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LETTER FROM THE CHAIR

Dear Friends,

I am writing this letter to you from Mumbai in India where I have had the pleasure and the privilege of spending time meeting with ICPCN Steering Group member and representative for India, Dr Maryann Muckaden as well as members of the Indian Association for Palliative Care and David Praill of Help the Hospices. It has been an exciting time as we appoint a project leader and map out future plans to expand access to palliative care for the children of the Maharashtra Region with funding obtained from the UK Department of International Development (DFID). Included in this DFID grant, is funding to improve access to children's palliative care in Malawi. In this country we will soon appoint a project leader and are working closely with the Umodzi programme in Blantyre and with the Palliative Care Association of Malawi (PACAM). The ICPCN is excited to be playing a significant role in this historic development project.

I would like to take this opportunity to congratulate Cardiff University, Dr Richard Hain and his hard-working team on the excellent 5th International Cardiff Paediatric Palliative Care Conference held at Cardiff University Campus in July this year. This conference attracted top presenters and delegates from around the globe and provided inspiration and much food for thought for all. ICPCN is proud to be associated with this prestigious conference and we look forward to our continued alliance.

The occasion of this conference also afforded an excellent opportunity for members of the ICPCN Steering Group and the newly formed ICPCN Research Committee to meet face to face for the first time. There was a palpable energy in the room at this historic meeting as some of the stongest and most passionate proponents of children's palliative care from around the globe debated strategic planning for our organisation in the years ahead. The outcome of this meeting has already begun to make ripples within both the structure and the remit of the ICPCN, which I look forward to sharing with you soon.

It is with sincere appreciation but also some sadness that

the ICPCN bids farewell to one of its most devoted and ardent supporters over the past five years. Avril Jackson, who held the post of International Information Manager for Help the Hospices and St Christopher's Hospice retired from this position at the end of August. Avril has not only been a loyal friend and an Observer on our Steering Group, but she has also given, in her always gracious manner, unstinting support and mentorship from the inception of the ICPCN international information service back in 2005. Thank you, Avril, for all you have meant to the ICPCN, and may your retirement be a time of rest and adventure, great joy and lasting satisfaction in the knowledge of a job well done.

At the recent African Palliative Care Association (APCA) Conference in Namibia, the theme of "Creativity in Practice" was woven cleverly throughout the presentations and messages and delegates were constantly reminded that palliative care can be provided anywhere, at any time and, as is often the case in Africa, is not dependent on beautiful buildings or expensive equipment, but on passionate people with the right training. While funding and resources are vital to the functioning of any palliative care programme, a spirit of "resourcefulness" is what is needed in the current global financial climate and I am humbled by the words of young Gabatshwane Gumede, an AIDS orphan and representative for children's rights, who said at last year's World Hospice and Palliative Care celebration held in Krugersdorp, South Africa: "You do not have to drive fancy cars, dress in fancy clothes or live in fancy houses to be able to help someone. Let us together dream for a better world. Let us make a difference in other peoples lives." Making a meaningful difference in the lives of life-limited children is what the ICPCN is all about and I would like to challenge our members to consider "making a difference" by initiating a partnership with a hospice in another part of the country or the world, using the guidelines found in our recently launched "ICPCN Guide to Children's Hospice & Palliative Care Partnership" featured below.

With warmest greetings to all,

Joan

THE ICPCN GUIDE TO CHILDREN'S HOSPICE & PALLIATIVE CARE PARTNERSHIPS

There is a growing global community of people working in the sphere of children's hospice and palliative care providing countless opportunities for practitioners to reach out and make contact with one another. Are you interested in sharing your knowledge and experiences with others, looking for an opportunity to volunteer your services or would you like to travel and learn about children's palliative care in other parts of the world?

Can you make time to join hands across your country, your continent or the globe to support, encourage and get to know people who are working in the same field as you?

The ICPCN Guide to Children's Hospice & Palliative Care Partnerships encourages ICPCN members and member hospices to transform the words and desires behind the

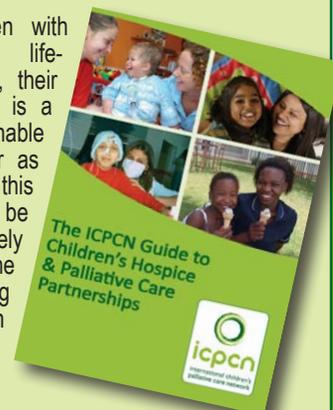
ICPCN Declaration of Cape Town into actions. Partnerships need not be onerous or about one hospice providing financial support to another. The ICPCN would like to encourage links not only between hospices, but also between people working in similar fields around the globe.

The ICPCN Guide to Children's Hospice & Palliative Care Partnerships contains an inspirational foreword by Dr Justin Amery, a background and history to the ICPCN and hospice partnerships, step by step guidelines for the implementation of successful partnerships, examples of existing partnerships and useful information on global contacts and resources.

It is hoped that this guide will inspire our members to reach out to their counterparts around the globe to learn from one another and to bring us closer to our vision of a world where "Quality palliative

care for all children with life-limiting and life-threatening illnesses, their carers and families" is a reality. In order to enable our members as far as possible to achieve this goal, this guide can be downloaded completely free of charge from the ICPCN website along with an application form to participate in this initiative.

To download the guide as well as the registration form, log onto our website at: www.icpcn.org.uk and follow the link entitled "ICPCN Partnership Initiative"



INTERNATIONAL EVENTS CALENDAR: OCTOBER - JANUARY 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

October

| | | |
|---------|--|----------------------------|
| 05 - 08 | 18th International Congress on Palliative Care | Montreal, Canada |
| 09 | World Hospice & Palliative Care Day | Worldwide |
| 11 - 14 | Children's Hospice International 21st World Congress | Washington D.C. USA |
| 12 - 13 | The Team Around the Child (TAC) System - 2 day course | London |
| 13 - 16 | 3rd Botswana International HIV Conference | Gaborone, Botswana |
| 14 - 17 | The 26th Annual International Conference on Young Children with Special Needs & their families | Kansas City, Missouri, USA |
| 21 - 23 | CAPC National Level I & II Seminar | Phoenix, Arizona, USA |
| 21 - 24 | 42nd Congress of the International Society of Paediatric Oncology | Boston, MA, USA |
| 24 - 27 | The 7th International Conference of Neonatal Nurses | Durban, South Africa |
| 30 | Community Service Volunteers - Make a Difference Day | UK |

November

| | | |
|---------|---|----------------------------|
| 31 - 03 | 1st OVC in Africa Conference - Don't Turn a Blind Eye | Johannesburg, South Africa |
| 04 - 06 | 2nd National Palliative Care Conference in Kenya | Nairobi, Kenya |
| 05 - 06 | The Fourth Annual Pediatric Palliative Care Conference - Quality of Life for the Children | Washington D.C., USA |
| 09 | The Lifeline of Bereavement for Children, Young People and their Families | Chorley, Lancs, UK |
| 19 | First International Palliative and End-of-life Care Symposium | London, UK |

January 2011

| | | |
|---------|---|-------------------|
| 21 - 23 | International Conference on Public Health and Palliative Care | Dakha, Bangladesh |
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DATES FOR YOUR DIARY

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

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

PEDIATRIC PALLIATIVE CARE (Find out more at www.palliativecare.ca/)

Organisers and Chairs:

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

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

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

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

ACT launches national children's palliative care training and consultancy programme: Train to Care

In August ACT launched a dedicated children's palliative care learning and consultancy programme called Train to Care (www.act.org.uk/traintocare) for all professionals who work with life-limited children.

With funding from the Department for Education, ACT's Train to Care programme has been designed to raise standards in children's palliative care by encouraging organisations to develop their team's confidence, expertise, knowledge and skill set.

Train to Care is inspired by ACT's aim to share good practice and by a growing need to develop a more robust and sustainable workforce that can care for the country's 23,500 life-limited children. Train to Care draws on ACT's 21 years experience of working in the sector and the shared knowledge of many of the UK's leading children's palliative care experts.

Train to Care has two main elements:

1. Train to Care learning:

Self-contained modules on various topics in children's palliative care – to develop knowledge, skills and confidence.

A wide range of learning modules, including An introduction to children's palliative care, End of life care and Sharing significant news, will be delivered by a team of ACT accredited Train to Care providers. View ACT's full Train to Care portfolio at:

www.act.org.uk/traintocare

Train to care is flexible. Each training course can be tailored to specific needs and learning levels, and will be delivered at a time and place that is most convenient.

2. Train to Care consultancy:

Bespoke children's palliative care consultancy – to help improve,

evaluate or develop new services. ACT's Train to Care consultancy is a bespoke service, designed to help agencies evaluate or improve service delivery, drive up standards and achieve excellence in children's palliative care. ACT will design a value for money, individualised consultancy package that will help achieve specific organisational and personal goals, and optimise service delivery.

Launching Train to Care, Katrina McNamara-Goodger, ACT's Head of Policy and Practice said:

"Babies, children and young people with palliative care needs are a small and unique group, requiring very special skills, expertise and knowledge; and working with life-limited children, especially those at their end of life, can be very demanding.

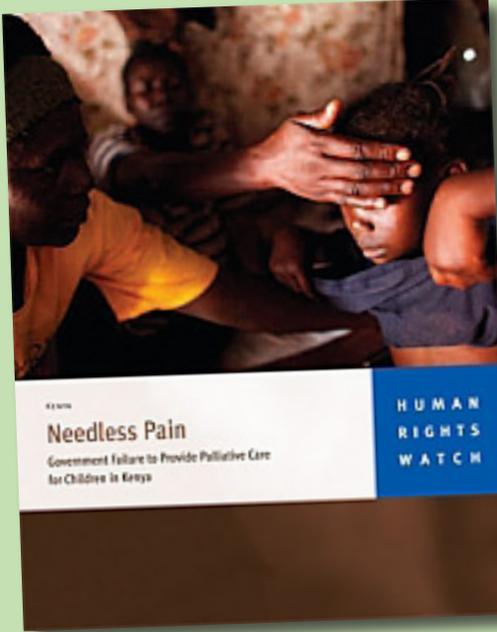
Every day staff may face a wide range of issues, from telling a family their new baby has only hours to live, to dealing with a child's distressing symptoms, to supporting a sibling who has just lost their brother or sister.

"Diverse skills, more experience and greater knowledge can help staff, from novice to expert, develop an increased confidence when supporting these children and families. We need a stronger, more responsive and reliable workforce and I hope that Train to Care will help us all to deliver excellence in children's palliative care."

To find out more about Train to Care

Web: www.act.org.uk/traintocare
Email: traintocare@act.org.uk
Phone: +44 (0)117 916 6422

NEEDLESS PAIN: GOVERNMENT FAILURE TO PROVIDE PALLIATIVE CARE FOR CHILDREN IN KENYA



This 78-page report by Human Rights Watch found that most Kenyan children with diseases such as cancer or HIV/AIDS are unable to get palliative care or pain medicines. Kenya's few palliative care services provide counseling and support to families of chronically ill patients, as well as pain treatment, but lack programs for children. In addition, the majority of sick children are cared for at home, but there is little support for low-cost home-based palliative care. Health care workers lack training in pain treatment and palliative care, and even when strong pain medicines are available, they are often reluctant to give these medicines to children.

Kenyan children in acute and chronic pain suffer needlessly because of government policies that restrict access to inexpensive pain medicines, a lack of investment in palliative

care services, and inadequately trained health workers, according to the report.

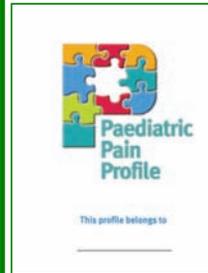
The report, "Needless Pain: Government Failure to Provide Palliative Care for Children in Kenya," found that most Kenyan children with diseases such as cancer or HIV/AIDS are unable to get palliative care or pain medicines. Kenya's few palliative care services provide counselling and support to families of chronically ill patients, as well as pain treatment, but lack programmes for children. In addition, the majority of sick children are cared for at home, but there is little support for low-cost home-based palliative care. Health care workers lack training in pain treatment and palliative care, and even when strong pain medicines are available, they are often reluctant to give these medicines to children.

"Kenyan children with cancer or AIDS are living, and dying, in horrible agony," said Juliane Kippenberg, senior children's rights researcher at Human Rights Watch. "Pain medicines are cheap, safe, and effective, and the government should make sure that children who need them get them."

The Kenyan government has taken a step in the right direction by establishing a few hospital palliative care units in recent years, Human Rights Watch said. But much more needs to be done to stop sick children from suffering needlessly.

To download a copy of the full report or to purchase a printed copy, please go to: <http://www.hrw.org/en/reports/2010/09/09/needless-pain-0>

Paediatric Pain Profile



The Paediatric Pain Profile (PPP) is a behaviour rating scale for assessing pain in children with severe physical and learning impairments.

The Paediatric Pain Profile has been developed by researchers at the Royal College of Nursing Institute, Oxford and the Institute of Child Health, London.

Background to the study:

Severe physical and learning impairment is a feature of many chronic and disabling conditions in children. These children have many potential sources of pain. Pains may arise from the disease process itself (e.g. neuropathic pain or muscle spasm), be secondary to the disease (e.g. musculo-skeletal pain or pain from reflux oesophagitis) or incidental (e.g. tooth ache or otitis media). However, because the children have difficulty in communicating their pain it can go unrecognized and untreated. It is the child's behaviour often, rather than their verbal report, which has to be interpreted to determine if they have pain. Because it can be difficult sometimes for parents and for health care professionals to distinguish which behaviours do indicate pain and to follow the progress of pain relieving treatments, the pain assessment scale has been developed specifically for this population of children.

The PPP can be downloaded from the following site:
www.ppprofile.org.uk/

If you have any questions or require any further information on any aspect of the PPP tool or this research, please contact:

Dr Anne Hunt RSCN PhD,
Senior Research Fellow in Children's Palliative Care,
Department of Nursing
University of Central Lancashire
Email: ahunt@uclan.ac.uk

The producers of the Paediatric Pain Profile give their permission for pages to be photocopied and used in the care of children with severe neurological and learning impairments.

Translations of the Paediatric Pain Profile in both **Urdu** and **Punjabi** are available and should anyone wish to receive free printed copies of these translations, please send an email Dr Anne Hunt.

OFFER OF FREE ESSAY ABOUT EARLY CHILDHOOD INTERVENTION AVAILABLE TO PEOPLE LIVING OUTSIDE THE UK

Essay: TAC (Team Around the Child) as the family-owned organisational nucleus making the best use of limited resources (2010) *By Peter Limbrick*

Summary

The focus in this essay is on how each child's TAC (Team Around the Child) can function in early childhood intervention as the family-owned organisational nucleus – a persisting organisational nucleus that is essential for each child who has a 'multifaceted condition' to keep all separate agencies, services and practitioners working together in an integrated and coherent approach. The essay describes the relevant characteristics of the TAC approach and the potential achievements of a child's TAC, with just three or four people, functioning as the organisational nucleus for multi-agency, child and family-centred support. Peter Limbrick argues that the TAC System's work patterns bring real benefit to busy practitioners, make the best possible use of limited resources and, most important of all, recognise parents' natural central role in caring for their children.

This essay has five sections:

- Introduction
- The children and families who benefit from having a TAC as their own organisational nucleus
- The main characteristics of each child's TAC as the family-owned organisational nucleus
- What each child's TAC as the organisational nucleus can achieve for the child and family
- Conclusion

If you live outside the UK and wish to receive a free copy of this essay, please contact:

Peter Limbrick
Email: p.limbrick@virgin.net
Tel/fax: 01497 831550
Web: www.icwhatsnew.com

REMEMBER World Hospice & Palliative Care Day - 9 October 2010

At the World Hospice & Palliative Care Day Celebration held in Klerksdorp, North West Province, South Africa on the 9th October 2009, with the theme, "Voices for Hospice", a group of people were asked to give speeches to represent those involved in palliative care. These "voices" included the voice of a nurse, a care worker, a funder, the family, a patient and a child. We share two of the speeches given on this day. The first from Gabatshwane Gumede, a 14 year old AIDS orphan and singer who has written a song and sung it to Nelson Mandela and the second from Martha, a young adult who had to take over the responsibility of looking after her siblings after losing her mother to AIDS when she was still a child. Their messages are touching in their simplicity and serve as a powerful reminder of the difference that hospices make in the lives of ordinary people.



Gabatshwane Gumede

Gabatshwane Gumede's speech given to represent the "Voice of the Child"

My name is Gabatshwane Gumede, I am an Ambassador of children's rights, representing South Africa in the whole world.

My work is to fight for rights of AIDS orphans and get additional support and assistance for children who find themselves vulnerable. I am a child from this beautiful province which I love very much. I love myself and respect everyone else. I am also firm on what I believe in.

Ka setswana go bo motho go thebe phatshwa.
We need to love one another, we need to care for one another.

We are gathered here to celebrate the love and care that institutions – hospices – give to us. Some of us think that if someone is sick and we cannot take care of him or her, we just dump them at Hospice - WRONG!

A hospice is not a dumping site!

I can assure you all adult friends and my fellow children friends, that people find new "homes away from home" at the hospices.

That is why we are celebrating the World Hospice Day today.

And we need to make additional efforts to make sure that these institutions are fully supported and assisted. As I speak here today my friends, something came to my mind and I think that maybe...maybe if my MOM and DAD had had an opportunity to be taken to a Hospice maybe – maybe they would still be alive today.

We are celebrating the love, care and dedication of people who stand and say that I am going to do something to help change the world by helping people who are in need.

So today – THE WORLD HOSPICE &

PALLIATIVE CARE DAY – I urge institutions and individuals who are in a position to do so, to think about all that you have done for someone in need, and if you haven't done anything, start today.

You do not have to drive fancy cars, dress in fancy clothes or live in fancy houses to be able to help someone. Let us together dream for a better world. Let us make a difference in other peoples lives.

Adult friends, to prepare us children for the future, education must be highlighted. Teach us about humanitarian growth, people's rights and our responsibilities, and keep us informed all the time about what is happening in the world. We have to learn where we come from in order to know where we are going.

To all hospices in South Africa and elsewhere, I thank you and may God bless your work.

Gabatshwane Gumede
October 2009

Martha's Speech given to represent the "Voice of the Patient"

By Martha

I come from a child headed family.

In December 2003 my mother was very ill. I had to take care of her, being the eldest child in the family of five children.

One day a woman came to our house and told us about Hospice and wanted to know if it was ok with us if she called in the sister from Hospice to help us with the care of our mother. I agreed and that was the beginning of a long and lasting relationship with Hospice. Our mother passed away in 2004. My youngest sister was only 2 years old then. She was admitted to Hospice Creche, Khaya Tshepo until she graduated two years ago. Care continues for my younger sister as she is also infected.

In 2008 my other younger sister also became very ill during her pregnancy, only to find out that she was also infected. Hospice stepped in to help her, she was admitted at the In-Patient Unit, and Hospice helped her until she was back on her feet.

In 2009, this year, a year that I will never forget, I became ill; I was diagnosed with HIV and TB. I was too ashamed to meet the Hospice Sister.

I said to myself, "How will the Sister react? How can the whole family be infected?" I was actually cross and ashamed of myself. I had to hide myself when I saw the Hospice car, until one day the [hospice] Sister came in to visit. My other two sisters and a cousin of mine who was taking care of me reported to the Sister that I was ill. The Sister insisted on seeing me. We met and the Sister was very supportive. She encouraged me to take the treatment and to go to my check-ups at the hospital. She also encouraged me to attend day care once my condition was better.

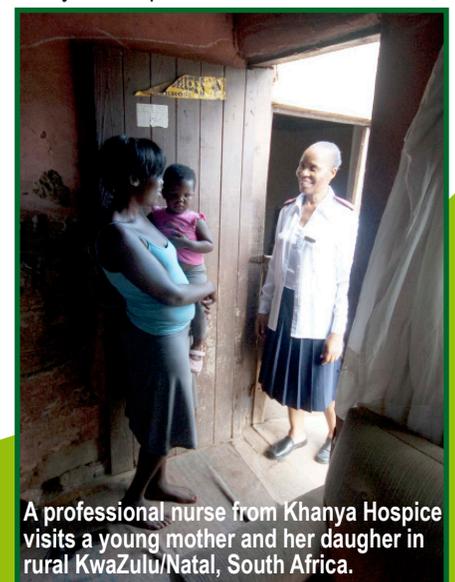
Three weeks after going to Hospice I attended day care. There I met people who are diagnosed just like me, they gave me hope and courage, and they also encouraged me to believe in God and to have hope that one day I will be well. I also started to learn to do beadwork. As I am reading this message I am back on my feet and am employed in one of the shops in town.

Hospice is my everything; they gave my family love, care and support.

Hospice is the pillar of our home, the sisters, caregivers and even our daycare driver are very good people. We thank you!

May Hospice go forward and never get tired of helping the sick and orphans. Hospice made it easy to go through the pain of losing our mother because they are always there for us and are still there for us, as almost the whole family is infected or affected [by AIDS].

Thank you Hospice!



A professional nurse from Khanya Hospice visits a young mother and her daughter in rural KwaZulu/Natal, South Africa.

EXPERIENCES FROM THE YOUTH HOSPICE "BALTHASAR" GERMANY'S FIRST HOSPICE FOR ADOLESCENTS



The attractive entrance to the Balthasar Hospice for adolescents and young people

In January 2009 the Youth Hospice Balthasar was inaugurated as the first of its kind in Germany. Since then feedback from visitors has been overwhelmingly positive. The youth hospice provides its visitors with more privacy, more space and more age-appropriate attractions. Situated next to the existing children's hospice, so both can make use of the same facilities, the new institution offers teenagers more free space and opportunities for retreat. A new big hall in the hospice can be used for sports and play and a workroom was installed for creative pursuits and development. Teenagers often find it difficult to talk about their condition so they are encouraged to express feelings such as anger and sorrow through other means. In the "Snoezelen" room the visitors can relax and in the Computer Room guests cannot only play games but also surf the internet. For many teenagers in the hospice this is often the only way to participate in a social life, allowing them to stay in contact with old friends and exchange their experiences with other people.

Independence

Being diagnosed and living with a life-limiting condition often leads teenagers into an identity crisis. Their condition or illness makes them far more dependent on their parents and on other people. They experience a loss of privacy and independence, both of which are extremely important at this age. They are often forced to give up things they were used to doing, or activities that they may have just started; their social contacts dwindle and sometimes break off completely and their physical and often mental skills decrease.

The hospice aims specifically at maintaining the teenagers' quality of life. Specially trained

personnel and close cooperation with medical scientists who specialise in pain therapy help to ensure a professional palliative care service. Furthermore, the teenagers are encouraged to be as individual as is possible. Special equipment in all the rooms enables a high degree of freedom, even with their limited mobility. Lights, blinds and music volume can be controlled without help – true to the hospice's motto "as much independence as possible". All employees are nurses and empathetic companions at the same time who help the teenagers to cope with their sorrows

and who enable them to experience their remaining time as intensely as possible.

"I really love that our nurses take part in all activities. I can tell them what I would like to do that day and most of the time we do it.", says Tim, a 17-year-old guest.

Thanks to the individual daily routine, every teenager can be taken care of individually and employees have time for intensive talks.

Farewell and bereavement

In their last phase of life the teenagers can be accommodated in the hospice at any time in order to experience their last moments without pain and with full dignity. A specially created farewell area for family and friends can be arranged individually with photos and personal belongings. Here they can say goodbye to the beloved young person. Memorial symbols are fundamental elements of bereavement work. The fact that no one is forgotten comforts the relatives. In a spirally designed farewell garden you can find stones of remembrance



A young guest, delighted to be in a facility designed with space for both leisure and retreat.



Guests are encouraged to express themselves through creative outlets such as art and music

Family members and those who accompany the young people appreciate the calmness and the opportunity to share their experiences with others. "It is evident that the topics in the youth hospice differ from those in the children's [hospice]", says one of the mothers. "We experienced totally different things during all these years when it comes to sponsors and questions about help and support at home." Parents also benefit from the environment which suits their children. The fact that there are no teddy bears in the Youth Hospice is taken as a signal to start treating their children like adolescents and grown-ups.

with names of every deceased guest. On the day of their death a candle is lit and a memorial corner with a photo and a personal text is prepared. The teenagers continue to live in these symbols and in the memories of all the beautiful moments experiences together. Even after the death of a young person, the institution in Olpe remains a place of refuge for families and friends in order to support them on this bereavement part of their journey.

Funding

Unfortunately youth and children's hospices in Germany are not previewed in the existing financing models. Up to 70% of the work has to be financed by donations and depends on the help of many people who get involved with small donations and events in order to help the sick young people.

Written by Nicole Binnewitt



<http://www.kinderhospiz-balthasar.de>

HOSPICE CASA SPERANTEI ORGANISES A DREAM SEASIDE VACATION FOR 29 CHILDREN AND THEIR PARENTS



Written by Dr Delia Birtar, Paediatric Project Coordinator of Hospice Casa Sperantei in Brasov, Romania.

For the past 7 years, every summer Hospice Casa Sperantei has organised a summer camp for our young patients in a beautiful mountain area near Brasov. The children and their families were always thrilled, since for most of them this was the only vacation they could afford.

Knowing that the majority of our patients have never seen the seaside, because of its distance from Brasov and an expensive destination for vacations, this year we tried to fulfill a dream of many of our patients and looked for sponsors to organise a summer camp in a holiday resort at the Black Sea.

Thanks to the work of our passionate social worker, Codruta Popa, and her colleagues, we set out on August 25th with 29 children, 16 of them in wheelchairs, and their parents and siblings (80 people altogether) for a vacation with a difference! She struggled to find a location accessible for children in wheelchairs, and the appropriate transport.

It was a very big challenge to travel 12 hours by train (the whole night) and to ensure the safety and comfort of all. The railway company supported us with special carriages and extra staff.

We were welcomed by very kind people who did everything to make our stay as enjoyable as possible, starting with the accommodation and excellent food and finishing with the big birthday cake for two girls.

Our daily activities included:

- ☀ Sun and seawater therapy
- ☀ Playing in the water
- ☀ Craft work everyday
- ☀ Gym for the mothers in the morning
- ☀ Visiting the town in the evening for entertainment and shopping

The children's impressions:

A seventeen-year old boy with muscular dystrophy said: "For me the excitement started when I got up in the train for the first time in my life. I was impressed to see different places - the big bridge over the Danube, the harbour that I had only seen on the TV."

A fourteen-year old girl with spinal muscular amyotrophy said: "The most exciting thing for me was going into town for shopping. The organisers, special people, friendly and loving, made us feel well. This was the best camp ever."

An eighteen-year old girl with congenital heart disease said: "For me this was the best vacation ever, and I hope that this

experience will be repeated."

Another girl said: "This was an unforgettable camp for me because I was at the seaside for the first time and we had an excellent programme which combined the time to relax on the beach with other activities."

The parents said that they admired our courage to take this huge responsibility with so many children with big health problems, and that they felt it was a good time for them, too. Many of the parents had never visited the seaside before. Some of them looked like big children enjoying the sea, the waves, the sand, the craftwork and the entertainment park!

The camp was a big challenge for the hospice staff but also a rewarding success because we all worked together as a team, with the sole aim to fulfill a dream for our special children.



The children had great fun participating in craft activities.



A birthday cake big enough for all to enjoy in celebration of the birthdays of two of the girls.



The entire group express their thanks to the hospice for organising such a wonderful seaside vacation

Cardiff 2010



Some members of the ICPCN Steering Group and Research Committee at the first face-to-face meeting held in Cardiff in July
From left to right: Barbara Gelb; Dr Jan Aldridge; Sabine Kraft; Dr Rut Kiman; Lizzie Chambers; Dr Ross Drake; Dr Maryann Muckaden; Professor Susan Fowler-Kerry; Joan Marston; Dr Jenny Hynson; Dr Julia Downing

Goodbye Avril



ICPCN thanks Avril Jackson for her invaluable input as an Observer on the Steering Group and wishes her a well-earned, joyful and leisurely retirement.

SEEN & HEARD AT THE APCA CONFERENCE : CREATIVITY IN PRACTICE

The 3rd African Palliative Care Association conference held in Namibia from 15 - 17 September cast a significant spotlight on the needs of the children of Africa. The clear message of the conference was that the provision of palliative care for all who need it on the continent of Africa will demand a great deal of resourcefulness and creativity from its overstretched practitioners. Sincere gratitude was expressed to the handful of loyal funders who have shown great generosity and guidance over the past decade and more. Particular mention was made of The Diana, Princess of Wales Memorial Fund as this would be the last APCA Conference before 2012, when the fund will cease to exist.

APCA HONOURS ICPCN CHAIR FOR HER CONTRIBUTION TO PALLIATIVE CARE FOR THE CHILDREN OF AFRICA



At the recent APCA Conference held in Windhoek, CEO of APCA, Dr Faith Mwangi-Powell presented ICPCN Chair, Joan Marston, with an award in recognition of her work and her outstanding achievements in bringing palliative care to the children of Africa.

Joan Marston and ICPCN Research Committee Vice Chair, Dr Julia Downing were thrilled to meet up with new ICPCN members, