Horses naturally provide these benefits. The use of horses is growing and gaining popularity with the rise of new approaches in working with the horses, including the field of Equine Facilitated Psychotherapy.

Horses are large and powerful, which creates a natural opportunity for some to overcome fear and develop confidence. The size and power of the horse are naturally intimidating to many people. Accomplishing a task involving the horse, in spite of those fears, creates confidence and provides for wonderful metaphors when dealing with other intimidating and challenging situations in life.

*We are often asked, "Why horses? Why not other animals?"*

Horses are very much like humans in that they are social animals. They have defined roles within their herds. They would rather be with their peers. They have distinct personalities, attitudes, and moods. An approach that seems to work with one horse, does not necessarily work with another. At times, they seem stubborn and defiant. They like to have fun. In other words, horses provide vast opportunities for metaphorical learning. Using metaphors, in discussion or activity, is an effective technique when working with even the most challenging individuals or groups.

Horses require work, whether in caring for them or working with them. In an era when immediate gratification and the "easy way" are the norm, horses require people to be engaged in physical and mental work to be successful, a valuable characteristic in all aspects of life.

Learn more about this fascinating subject at: [www.eagala.org/whyhorses.htm](http://www.eagala.org/whyhorses.htm)



Liesl Jewitt with two of the horses that help her with therapy. To find out more, visit: [www.mizpahretreat.co.za](http://www.mizpahretreat.co.za) or email Liesl at: [liso@polka.co.za](mailto:liso@polka.co.za)

# INTRODUCING MEET THE DFID PROJECT COUNTRY CO-ORDINATORS



**D**r Raj Bhandari was appointed to the position of Country Coordinator for the DFID project in December 2010 and has already been asked to produce a White Paper for the Indian Academy of Paediatricians (IAP). Both the incoming and outgoing Presidents have given their support to children's palliative care development.

Raj is doing a baseline survey of the knowledge and attitude of paediatricians and general practitioners in four areas of India with some interesting results

Dr. Raj Bhandari  
Country Coordinator for India



**S**ydney Kabambe, a Clinical Officer and the new Country Coordinator for Malawi has already held fruitful meetings with the Ministry of Health and is in the process of drawing up a situational analysis of the need for Children's Palliative Care in Malawi.

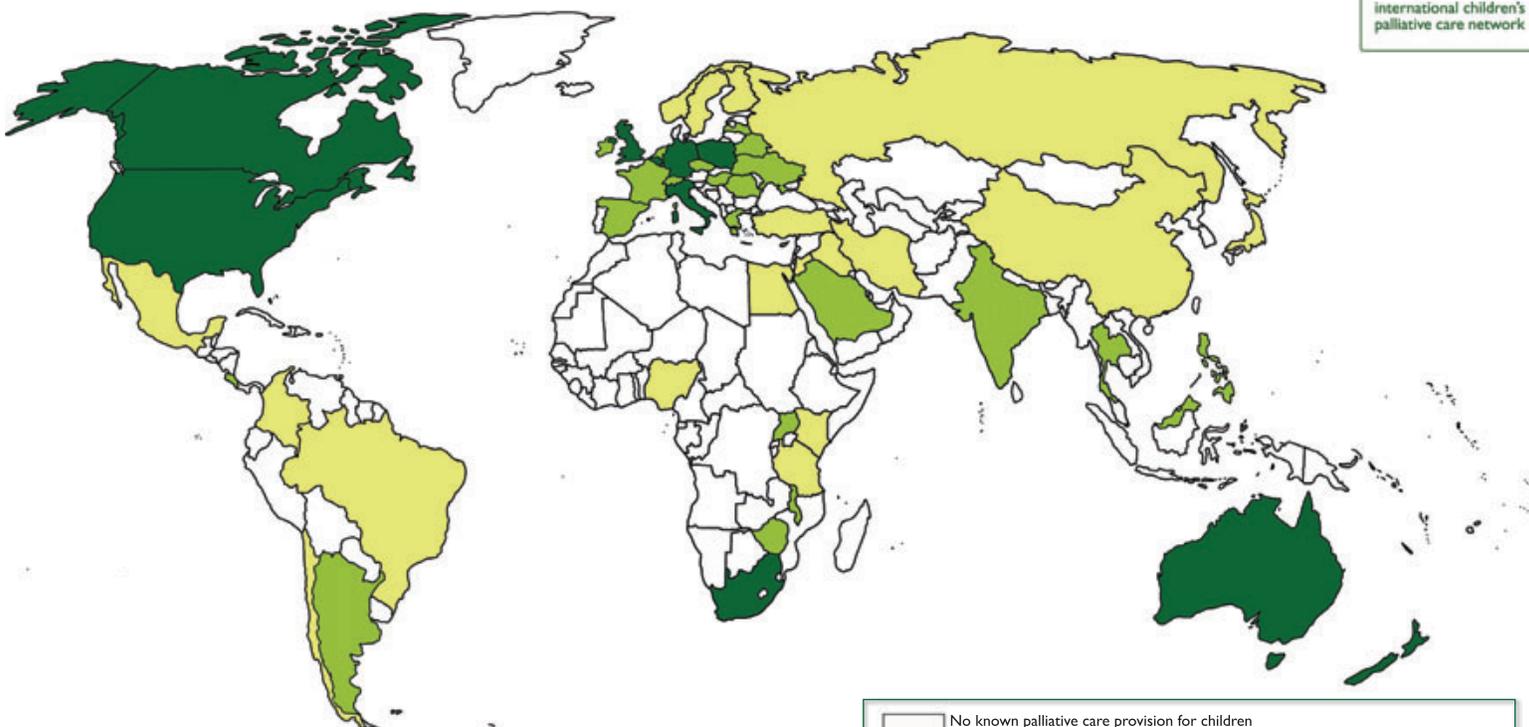
Sydney Kabambe, Clinical Officer  
Country Coordinator for Malawi

To learn more about the DFID two country project and the impact we hope to have in Malawi and India, visit our website: [www.icpcn.org.uk](http://www.icpcn.org.uk)

## ICPCN ESTIMATE OF GLOBAL PROVISION OF CHILDREN'S PALLIATIVE CARE

Based on membership figures and information received from members and outside sources, the ICPCN has drawn this map as an estimate of the provision of children's palliative care worldwide. Please note that this information *is not based on research*, but on information received incidentally. Readers are encouraged to open a dialogue with the ICPCN on whether or not they agree with how their country has been represented on the map. We welcome input in order to make this a more accurate reflection of global palliative care provision for children.

## ICPCN ESTIMATE OF GLOBAL CHILDREN'S PALLIATIVE CARE PROVISION



	No known palliative care provision for children
	Evidence of capacity building activities for the provision of children's palliative care
	Evidence of localised palliative care provision for children and availability of training
	Evidence of broad palliative care provision for children with the availability of training and focused plans for development of services



The ICPCN is administered from the offices of the Hospice Palliative Care Association of South Africa (HPCA) in Cape Town.  
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[www.truecolourstrust.org.uk](http://www.truecolourstrust.org.uk)