network news

Issue 9
April 2010

icpcn
international children's
palliative care network

LETTER FROM THE CHAIR

Dear Friends

The tragic earthquake in Haiti, with the unimaginable level of suffering that it caused, led many of us to question what our role, as paediatric palliative care practitioners, could be. An active member of the ICPCN, Colette Cunningham went to Haiti to work with an aid organization, and kept us informed of her work there. She wrote to us of what she saw and experienced, of the suffering, and of the incredible resilience of a number of adults and children despite their loss. We were able to identify a children's hospice in Haiti, Holy Angels Hospice, and thanks to Colette's assessment , and relationship with Catholic Relief Services, bring some measure of relief to the children and staff.

The value of networking relationships were highlighted when through a long-standing partnership between Sunflower Children's Hospice in South Africa and Vitas Health Care Corporate Office in Miami, Vitas generously provided essential nutritional support and other gifts to Holy Angels Hospice. Please continue to support Holy Angels Hospice wherever you can as the children will need outside encouragement for some time to come.

We would also welcome news of any children's palliative care programmes that could be supported if we highlight their activities in this newsletter and on the website. Colette has willingly agreed to head up a discussion forum to consider how we as a children's palliative care community can respond to such disasters in future and my thanks to those who have offered to be part of this group and to Dr Colin Murray-Parkes from Cruse Bereavement Services who spontaneously offered support and materials. We would be delighted to have more members for this group or any ideas you may have to support the discussion.

We are delighted that the ICPCN Scientific and Research committee has been established with representation from a variety of regions and professions, and wish Prof Sue Fowler-Kerry, the first Chair, and her team , strength as they develop this essential portfolio. My recent participation in the development of international guidelines for children shows that there is a dearth of strong evidence for what we believe is good practice.

The world of palliative care for children continues to grow and reach more children and families and we are always excited by news from around the globe, on palliative care services and innovative responses to children's suffering. It was exciting for us to be present at the initial founding of the Paediatric Commission of the Latin-American Palliative Care Association, during the excellent ALCP conference in Buenos Aires, where Dr Rut Kiman arranged a plenary and "Meet the Expert" session on the ICPCN .

May you all be blessed in the work you do and my sincere thanks for your participation in the ICPCN.

Alll good wishes,

Joan

FIRST UK CHAIR IN PAEDIATRIC PALLIATIVE CARE APPOINTED

The ICPCN welcomes the appointment of Myra Bluebond-Langner as the True Colours Chair in Palliative Care for Children and Young People. This post is the UK's first Chair in paediatric palliative care. Funded by **The True Colours Trust**, the appointment will be jointly held at UCL Institute of Child Health (ICH) and Great Ormond Street Hospital (GOSH) Myra comes to this new role from Rutgers University where she was the Distinguished Professor of Anthropology. Her early work on leukaemic children is regarded as marking an important change in the way children are studied and regarded by researchers. Her recent studies of decision making for children with cancer when standard therapy has failed broke new ground in approaches to the study of decision making and in the involvement of children in research.

Talking about her new appointment, Professor Myra Bluebond-Langner said: "We are at a critical juncture in the development of palliative care for children and young people. As the field continues to advance we need to increase both the evidence-base and the capacity of the current work force to carry on the research and clinical work necessary to deliver the highest standard of care to these children and their families. My goal as the True Colours Chair in Palliative Care for Children and Young People is to help us to meet these challenges through the development and implementation of a multi-disciplinary and integrated program of research, clinical practice and education. I look forward to working with people here, whose pioneering work grounds the field and sets the standard for excellence."

The True Colours Chair in Palliative Care for Children and Young People is funded by The True Colours Trust, and the appointment will be jointly held at UCL Institute of Child Health (ICH) and Great Ormond Street Hospital (GOSH). Once in post, it is anticipated that Professor Bluebond-Langner will work closely with key children's palliative care agencies throughout the UK as well as the ICPCN.

The True Colours Trust

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

CONFERENCES, CONGRESSES & COURSES

INTERNATIONAL EVENTS CALENDAR: APRIL - JUNE 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

April		
11 - 16	International Multi-Professional Paediatric Palliative Care Course	Haltern, Germany
14	Finding the Right Balance	Preston, UK
May		
06 - 07	The 2nd Pediatric Palliative Care Forum	Minneapolis, MN, USA
17 - 22	Play for Life World Congress	Morocco, Marakech
18 - 19	"House with Walls" Congress on Children's Palliative Care	Pécs, Hungary
June		
01 - 04	2nd TB Conference	ICC, Durban, South Africa
02 - 03	9th Annual Kaleidoscope Conference - Caring and Connecting in Palliative Care	Dublin, Ireland
12 - 18	3rd Paediatric Pain Master Class	Minneapolis, MN, USA
29	Respiratory Conditions and Care in Children and Young People	Chorley, UK

SAVE THE DATES

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 Dunne, 1618

Reduction in Conference Fee

We are delighted to be able to announce a substantial reduction in the delegate fees for the Cardiff conference in July 2010. We are aware of the difficult global financial climate, and the constraints this has meant on funding and study leave. The cost will now be £199 per delegate: a reduction of more than £50 on the original fees.

Change in Venue

We have been able to achieve this by changing the venue of the conference to one of the bigger buildings at Cardiff University (Main Building is No 39 on the Cardiff University Location Guide). The change of venue is ONLY for the conference itself; the Hilton Hotel remains the venue for the conference dinner, and we would also encourage you to take advantage of the discount they are offering on residential accommodation. Remember that accommodation within the University itself is very basic (it is designed for students). It is really recommended only for those keen to keep costs to an absolute minimum!

