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LETTER FROM THE CEO



Dear Friends,

There is much to be excited about in the field of children's palliative care, not least the imminent registration of the ICPCN as an independent UK registered charity with a formal Board, and the preparations for registering the first regional branch of the ICPCN as a not-for-profit company in South Africa, where most of the staff are employed.

Our new board committees - Finance and Resource committee chaired by our Treasurer, Richard Carling and the Advocacy committee, chaired by Sabine Kraft, our vice-chairperson, will help us to meet our strategic objectives; and the existing Scientific committee is very active on a number of projects, all increasing the impact of our work for children needing palliative care.

At a recent EAPC conference in Lisbon we held very challenging discussions with active professionals from different countries, and Dr. Rene McCullough spoke of the need for a "Global Strategy". If we are to reach all children in need of palliative care we surely need both a global strategy and the will to make things happen.

Committed and passionate leaders are

taking children's palliative care forward in a number of countries and the need to work collaboratively and support each other is becoming increasingly important. There are at least three children's palliative care conferences planned for the last few months of this year, with another five planned for 2012, a sure sign of the energy that is working to help life-limited children in many regions of the world.

Charles Kingsley wrote: "We speak as though comfort and luxury are the most important things in life, when all that we need to make us really happy is something to be enthusiastic about."

Thank you for adding your energy and excitement to ensure access to palliative care for the millions of children who need our compassion and support.

I salute each one of you!

Warmest good wishes,

Joan

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

You could still win one of two US\$50 vouchers for amazon.com by taking part in our ICPCN training survey

ICPCN is undertaking a survey of training needs and training programmes in children's palliative care. We hope that it will help us to understand training needs from around the world in order to help shape future training programmes and also to develop a comprehensive database of training programmes on children's palliative care from around the world.

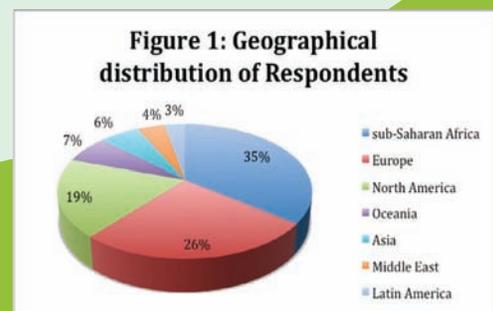
Since the survey went live on the ICPCN website more than 260 people have completed the survey from across the world (see Figure 1)

representing the multi-disciplinary nature of children's palliative care including nurse, doctors, social workers, clinical officers, physiotherapists, occupational therapists, teachers, religious leaders, and researchers. More than 50 training programmes and 30 study days have been identified, with 80% of courses lasting for less than six months, and 20% for longer than six months.

We would appreciate it if we could have over 350 people completing the survey from across the world - so if you have not yet done so, please do go to the ICPCN website www.icpcn.org.uk and click on the link in the bottom right hand corner. By completing the survey you will automatically be entered into the draw to

receive one of two amazon.com vouchers worth \$50 each.

Thank you and we look forward to letting you know the results of the survey in the future.



THE DAWN OF A NEW ERA FOR THE ICPCN



A historical moment as Co-Chairs, Lizzie Chambers and Barbara Gelb sign up to become the first Trustees of the soon to be formed ICPCN Board.

At the recent meeting of the ICPCN Steering Group which took place in Lisbon a day before the beginning of the EAPC Congress, some momentous decisions were made.

The ICPCN is in the process of being registered both as an independent charity and a company in the United Kingdom. The network will also be registered within South Africa as that is where most of the staff is

situated. The board in the South African registered branch will report to board in the UK.

At this meeting the Articles of Association were approved and agreement reached on the rules of representation on the board. Steering Group members present at this meeting were all willing to sign up as Trustees to the Board.

Much of the work of the ICPCN would be taken forward through three committees, these being the Finance and Fund Raising Committee, the Advocacy Committee and the already established Scientific Committee.

As far as its global strategy was concerned, it was also agreed that the ICPCN would rather work with any existing regional groups to strengthen their work with children rather than setting up separate working groups in competition.



The ICPCN would like to congratulate ICPCN Steering Group member, Dr. Delia Birtar, for winning second place in the Poster competition at the EAPC Congress for her poster on the evaluation and approach to symptoms in the advanced phase of childhood cancer. We were very proud of her!