Registration

For those of you who have already sent your registration forms the price will automatically be changed.
If you have any queries about this change in venue and cost, please do not hesitate to e-mail us at: PPC2010@cardiff.ac.uk
To learn more go to: http://www.icpcn.org.uk/page.asp?section=000100010028&sectionTitle=5th+International+Cardiff+Conference+on+Paediatric+Palliative+Care

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

Organizers and Chairs:
STEPHEN 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.

A pre-conference pediatric palliative care workshop will be presented featuring;
Advanced pain and symptom management in children & Models of Care

CHI
21st World Congress
WASHINGTON D.C. USA • OCTOBER 11-14, 2010
The Future of Children's Hospice & Palliative Care: Completing the Circle of Care
L' Enfant Plaza Hotel, 480 L'Enfant Plaza, SW,
Washington DC, USA
For more information visit: www.CHIonline.org


The 26th International Pediatric Association Congress of Pediatrics 2010 (IPA)
"Simunye" We are one
Johannesburg
South Africa
August 4-9
2010


1ST OVC IN AFRICA CONFERENCE
DON'T TURN A BLIND EYE
31 OCT - 3 NOV 2010
SANDTON CONVENTION CENTRE JOHANNESBURG

Regional Round-Up

UNITED KINGDOM

Lobbying of political parties for sustainable funding for children's palliative care within the UK is a priority. To date the following progress has been made:

Children's Hospices UK met with the Leader of the Opposition Government which led to the draft health manifesto given by Tory party for continuation of central government funding for children's hospices as of April 2011, and a pledge to introduce a new per patient funding system for all palliative care providers "to ensure proper support for sick children".

The Government announced their plans for improving access to community children's nursing services and to ensuring that this is available 24/7 to enable families to have choice about their child's place of death. Further lobbying will need to take place to ensure that this becomes a Manifesto commitment.

ACT launched a direct campaign action to all of its 900 members to request that they contact their local MP to ask about their party's manifesto commitments to children's palliative care.

ACT

ACT published 'Best practice prompts in End of Life Care' in February 2010. This is a new good practice tool which provides a checklist to help professionals plan and prepare when they are caring for a child or young person in the last hours and days of their life.

ACT is developing a series of twelve training packages and will be training and accrediting a number of people to deliver this training to a wide range of health and social care professionals.

Children's Hospices UK

Children's Hospices UK is running a series of workshops on commissioning for children's hospices in April 2010.

Children's Hospices UK has produced a draft Toolkit on User Involvement which has been distributed to all Children's Hospices for feedback prior to final publication in June 2010 .The toolkit is intended to enable children's hospice services to improve the way that they engage with children, young people and their families to influence the strategic development of their services

Safeguarding - We are engaging with children's hospices to explore ways in which we can ensure that there are appropriate safeguarding procedures and practises in children's hospice services.

Children's Hospices UK and ACT are organising a joint conference for children's palliative care practitioners in June 2010

With the imminent election due to take place in Spring 2010, we are very focused on lobbying for a commitment to sustained funding for children's hospices and palliative care from the current government and the third main political party, having secured a commitment from the main Opposition Party, the Conservatives. Alongside this, we are urging our members to do their utmost to make commissioning arrangements with local health and social care budget holders work.

Report by Barbara Gelb & Lizzie Chambers

CENTRAL & SOUTHERN AFRICA

Palliative Care for children in Africa continues to gain momentum. Here are some updates on what is happening in and around central African countries:

THE APCA PALLIATIVE OUTCOME SCALE (POS)

We have been finalising the initial pilot for the APCA African Children's Palliative Outcome Scale. A review meeting was held on the 6th March to look at the results from the pilot, in order that we may review and amend the tool as appropriate, and plan the second phase of the piloting.

POCKET BOOK

Work is also ongoing on the integrated pocket book for palliative care in Africa for both adults and children as well as a pocket book looking at issues around pain, which will include both adults and children. These have been drafted and sent for review and are now being edited in line with the comments from reviewers.

APCA CONFERENCE

Another area we are looking into is the issue of how we can best integrate children's palliative care throughout the **APCA Conference** from the 15th to the 17th of September 2010. The conference will take place in Windhoek, Namibia with the theme:

Palliative care in Africa: Creativity in Practice

If you would like to find out more about this conference please visit the website at: https://ssl-id1.de/apca-windhoek2010.com/home/home

We are currently undertaking a review of policy in 15 African countries and are looking for issues around children as well as adults in palliative care.

A meeting was held to discuss the place of Decent Care in palliative care and this meeting included a special interest group on children.

SOUTH AFRICA

At present there are a total of 56 children's palliative care programmes up and running within South Africa. The Diana, Princess of Wales Memorial Fund "Three Country Project" is progressing well with navigators running training courses in April. The Human's Rights Watch has made contact as they are plannng a visit to Kenya and taking up the issue of Children's Pallliative Care as a human right in this country. We plan to link this to ICPCN through our scholarship programme, funded by OSI. Kenya, Zimbabwe and Zambia are keen to move their programmes forward and we plan to bring people from those three countries into South Africa to train them as trainers and support them to go back and train others within the field of children's palliative care.

Reports by Dr Julia Downing & Joan Marston

AUSTRALIA & NEW ZEALAND

The main focus of services around Australia and New Zealand has been the completion of the National Standards Assessment Program. Six of the 8 services have now completed the first phase and from this they have developed a work program specific to their service need.

High level work at state and federal level continues in a number of Australian states and in New Zealand with this work ranging from a recognition of the PPC service in South Australia as a high level provider in the state wide palliative care plan, to Queensland holding a key stakeholder forum on PPC to discuss issues of concern - including barriers, gaps in service provision and suggestions for future improvement.