THE ICPCN IS LOOKING FOR MEMBERS FOR ITS FINANCE/FUND RAISING AND ADVOCACY COMMITTEES

Welcome to Richard Carling ICPCN's new Treasurer



Richard is the Director of Finance & Resources at Children's Hospices UK, the national body for the 45 children's hospices across the UK. He is a qualified chartered accountant specialising in the charity sector. His

previous posts include Finance Director at Tree Aid, a charity focusing on sustainable development in the Sahel region of Africa; and Business Manager for the National Autistic Society, responsible for the financial planning and management of its 23 schools and residential homes. He has also spent 5 years in the charity unit at Binder Hamlyn (part of Arthur Andersen worldwide) where he provided audit and other financial services to various charities. He is the Group Scout Leader for his local scout group and also the treasurer of the Campaign for National Parks, a charity that campaigns to protect and promote the National Parks of England and Wales. In Richard's spare time he enjoys cycling, swimming, running and camping.

FINANCE & FUND RAISING

ICPCN is looking for people with skills and experience in Finance and/or Fund raising to help develop the future of the International Children's Palliative Care Network (ICPCN).

ICPCN is at an exciting stage in its development, becoming a registered charity in the UK and South Africa, and we are setting up a Finance and Fund raising Committee to drive forward these key aspects of its work. ICPCN has grown quickly since its inception just a few years ago, and we now want to establish it on a firmer footing financially.

We would welcome members with expertise in fund raising, particularly those who will be able to operate at the strategic level, informing the long term fund raising strategy, but also able to advise of likely fund raising sources within their own regions.

We also need members with financial expertise, able to advise on the long term financial strategy, annual budgets, to scrutinise the organisations accounts and ensure that we follow best practice in the areas of financial control, risk management and compliance with regulations.

The role is voluntary, and will require participation in four meetings per year, mostly

via teleconference. We would welcome members from all areas of the world to fill these roles.

The draft Terms of Reference of the committee can be viewed online at www.icpcn.org.uk

If you are interested in becoming a member of the committee, please send a CV by 15 July to Barbara Steel at admin@icpcn.co.za

ADVOCACY COMMITTEE

Advocacy is a strategic objective of the ICPCN and to support this important activity, we are establishing an international advocacy committee as a sub-committee of the board. The ICPCN is calling for volunteers who have a proven track-record of effective advocacy at national level, and who would like to be part of this initiative. The committee will meet by teleconference 3-4 times a year and when necessary.

Terms of Reference can be found online at: www.icpcn.org.uk

Please submit a short CV and a report on any successful advocacy initiatives that you have successfully completed by 15 July to Barbara Steel at admin@icpcn.co.za

More information and contact details for all these conferences, courses and events can be found on our website. Go to www.icpcn.org.uk

July

06 Managing Challenging behaviour in Paediatric Care
 11 Symptom Control in Paediatric Care
 14 9th Asia Pacific Hospice Conference
 17 - 20 6th IAS Conference on Pathogenesis, Treatment and Prevention

Derian House Children's Hospice, United Kingdom
 Derian House Children's Hospice, United Kingdom
 Hotel Equatorial Penang, Malaysia
 Italy, Rome

August

25 - 26 4th Bi-Annual Palliative Care Conference "Palliative Care, Relieving Pain, Restoring Dignity"
 26 - 27 Eighth Annual Oncology & Hematology Review Symposium

Imperial Royale Hotel, Kampala, Uganda
 Loews Vanderbilt Hotel, Nashville, TN

September

26 - 28 Help the Hospices Conference 2011

Bournemouth International Centre, Bournemouth, UK

LIFE before Death films

50 powerful Short Films created for the LIFE Before Death project have been made freely available to any pain, palliative care, hospice and end of life health professionals around the world to download and use for training and public advocacy. To find out more visit the brand new FREE TRAINING FILMS section of the LIFE Before Death website at <http://lifebeforedeath.com/movie/training.shtml>

LIFE Before Death is a documentary project supported by the Lien Foundation, the IASP, the Mayday Fund, the UICC and the Institute for Palliative Medicine at San Diego Hospice.

The 50 Short Films produced will be released at a rate of one per week for a year. They were filmed in 11 countries in North America, Europe, Asia and Africa to gain a broad cross-sectional view of the issue of pain. Over 150 individual health professionals, cancer, HIV/AIDS and chronic pain patients, family members, activists, bureaucrats, regulators, pharmaceutical industry representatives, ethicists and law enforcement officers over a period of 18 months were filmed.

The MEDIA DOWNLOAD section of the LIFE Before Death website has high-resolution images of Palliative Care in action for free download.

The Children's Palliative Care Handbook for GPs

In May ACT launched a brand new free resource aimed at supporting GPs when a child with palliative care needs comes into their care. The launch of The Children's Palliative Care Handbook for GPs (www.act.org.uk/gps) marks a new departure for ACT, by reaching out to support professionals outside of the children's palliative care specialty. This handbook has been designed as a practical and emotional guide to support GPs when they face the challenge of caring for a child with palliative care needs, to guide them through the pathway approach to planning and delivering care, and to signpost them to more detailed resources should they be required.

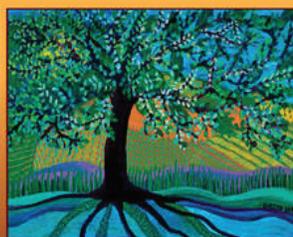
This new resource addresses the main questions GPs are likely to ask when caring for a life-limited or life-threatened child, and breaks down what can sometimes seem like an overwhelming task into manageable sections for them to refer to as and when each issue arises in practice.

The Children's Palliative Care Handbook for GPs is a fully interactive PDF with 13 sections ranging from handling strong emotions and difficult questions; assessing pain; spiritual care; management of terminal symptoms; and helping the family with grief and bereavement.

The ACT Children's Palliative Care Handbook for GPs is available free to download at www.act.org.uk/gps

TEXTBOOK OF INTERDISCIPLINARY PEDIATRIC PALLIATIVE CARE

Textbook of Interdisciplinary Pediatric Palliative Care



JOANNE WOLFE • PAMELA HINDS • BARBARA SOURKES

By Joanne Wolfe, MD, MPH, Pamela Hinds, RN, PhD, FAAN, Barbara Sourkes, PhD.
 ISBN 978-1-4377-0262-0

The Textbook of Interdisciplinary Pediatric Palliative Care, by Drs. Joanne Wolfe, Pamela Hinds, and Barbara Sourkes, aims to inform interdisciplinary teams about palliative care of children with life-threatening illness.

It addresses critical domains such as language and communication, symptoms and quality of life, and the spectrum of life-threatening illnesses in great depth. This comprehensive product takes a first-of-its-kind team approach to the unique needs of critically ill children. It shows how a

collaborative, interdisciplinary care strategy benefits patients and their families.

If you deal with the complex care of critically ill children, this reference provides a uniquely integrated perspective on complete and effective care.

To order the book visit:
http://www.elsevier.com/wps/find/bookdescription.cws_home/723289/description#description

CHILDREN OF THE DRUG WAR

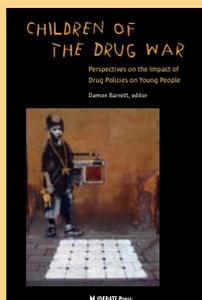
Perspectives on the Impact of Drug Policies on Young People
 Damon Barrett, editor

CHILDREN OF THE DRUG WAR is a unique collection of original essays that investigates the impacts of the war on drugs on children, young people, and their families. With contributions from around the world, providing different perspectives and using a wide range of styles and approaches, including ethnographic studies, personal accounts, and interviews, the book asks fundamental questions of national and international drug control systems:

- What have been the costs to children and young people of the war on drugs?
- Is the protection of children from drugs a solid justification for current policies?
- What kinds of public fears and preconceptions exist in relation to drugs and the drug trade?
- How can children and young people be placed at the forefront of drug policies?

Four thematic sections address:

- Production and trade
- Race, class, and law enforcement
- Families and drug policy
- Children, drug use, and dependence



DAMON BARRETT is the senior human rights analyst at Harm Reduction International, based in London. He is a cofounder and project director of the International Centre on Human Rights and Drug Policy and an editor of the *International Journal on Human Rights and Drug Policy*.

ISBN: 978-1-61770-018-7 \$25.95 / £23.95 Paperback

Order from: www.bn.com, www.amazon.com, www.amazon.co.uk and other fine bookstores



Stand Alone Module - Care of the Child & Family with a Life Limiting Illness

Calling all nurses working in Palliative Care, Paediatrics, Oncology, Public Health, Neonatal Care, or Intellectual Disability...

Is caring for Children with Life Limiting or Palliative Care Needs and their families your area of interest in nursing?



If so, this innovative stand alone module will interest you. This module is delivered in a Blended learning format by the School of Nursing and Midwifery, NUI Galway, Ireland



Want to increase your knowledge? Fit your learning around home & work commitments? Learn at your own pace?

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Study on line and attend 2 workshops (Overseas participation may also be available with on line technology)

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 Enquiries to Laura Dempsey Email @ laura.dempsey@nuigalway.ie or Call 00 353 91 495353
 OR Claire Quinn Email @ claire.quinn@nuigalway.ie or Call 00 353 91 494229

CHINAKIDZ is looking for volunteers

Chinakidz is China's only children's hospice, doing pioneering work in the field. Lyn Gould, the director of this programme says, "This is pioneering work here and it is wonderful to find parents who want help to care for their child when diagnosed as 'dying' instead of having to care for them as abandoned 'orphans'."



We are in need of western nurses and doctors to get this work off the ground and into mainstream culture here; any volunteers or visitors to teach/lecture local staff will be very welcome." To find out more, you can contact Lyn at the following address: lyn.chinakidz@yahoo.com

Save the Dates

Rights of the child: Right for the child?

- Withdrawing treatment
- Mental capacity
- Assisted suicide
- Organ donation
- Advance care plans
- Babies born too early
- When parents and children disagree
- When personal beliefs get in the way

Ethical challenges in children's palliative care

Join us to tackle some of the thorny issues, taboo subjects and ethical challenges in children's palliative care.

ACT Conference 2011
Tuesday 11 October 2011
 Deaf Cultural Centre, Birmingham



ACT for children ACT for families ACT together ACT now!

First Annual Paediatric Palliative Care Symposium of Zambia
 November 22 - 25th 2011

The first annual Paediatric Palliative Care Symposium of Zambia will take place in Lusaka, Zambia. This will be the first of its kind in Zambia and will focus on all aspects of paediatric palliative care; medical, psychosocial and spiritual. It will play a crucial role in the scaling up of paediatric palliative care services in the country. Elizabeth Glaser Pediatric AIDS Foundation is sponsoring the Symposium, in association with Tiny Tim and Friends Zambia (TTF) and the Palliative Care Association of Zambia (PCAZ.)



The 5th International Conference "Children's Palliative Care in Eastern Europe"



27 - 29 October 2011
 Minsk, Republic of Belarus

We invite you to take part in!

Non-profit charitable organization "Belarusian children's hospice" jointly with Ministry of Health give the 5th International Conference on palliative care.



Palliative care is relatively new branch of medicine, the main purpose of which is to provide a seriously ill person and his family with worthy quality of life.

Palliative care for children is developing very successful in Western Europe and USA, at the same time in the territory of former Soviet Union countries and in Eastern Europe children's Palliative care is developing slowly.

So, during this conference we would like to analyze present situation with children's palliative care in Eastern Europe, to discover obstacles in it's developing and work out a strategy, which would promote of improvement of palliative care for children in this region.

Also we invite experts in Palliative Care from Western Europe to share their successful experience.

We also will have independent seminar in palliative care for adults during this conference.

Foreign participants of the conference will stay in "Minsk" hotel
 Meals and fee will be paid by the conference organizes
 We offer free dwelling and cover travelling expenses only for lecturers
 Address of the conference: Minsk, Nezavisimosti Ave, 11
 Conference program and application form are available online.

Please, confirm you participation till the 30th of August

- E-mail: hospice@mail.belpak.by
- Tel.: (8-375-17) 505-27-45 (46,47), Fax: (8-375-17) 548-48-40
- Address: NGO "Belarusian Children's hospice", Berezovaya Roscha, 100A, Borovlyany, Minsk region, 223053, Republic of Belarus

www.hospice.by



NGO: «Belarusian children's hospice»
 Tel.: +8 (017) 505-2745, 505-2746; fax: +8 (017) 548-4840
 e-mail: hospicepall@mail.belpak.by

Anna Garchakova, Hospice CEO, and Maksim Padbiarozkin survey the new piece of land donated by the State for the building of a larger Children's Hospice in Belarus.



The present Children's Hospice in Belarus



Some of the happy children who benefit from the services provided by the Hospice



The Children's Hospice of Belarus have been donated land by the State for the purpose of building a new Children's Hospice with more room for in-patients. This project will take a long time to come to fruition as a great deal of money is needed for the building. Their current building no longer serves their growing needs as it has only two small rooms for their in-patient department and only one room for their respite care programme. The in-patient department is also situated on the second floor and the patients need to access this by means of a very narrow and steep stairway.

Maksim Padbiarozkin, director of fund raising at the Belarusian Children's Hospice, reports that while they are pleased to have developed as quickly as they have, this has caused some problems for the organisation.

During the last two years they have employed three people and created a fund raising department. This new department has been most successful with increased funding coming from the people of Belarus. They have also begun a volunteer programme, with one of

the recent employees coordinating volunteer activities. There are now over 250 registered volunteers who regularly take part in their activities.

Translation of the website

Another innovation by this organisation is to have their website translated into English and partially into German, French and Italian. In this way they are looking to improve their relationships with other hospices in Great Britain, Poland, Hungary, Latvia, Germany, South Africa, USA and other countries.

The hospice has worked hard to improve relationships with Government Departments such as the Department of Medical Health Care, Social Protection, Labour, and the Department of Education as well as with local public Health Care Organisations.

A new hospice in Gomel

In 2010 the hospice cared for 143 families with terminally ill children (45 families from rural areas). Their medical specialists, both doctors and nurses, made more than 1300 visits to patients at home. In February 2010 they

started a new project, creating a children's hospice in Gomel, the second largest city in Belarus. Today a doctor, two nurses and a psychologist work at that hospice.

A major achievement has been the signing of an agreement of cooperation with the local children's hospitals and policlinics.

Palliative Care Resource Centre

In November of 2010 the Belarusian Children's Hospice was a key partner in the establishment of a Palliative Care Resource Centre. This centre has been established through mutual cooperation between the state health care and the Belarusian Children's Hospice. The Centre is working towards creating a solid methodological base on children's palliative care, with the Hospice leading these activities. The Hospice contributes with its vast experience and expertise in children's palliative care by developing materials and sharing international best practices, working at the same time on the adaptation of foreign standards and models to suit local situations.

They are currently developing a

Glossary on children's palliative care which will form useful reference material for a wide variety of professionals from various spheres.

The Hospice maintains a good cooperative relationship with Russia, Latvia, and with other former Soviet Union countries. In the near future they plan to join with Russia to create a regional Association of Children's Palliative Care.

International Conference in October

In order to further promote Children's Palliative Care the Belarusian Children's Hospice will be holding an International Conference from 27 - 29 October 2011. This conference will take place in Minsk and will look at the adaptation of European models of children's palliative care for countries in Eastern Europe.

Maksim Padbiarozkin
Director of Fund Raising &

Tamara Reshko
Fund Raising Officer

www.hospice.by

Welcome to Dr. Bob's Place - a dream come true



Dr Bob's Place in downtown Baltimore, Maryland

The pediatric hospice community welcomes Dr. Bob's Place to the continuum of care for children in the United States. The program is named for a local pediatrician whose dream was to provide a special end of life facility to ease suffering for children and families.

Dr. Bob's Place is located in downtown Baltimore, Maryland, and is the first licensed, Medicare and Medicaid certified, and CHAP accredited pediatric inpatient hospice facility in the United States. It is located near area pediatric academic medical centers.

A project of Joseph Richey Hospice, Dr. Bob's is led by Janet Will, RN, MS as its Director: a pediatric nurse with extensive palliative and end of life care experience. Dr. Bob's provides skilled inpatient, transitional, respite and hospice home care to children with life limiting illness throughout the greater Baltimore region.

The 10-bed facility has a 'home-away-from-home' atmosphere and provides a venue to transition from the hospital, or from home for a sometimes needed "recharge" for families. When a child's care may be too complex for a family to be at home without medical support, Dr. Bob's Place is their new option. One parent is able to live-in while other family may visit when it is convenient. Dr. Bob's has hired pediatric staff with extensive experience in providing palliative and end of life care.

Dr. Bob's Place focuses on pain and symptom management, simplifies care, creates a homelike venue for end-of-life, and coaches parents so that they may take their child home supported by the hospice home care team.

Dr. Bob's goal is to help ease the many symptoms that trouble terminally ill children and to maximize comfort so that the child and family can make the most of each day they have together.



The 'Froggy Room' at Dr. Bob's Place



The "Newborn" Room at Dr. Bob's Place

Children's Hospitals and Clinics of Minnesota in Minneapolis/St. Paul is seeking a full-time physician to join the Pain, Palliative Care & Integrative Medicine Program

This specialty program aims to control acute, chronic and complex pain in all in- and outpatients at Children's of MN, and throughout the surrounding community.

Qualifications include:

M.D. with State of Minnesota medical license, or eligibility.
Successful candidates will have excellent communication skills, the ability to work effectively within a interdisciplinary team, and strong collaboration skills with medical personnel.

For further questions, inquiries, or applications contact the medical director at phone 612-813-6405 or Stefan.friedrichsdorf@childrensmn.org



Attendees at the symposium on paediatric palliative care held in April this year in Kenya.

The infant Mortality rate in Kenya is 52 per 1,000 live births, while the under five mortality rate is 74 deaths per 1,000 live births. This implies that one in every 19 children born in Kenya dies before its first birthday, while 1 in every 14 does not survive to age five. Neonatal mortality is 31 deaths per 1,000 live births while postneonatal mortality is 21 per 1,000 live births during the same period. Thus 60% of infant deaths occur in the first months of life (Kenya Demographic Health Survey 2008-2009).

It is estimated that 180,000 children are living with HIV/AIDS and that the approximate number of new cases of cancer is 500 per year. Kenya does not have a cancer registry; hence actual figures are not available. However, it is clear that there is an urgent need to integrate paediatric palliative care services into health services provided to children at all levels of care. Paediatric palliative care in Kenya has, until recently, been neglected. This is mainly due to lack of awareness; lack of training of clinicians and other health care providers; and also lack of champions.

In 2010, Kenya Hospices and Palliative Care Association (KEHPCA) identified two paediatricians and one child psychologist to undertake a two week training course on paediatric palliative care in Cape Town. This training was supported by ICPCN (International Children's Palliative Care Network). The three were Dr. Laura Oyiengo; Dr. Sammy Kilonzo and Catherine Wangechi. The team of three gained a lot of new knowledge

and skills on how to support children with life-threatening illnesses and are looking forward to transferring their new knowledge and skills to others across the country.

On 13th April 2011, KEHPCA, in partnership with the team of three and

were pain management; talking to the sick child; telling the diagnosis, psychosocial support; supporting the family; when to refer a child for palliative care and hospice care; how to deal with a dying child and their families; bereavement support.

KEHPCA plans to work closely with clinicians in Kenya to improve the status of pediatric palliative care in the country so that children with life limiting illnesses and their families live a dignified life; free of pain and suffering. This will be through continued advocacy, education

and training and scaling up pediatric palliative care services. Eleven government hospitals are currently in the process of integrating palliative care into their services and this will include pediatric palliative care as well.

KEHPCA is not working in isolation and has partnered with Kenya Paediatric Association to make this dream a reality. KEHPCA is also very grateful to various organizations and donors for their support to improve the quality of lives of suffering children and their families in Kenya. KEHPCA would like to acknowledge ICPCN for supporting the initiative, especially training; Open Society Foundation and Human Rights Watch for supporting the symposium,

The Diana Princess of Wales Memorial Fund; The African Palliative Care association (APCA) and all other well wishers who have supported and continue to support us in our endeavors to advance paediatric palliative care across the country. Children are a precious gift from the almighty; we need to treat them like special gems.

Dr. Zipporah Ali
National Coordinator
Kenya Hospices and
Palliative Care Association
(KEHPCA)



Dr Sammy Kilonzo receives a certificate from ICPCN CEO, Joan Marston after completing the 2 week course in paediatric palliative care held in Cape Town, South Africa

Juliane Kippenberg from Human Rights Watch facilitated a symposium at the 12th Kenya Paediatric Annual Scientific Conference that was held from 13th to 16th April 2011. The focus of the symposium was an overview of paediatric palliative care; the need for pain and symptom management; palliative care for HIV/AIDS and why Kenya needs to integrate paediatric palliative care services into health care services. The symposium generated a lot of interest from the clinicians and requests for continued medical education and further training in paediatric palliative care, including specialisation opportunities. Special challenges for the clinicians