Allow Natural Death Policy

Westmead Children's Hospital in Sydney and Starship Children's Hospital in NZ have both recently instituted "Allow Natural Death" policies and "End of Life" care plans.

Needs of children with severe disabilities

Another common theme amongst services in the region has been the establishment of a variety of positions ranging from an Occupational Therapist in Victoria, so as to recognise the needs of the large group of children with severe disabilities and the difficulty they have in obtaining equipment through to medical training positions to aid succession planning and to address the requirement for improved access to medical expertise.

Support for families at home

There are a number of excellent projects happening across the region focussing on improving support for families at home through packages of care, volunteer programs, information in the form of multilingual resources and publication of the 2nd edition of "A Practical Guide to Palliative Care in Paediatric Oncology".

Work across the region of Oceania often reflects how well established services are in their areas. The range of work covers service improvement, service recognition, education of healthcare workers, the 7th Annual Paediatric Palliative Care Symposium at Westmead Children's Hospital (NSW) and tailoring services to the needs of families by seeking consumer feedback and conducting a randomised controlled trial of existing videoconferencing facilities in Queensland.

All services are actively engaged in strategic work at state or national level, with these at various stages of development.

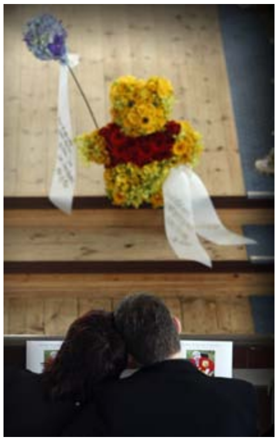
Challenges

Our challenges include timeliness/gate-keeping of referrals as well as equity of service provision, particularly for rural and remote populations and in New Zealand, access to specialist Paediatric Pallliative Care outside of the Auckland region. Succession planning and inadequate respite were also highlighted with the latter particularly acute for Queensland following the closure of the children's hospice in Brisbane in 2009.

Report by Dr Ross Drake

Regional Round-Up cont.

NORWAY



Andrea, the child responsible for the founding of "Yes to Palliative Care and Units in Norway", died in her mother and father's bed, February 7th 2010, aged 17 years. Natasha and Jim, her parents will continue to work for palliative care for all the children of Norway. The funeral was beautiful, the church was packed full of friends and family and others who wanted to pay their last respects. Her very best friend, Winnie the Pooh (Andrea was his biggest fan) was the guard of honour and followed her to Heaven.

"Yes to Palliative Care Units for Children" raised more than USD450 at the funeral, and in the following days, the amount increased to USD3000.

The very same day that Andrea was buried, our government finally talked about a "Plan to Help Living", which will occur on 2 March 2010. Several times our organization has been mentioned in the Norwegian Parliament. In a very short time, we have accomplished a lot! We have 47 paying members. We are working on translating books and literature, which we will sell to doctors and health workers as soon as possible. Also we have also formalized a "partnering" with Children's Hospice International. Ann Amstrong-Dailey has agreed to be a mentor for our CEO, Natasha Pedersen. We also sell T-shirts and stickers, and every penny will go to the organization.

We are very lucky to have a child-physiotherapist on the Board, and we also co-operate with Doctor Eva Albert who works with Palliative care unit for adults. We hope to cooperate with NPFM, and have been invited to a Norwegian conference in Bergen in September. We have also been interviewed by the local paper, magazines and national television.

One of our goals is to raise enough money so that we can travel around the country and teach doctors, parents, sisters and brothers how to give the best possible care to the sick child. And last, but not least, start a support-group for everybody who is, and will be, in this situation.

Our work will continue in Andrea`s spirit.

Froeydis Vatne Graham
Member of the Board "Yes to Palliative Care and Units in Norway"

ARMENIA

Narine Movsesyan, an Armenian doctor, has been working tirelessly to introduce the concept of both adult and paediatric palliative care into her country. Narine has been corresponding with the ICPCN and was pleased to report that in February this year she was able to arrange a meeting with Stephen Connor of the Worldwide Palliative Care Alliance (WPCA). Stephen gave a presentation about a needs assessment in Palliative Care in Armenia. Narine also organized a meeting with their onco-haematologists working with children, and introduced him to the working group for children's palliative care in her hospital.

Concert

Events have been organised in Armenia in order to promote and gather funding and support for palliative care, including a special concert. Narine reports, "There were many famous Armenian artists who played for Armenian children. There was an amazing artist who created pictures from sand. The child in the picture is from our hospital. Her name is Malvina. Many sick children were not allowed to attend the concert because of the unfavorable epidemic conditions caused by swine flu."

Inspiration from the book

Narine writes, "I have started to read the book "Children's palliative care in Africa", and the further I go through the book the more excited I become. This is the most interesting and exciting book I have ever read before. Being a doctor for adults, I have never thought about the things I can come across when dealing with children. Moreover, I think that this book has to be translated into Russian and Armenian in order that a greater audience can read it. And this can be the guidance for those who take the first steps towards Paediatric Palliative care in Armenia. Now I am doing a liitle research in the borders of our department of haematology to figure out how many children really need palliative care at this moment. This can orient me in the direction I have to move. Expect some new members of ICPCN!

Narine Movsesyan

Creating pictures from sand at the concert in Armenia

LATIN AMERICA

A Venezuelan Association of Palliative Care has been created. We are very pleased that the voice of children will be represented by a Paediatrician on the Executive board: Dr. Carolina Kamel.

Study to map the resources for children's palliative care in Latin America

The Latin-American Association for Palliative Care (Paediatric Commission) is committed to improving the care of the Latin-American children at the end of life. We have begun a study to describe the resources for palliative care for children in diverse countries in Latin America during the Latin American Palliative Care Congress. We will share the results of the study with the participants over the next few months. For questions or comments about this study please contact Ana Milena Sanchez MD, MPH at asanchez@unch.unc.edu or 01786-338-8424.

The ALCP Congress

The ALCP congress took place from 16 - 18 March in Buenos Aires. Children's palliative care took prominent place in this event with numerous workshops and round tables, a plenary (presented by Joan Marston, ICPCN Chair) and oral poster presentations.

Joan Marston and Rut Kiman met with doctors in the Ministry of Health involved in the HIV/AIDS programme in Argentina.

Joan and Rut had a productive meeting to promote children's palliative care with Edith Grynszpancholc of the Natali Dafne Flexer Foundation in Buenos Aires, an organization which cares for children and families coping with cancer

During the event we were able to network with the local authorities involved in the AIDS Programme from the Argentine Ministry of Health, the Paediatric Commission of the ALCP as well as Non Government Organizations.

Challenges

Future challenges include advocacy to strengthen the voice of paediatric palliative care to be heard by the Public Health decision makers in the region; to develop guidelines and tools which are validated for our culture as well as education and training materials in Spanish.

Finding funding for the development of paediatric pallitaive care Teams in Latin America is becoming more difficult as the economic crisis hits and international organizations such as the Global Fund decrease their contributions.

Report by Dr Rut Kiman

CONGRATULATIONS ALL ROUND

Our very own "Woman of the Year"!

We are so proud of our very own Steering Group member, **Dr Anna Garchakova**, for recently being awarded "Woman of the Year" in the category "Charity & Mercy" in Belarus. A well deserved award for Anna. Anna founded the Belarusian Children's Hospice in 1994 as a hospice only for children with cancer related diseases. However, by 1995, 40% of the children the hospice was caring for had diseases unrelated to cancer. After three years Anna again responded to the need to expand their services to include respite care. By the year 2000 it became evident to Anna that one hospice was not enough to cater for the needs of all the children in Belarus, and so she set about opening a network of hospices around the country. One of the first to open was a hospice in Gomel, the region worst affected by radioactivity after the Chernobyl catastrophe. In contrast to European countries where Hospices for adults were initially created followed by hospices for children, Belarus has had the reverse experience. With the help of the Belarusian Children's Hospice programmes the first hospices for adults in the Republic of Belarus were created.

We cannot think of anyone more worthy of this prestigious award. Congratulations, Anna!

Anna, on the extreme right, receives her Woman of the Year award at a Gala Function.

Recognition from the President of the All India Congress Committee

Dr Maryann Muckaden, ICPCN Steering Group member and representative for India had the distinct honour to receive a letter of personal recognition from Sonia Gandhi, the president fo the All India Congress Committee (A.I.C.C.) recently. The A.I.C.C. is the central decision-making assembly of the Indian National Congress party and the position of president the most powerful position within the party. In her letter to Dr Muckaden, Sonia Gandhi wrote:

"It is always an immensely humbling experience to see the courage with which children who have cancer and other life-limiting conditions face their illness. There are at least 50,000 such children in India today, in need of palliative care, but only three centres in the country to provide them with it. Every such child, whose courage and indomitable spirit is an inspiration to all of us, has the right to such care and it is our duty and responsibility, as a society and a nation, to ensure that they get it."

She went on to congratulate Dr Muckaden and her colleagues at the Tata Memorial Hospital for their dedicated work for the cause of children's hospice care in India.

Phones : [illegible]

ALL INDIA CONGRESS COMMITTEE
24, AKBAR ROAD, NEW DELHI - 110 011

Sonia Gandhi
President

MESSAGE

For children suffering from a life-threatening or life-limiting condition, even the best medical treatment is not enough. They also need loving and dedicated palliative care for the mind and spirit, to help them have as good a quality of life as is possible in the final stages of their life. Their families too need succour at a time when they are going through great anguish and despair.

It is always an immensely humbling experience to see the courage with which children who have cancer and other life-limiting conditions face their illness. There are at least 50,000 such children in India today, in need of the palliative care, but only three centres in the country to provide them with it. Every such child, whose courage and indomitable spirit is an inspiration to all of us, has the right to such care, and it is our duty and responsibility, as a society and a nation, to ensure that they get it.

I congratulate Dr Muckaden and his colleagues at the Tata Memorial Hospital for their dedicated work for the cause of children's hospice care in India, and wish them every success in their endeavours to provide hospice care to every child who needs it, as well as to their families.

New Delhi
February 12, 2010

10, JANPATH, NEW DELHI - 110 011 · PHONES : [illegible] · FAX : [illegible]

Lifetime Achievement Award

The ICPCN would like to congratulate Dr. Huda Abu-Saad Huijer (seen here in the centre of the photo) on being presented with the International Journal of Palliative Nursing Lifetime Achievement Award at a recent ceremony in London.

Dr Huda Abu-Saad Huijer RN, PhD, FEANS is a Professor of Nursing Science and Director of the Hariri School of Nursing at the American University of Beirut. Huda received this Lifetime Achievement Award in London for her work in paediatric pain and palliative care.

ACT Plays Key Role in development of the UK's first National Framework for Children and Young People's Continuing Care

Leading children's palliative care charity ACT has welcomed the England-wide and first ever dedicated guidance which should provide a new and equitable process for assessing, deciding and agreeing bespoke packages of continuing care for those children and young people who have the most complex heath care needs.

The guidance, National Framework for Children and Young People's Continuing Care was launched on 26 March 2010 by the Department of Health. Continuing care is the care required for those children and young people under the age of 18 who have needs arising through illness, disability or accident that cannot be met by existing universal and specialist services alone. Some of this group of children will have a life-limiting health condition that requires palliative care.

ACT has played a key role in feeding into this framework; representing the needs of families and children with life-limiting or life-threatening conditions, some of whom will benefit greatly from this new development. The National Framework for Children and Young People's Continuing Care includes a continuing care pathway model, which is based on ACT's care pathways for children with palliative care needs.

You can download a copy of National Framework for Children and Young People's Continuing Care at http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_114784

A NEWSLETTER FROM HAITI

Colette Cunningham, an ICPCN member and a member of our newly formed ICPCN Scientific and Research Committee, wrote this Newsletter from Haiti to friends and supporters on the 13th of February 2010, a week before she was due to return home to Ireland. Colette, a registered nurse, fluent in French, had flown out to Haiti soon after the earthquake. She worked wtih the Catholic Relief Services, bringing much needed humanitarian and health aid to those who had been worst affected by this catastrophe.

Colette lands in Haiti soon after the earthquake struck the island in January 2010.

Another week has gone by so quickly – it is so hard to believe; I have lost track of the days. Its been one month since the earthquake.

I am now on the homerun and will be returning home this week. I cannot tell you enough how much I appreciate all the prayer, little notes on Facebook and emails of encouragement that I have received this past week... they have all meant so much and sometimes they are have been very timely. They have kept me going.

It has been a month since the earthquake.The needs are still very great here especially for water, food, and shelter – the World Food Program(WFP) divided the city into zones for food distribution based on a ration basis.. it has been good in one sense because people have been receiving food but on the other hand some smaller camps are being 'forgotten' and are still without food... in addition some of those smaller camps - that are our health sites - are not in our zone and under the jurisdiction of other organisations so we have no way of controlling who gets food and who does not. However, we hope to be able to track it all next week so that all sites will get the food. It is very difficult to have to walk away from a camp knowing that they have not yet received food.

The rains came this week—I awoke early to the sound of torrential rain pounding on the tin roof – I cried as I thought of the 3000+ people living in the camp below the house... a camp made of makeshift tents from wooden poles and sheets—at best some have a plastic tarpaulin for a roof – most do not. One of my colleagues and friends here from the US is also a Christian and at the breakfast table we prayed and cried together.

When I visited the camps that day, everyone was asking for a tent and telling me how wet they were during the night. I cried to the Lord—what else could I do? Tents have started to arrive into the country – we received a donation of 5000 this week but it is just a drop in the ocean for all those who need one – and I am only counting for the 10 health sites where I am working.

In one camp alone there are 70,000 people — it is on what used to be the most prestigious private club in Haiti – Petion Ville Golf Club. Visiting there is a surreal experience – as you enter the club it is a base for US Marines who run a small health clinic in one area of the camp. There are port-a-loos and port-a-showers all nicely lined up, clean and orderly. There's the club house with a widescreen TV showing a rubgy match and a bar, the tennis court, swimming pool and library; but when you look beyond you see a colourful landscape of squares—makeshift homes for 70 000 people.

In the midst of the needs, I have met some amazing people and have made wonderful new friends; there is a Christian couple in one of the camps—they are the camp committee leaders and have lost everything. Prior to the earthquake they were the directors of a school for communication, buisness and computer studies. They have lost their home and business, yet, they manage to say "We are well – thanks be to God." Many people have been an inspiration to me by their faith in the Lord.

The Government declared three days of Fasting, Prayer, and Worship this weekend: National Action for Grace. Since the early hours of yesterday morning people across the city in camps, tents, Churches, school yards, in the street have been singing and praying to the Lord. Its quite something to watch—people with their hands raised in praise to the Lord, with shouts of ' Halleluah' – You are the only one – Jesus our Saviour! – its not something CNN or BBC will show—but it is amazing.

The night is punctuated with shouts of Halleluah, AMENS and Praise the Lord – with clapping – and singing – always the singing. And all of this in the midst of their desperate needs and tremors that continue – last night we had one and quite a strong one again this morning. I was finally able to stay at my Haitian friend's house last night (Yveline and I know one another from Zambia) and I was also able to sleep in a bed—bliss!! This morning my bed was shaking but it did not last for too long.

Please continue to pray for the people of Haiti- they need all your prayer and support.

Love and blessings
Colette

UPDATE ON HOLY ANGELS HOSPICE

Some of the residents of Holy Angels Hospice sit underneath a temporary outdoor shelter

During her time in Haiti, and at our request, Colette visited the Holy Angels Hospice in Port au Prince, where she found that the building that housed the 17 resident children had been damaged to the extent that the children and their carers were sleeping outside.

CRS supplied the Hospice with much needed shelter in the form of 10 large tents. They also supplied the Hospice with food and water and the children have been registered with both CRS and UNICEF for Child Protection. This will ensure that their basic needs for health, food and shelter are taken care of for the foreseeable future. With the help of ICPCN contacts a supply of much needed Ensure was sourced and shipped to the hospice for Peterson, a child requiring tube feeding. This donation was made possible through the kindness of the Vitas Corporate Head Office in Miami.
The rebuilding and restoration of the facility is ongoing and Father John Bellezza asks that should anyone wish to contact him or help with any donations, they may do so via this address:
P.O. Box 185
Whiting, New Jersey
08759
Email: holyangels@live.com

Colette with a young survivor

Colette has agreed to head a discussion forum to look at ways in which the ICPCN can respond to future disasters such as this. Should you wish to be part of this group, please send an email with your name to Sue Boucher on sue@icpcn.co.za

The Haiti earthquake was a catastrophic magnitude 7.0w earthquake which occurred at 16:53 local time on Tuesday, 12 January 2010. By 24 January, at least 52 aftershocks measuring 4.5 or greater had been recorded. As of 12 February 2010, an estimated three million people were affected by the quake. Save the Children reports that up to 2 million children were affected by the earthquake and set up safe space areas for children as well as child tracing programs to reconnect children who were separated from their families during the emergency. Children and adolescents under 15 make up nearly 40 per cent of the population in Haiti and young people from 15 to 24 account for another 20 per cent. Even before the earthquake the needs of many Haitian children were not met. Nearly one in every fourteen children did not live to see their fifth birthday and children who survived were afflicted by high rates of malnutrition. About 50 percent of all Haitian children did not attend primary school and only 18 per cent of boys and 21 per cent of girls attended secondary school.

KENYA MARKS INTERNATIONAL CHILDHOOD CANCER DAY FOR THE FIRST TIME

Hope for Cancer Kids

CURE FOR EVERY CHILD, CARE FOR EVERY FAMILY

By James Nyaga

A riot of young soft voices and green colors marked the first International Childhood Cancer Day (ICCD) in Kenya.

The event, organized by a local charitable organization - Hope for Cancer Kids (HCK) and Kenya Hospice and Palliative Care Association (KEHPCA) attracted over 1000 participants, the majority of them children under 12 years. The pupils from Makini schools, Maxwell Academy, Compuera Academy and students from Nairobi braved the morning chill to show solidarity with their sick peers. The event started with a 4 km walk around Kenyatta National Hospital, Kenya's main referral hospital.

The guest of honor Prof. Anyang' Nyon'go sent Dr, David Kiima to represent him. Dr Kiima thanked the organizers of International Childhood Cancer Day and added that the government recognizes the role of the charitable organizations in the fight against childhood cancer "I believe this event will become the flagship in childhood cancer awareness in our health sector in the coming years," he said.

For his part, Kenyatta National Hospital's chief Executive Officer Dr. Jotham Micheni expressed confidence in the organizers and said the hospital management is doing everything possible to make lives of the affected children and families better. He appealed to Kenyans to join the State owned National Hospital Insurance Fund to reduce their financial burden, which he admits if too high for ordinary Kenyans.

Hope for Cancer Kids chairman Mr. James Munge outlined HCK's goals this year, chief among them being the establishment of a Paediatric Palliative Care Center. And he appealed for funds from corporates and well wishers from all over the globe.

"The dream of having a one stop centre for children with cancer and their families may take some time, but will certainly come true in our generation, and probably in the next one year. I therefore kindly request everyone to do their bit, and we will change the face of childhood cancer in this country" said the Chairman, in his passionate address.

> **"The dream of having a one stop centre for children with cancer and their families may take some time, but will certainly come true in our generation, and probably in the next one year. I therefore kindly request everyone to do their bit, and we will change the face of childhood cancer in this country"**

The majority of children present when the disease is too advanced, hence the worsened chance for cure. With Kenyatta National Hospital far outstretched by the number of patients, a Paediatric Childhood Palliative Care Centre will be a relief to hundreds of families that sleep on the hard cold floor of the hospital as they await their turn to receive treatment. In some instances, children spend over one year in hospital, some already discharged but unable to clear bills.

> **Kenyatta National Hospital records that there has been a 200% increase in childhood cancer cases in Kenya in the last 10 yrs, but no matching investment in terms of medical infrastructure.**

The International Childhood Cancer Day event was sponsored by Kenya's leading mobile company - Safaricom Ltd, New KCC, KEHPCA, Aquamist Water, Highlands mineral water and many others.

WEBSITE LAUNCH

Hope for Cancer Kids made use of the occasion to launch its new website:

www.hope4cancerkids.org

Hundreds of pupils under 12 years participated in the ICCD walk


Makini school pupils recite a poem during the event


Children release "feel better" balloons into the air.


Cancer survivor Michele Ongaro entertains participants (his son died of cancer 2 weeks before the event)


Children follow the proceedings

A Makini school pupil holds a placard bearing a palliative care message

These images show the children's excitement and enjoyment of this event. "More funding is needed for cancer treatment and palliative care" was the clear message of the day.

PARTNERSHIPS IN CARING

A look at the value of partnering and networking within the Grahamstown Hospice Paediatric Palliative Care Programme

Angela Hibbert, the Psychosocial Services Manager at Grahamstown Hospice shares some insights on the pivotal role of partnering with various organisations, Government Departments and individuals in running a successful paediatric palliative care programme. Grahamstown is a small University town, set in the hills of the Eastern Cape province of South Africa. Despite limited resources, through strategic partnering and networking the reach of their hospice goes miles beyond the borders of the town and into the less accessable rural and coastal settlements of the region.

Grahamstown Hospice Orphans and Vulnerable Children's programme is designed to meet the specific needs of the children in our care. These children are either patients, children of patients, recently bereaved or family members living in the home. In order to assist these children we rely on the support of various private and corporate donors

The paediatric patients are cared for by professional nurses who visit the children in their homes. They assess their holistic needs and work alongside hospice social workers and various networking partners in order to access the best care for the patients.

A professional nurse assigned to paediatric home based care, pays a visit to one of her patients. The pram was donated by a family in the UK

These vital partnerships with the paediatric palliative care ward at Settler's Hospital, primary health care clinics, ARV clinics and allied health care professionals at the hospital and developmental clinics assist in monitoring the growth and development of the child and ensure appropriate interventions and support around treatment adherence.

SUPPORT GROUPS

Newly formed carer support groups have been established in Grahamstown and Port Alfred to provide a platform where carers can raise their concerns and where education can be provided as required.

The paediatric patients of school going age attend weekly support groups run by social workers in Grahamstown, Port Alfred, Alexandria, Kenton-on-Sea and Alicedale. The programme includes stimulating and creative activities, resilience work and therapeutic interventions.

Children in the Support Groups immerse themselves in activities which encourage adherance and promote resilience.

Settlers Hospital is run as a state/private partnership. Working with the hospital resulted in the opening last year of an In Patient Unit for the children in our care. Generous donations from local Grahamstown businesses and the Grahamstown Rotary Club were used to refurbish and furnish this unit in calming pastels as well as with the latest medical equipment. Adult beds are also available to encourage family members to remain with their child in the unit for the duration of their stay.

At present our support groups are reaching a total of 85 children, 60 of which are patients and the remainder have been bereaved.

One of our donors made it possible for us to provide school uniforms and activity packs to needy children in our care.

Social workers work closely with Child Welfare and the Department of Social Development when children are found in need of care as well as SASA (South African Socialogical Association) for grant applications.

We have several poverty alleviation projects including food parcels, school uniforms, care packs, activity packs and also access funds through the Centre of Social Development at Rhodes University for early childhood education.

Report by Angela Hibbert
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TREATMENT GOALS IN THE MANAGEMENT OF PAIN IN CHILDHOOD

A look at individual pain management plans by Dr Rene Albertyn (PhD) of Red Cross Children's Hospital in Cape Town

Chronic pain can be described as pain that is endured beyond the time span of injury or normal pain stimuli. Both adults and children can experience chronic pain as it is due to a variety of conditions such as: cancer pain, headaches and abdominal pain (often observed in children), lower back pain, pain following traumatic nerve damage (such as burn injuries), arthiritis, peripheral neuropathies and in some cases, pain of unidentified cause.

It is clear that due to its nature, chronic pain can present a major problem to both the health care provider and the patient.

> **No two people experience pain in the same way. It is therefore needed to develop an individual pain management plan for each patient – a plan that is tailor made specifically for that person.**

No two people experience pain in the same way. It is therefore needed to develop an individual pain management plan for each patient – a plan that is tailor made specifically for that person. Included in the individual pain management should be treatment goals.

Treatment Goals

The first goal should always be the alleviation of pain. In pain management, this is probably the most important goal, even in cases where resistance against a certain drug is noted. It is important to find an appropriate analgesic and anxiolytic drug combination in conjunction with a supplementary health therapy (e.g. touch therapy, relaxation therapy, excercise).

The following approach is suggested for drug management planning:

Opioids

Opioids can be useful as it provides for short term, intermediate and long term analgesia. Side effects such as constipation, skin conditions, drug tolerance, chemical dependence and addiction (more so in adults) should be anticipated.

NSAIDS

NSAIDS may be administered on its own or in combination with other drugs. NSAIDS designated as selective COC-2 inhibitors could have significant coardiovascular and cerebrovascular risks as well as renal and liver problems when used for a prolonged time. Other useful drugs to consider in the management of chronic pain are tricyclic antidepressants and anticonvulsant drugs. Both these options have analgesic abilities. It is important to note that in the management of chronic pain, it is rarely possible to achieve absolute pain alleviation and sustained pain relief. The ultimate treatment goal should be to provide pain management with the aim to achieve pain tolerance.

> **The ultimate treatment goal should be to provide pain management with the aim to achieve pain tolerance.**

The second goal is the provision of psychological support. This involves an analysis of the impact pain has on the psyche of the patient. It is essential to be aware of the possible development of psychological problems such as depression, stress/distress or anger and agitation. An in-depth understanding of the patient's psychological situation is of great importance. Coping mechanisms, the availability of support systems, social issues such as the ability to socialize, forming relationships an family dynamics are important issues to explore.

The third goal in the management of chronic pain is to provide the patient with confidence and to restore function. Chronic pain, in relation to chronic illness often relates to a lack of confidence and low self esteem, leaving the patient unable to live a full life. Part of the support offered should focus on trying to restore "as far as possible" normal function. Decreased physical ability might develop in fear of exacerbating pain. For the paediatric patient, parenting skills, relaxation techniques and other forms of support and information can be offered to the parents of a child with for example a neurological disorder, or to the child who may be receiving palliative care. Unfortunately these strategies are time consuming and as a result are often omitted from the treatment plan.

The fourth goal in the management of chronic pain is the provision of education. Patients with chronic pain can be seen or treated in hospital wards, in out-patient clinics or in specialized wards (e.g. oncology or cardiac patients).

Care for these patients include the involvement of a number of health care workers such as nurses, medical doctors, physiotherapists, psychologists) as well as pain management teams.

The Value of Education

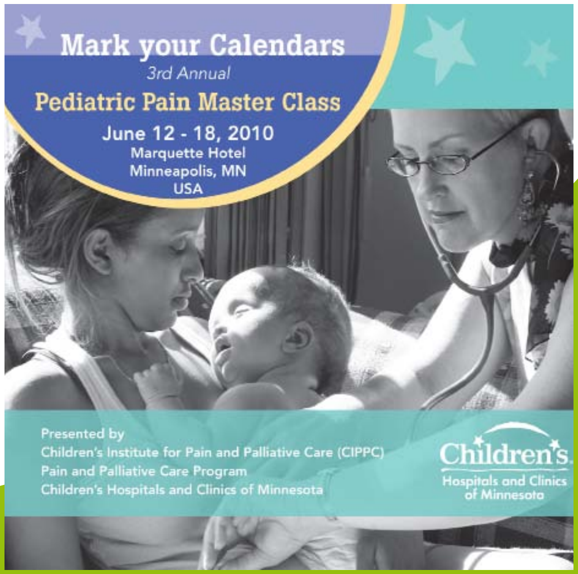
Health care providers involved in caring for the patient with chronic pain should be educated around a number of issues, such as coping mechanisms, psychological issues, family dynamics, as well as cognitive developmental levels in the case of a paediatric patient.

> **Insight into and an understanding and awareness regarding the patient's situation will provide for more optimal care.**

Insight into and an understanding and awareness regarding the patient's situation will provide for more optimal care. Patient and family education is equally important. Information around for example the initiated drug therapy, impact of disease and treatment plan could empower the patient / family and provide for better compliance and coping.

Report by Rene Albertyn
Red Cross Children's Hospital
Cape Town, SA
Email: R.Albertyn@uct.ac.za

An intriguing new study led by doctors at the Dana-Farber Cancer Institute in Boston aimed to explore the lengths to which a parent may be willing to go to end the pain of children suffering from a fatal illness. The research was carried out through a series of interviews conducted with 141 parents whose children had died of cancer. Read the Time Magazine article online at: http://www.time.com/time/health/article/0%2C8599%2C1968978%2C00.html



WE ARE PROUD TO INTRODUCE THE ICPCN SCIENTIFIC & RESEARCH COMMITTEE

December 2009 saw the formation of the ICPCN Scientific / Research Committee. The scope of work for the members of this committee include:

- to provide a forum of peer review for authors of articles and proposed research in the field of PPC,
- to identify, recommend and prioritise areas of required research in paediatric palliative care
- to develop a network to support researchers in the field of paediatric palliative care
- to develop a web-based database of articles and research being conducted or proposed
- to assist in developing a structure for multi-centre clinical trials and study protocols.

The recent formation of an ICPCN Scientific and Research Committee was first suggested by Dr Rut Kiman and discussed further at the ICPCN meeting which took place at the European Association of Palliative Care Congress in Vienna. The way forward in this endeavour was agreed upon at the subsequent ICPCN Executive Board meeting on the 5th June, 2009.

In October of 2009 a call for expressions of interest was circulated to the international ICPCN membership and forwarded to any interested parties. The selection committee were looking for members who would be representative of as many regions of the world as possible as well as representative of diverse fields within the palliaitive care world. The exceptional quality of the applicants made the choice of the final committee a difficult task but the selection committe feel that those chosen have a very strong research background coupled with years of experience. The committee is also representative of a broad spectrum of professionals working within the field of children's palliative care.

The selected members of the ICPCN Research committee are as follows:

Dr Jan Aldridge BA, MSc, PhD, CPsychol
Consultant Clinical Psychologist in Paediatric Palliative Care and Chair of the Research Committee - Martin House Children's Hospice
Honorary Senior Lecturer in Clnical Psychology - University of Leeds
Honorary Consultant Contract - St James University Hospital, Leeds
Yorkshire, United Kingdom

Dr Susan Cadell B.A., MSW, PhD
Associate Professor - Wilfrid Laurier University: Faculty of Social Work
Interprofessional Advisor and Affiliate Professor - University of British Columbia: Faculty of Medicine, Division of Palliative Care
Director - Manulife Centre for Healthy Living
Ontario, Canada

Colette Cunningham M.A.; B.A. H.Dip. Ed, R.N. R.M
International Health and HIV Consultant
Solas Consultancy
Cork, Ireland

Dr Julia Downing, B.N., Dip Cancer Nursing, M.A., PhD (Vice chair)
Deputy Executive Director - African Palliative Care Association (APCA)
Honorary Research Fellow - Dept. of Palliative Care & Policy,
Kings College, London
Fellow of the Higher Education Academy
Kampala, Uganda

Professor Dr Susan Fowler-Kerry B.A., B.S.N, M.N., PhD (Chair)
Professor
College of Nursing, University of Saskatoon
Director of the RBC Nurses for Kids Program
Saskatchewan, Canada

Dr Rosa Germ M.D.,
Cert Pall Care Teacher
Palliative Care Instructor
Hospital Garrahan
Bueonos Aires, Argentina

Dr Richard Hain MB BS, MSc, MRCP(UK), FRCPCH, Dip Pall Med
LATCH Senior Lecturer and Honorary Consultant in Paediatric Palliative Medicine
Dept. of Child Helath, Cardiff School of Medicine,
University Hospital of Wales
Cardiff, Wales

Dr Jenny Hynson MBBS., FRACP., PhD
Consultant Paediatrician - Victorian Paediatric Palliative Care Programme
Deputy Clinical Director - Children's Bioethics Centre
Melbourne, Australia

Dr Caprice Knapp, PhD, M.A., B.A. Cum Laude (Vice Chair)
Economist and Assistant Research Professor
University of Florida
Florida, USA

Professor Dr Christian Loffing, PhD
Professor
Hochschule Niederrhein University of Applied Social Sciences
Founding Manager
Bundersverband Kinderhospiz e.V., Freiburg
Monchengladbach, Germany

Dr Lulu Mathews M.B.B.S., D.C.H., MD (Pediatrics)
Retired Head, Dept of Pediatrics, Medical College, Calicut.
Medical Officer, Pain and Palliative Unit
Prof and Head, Dept of Pediatrics,
Medical College, Pariyaram, Kannoor, Karala
Calicut, India

At the first teleconference meeting of the committee, Susan Fowler Kerry was elected as Chair and Julia Downing and Caprice Knapp as Vice Chairs. "We hope that this committee will grow to have a very positive influence on international paediatric pallitiative care and on research in this field," commented Joan Marston, ICPCN Chair and ex-officio member of the committee.

Joan Marston, ICPCN Chair was thrilled to have the opportunity to meet with newly appointed ICPCN Scientific & Research Committee member, Dr Rosa Germ, during the recent Latin American Palliative Care Congress which took place in Buenos Aries, Argentina.

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

Membership of the ICPCN is free and open to all who work in the field of palliative care for children.
To join go to www.icpcn.org.uk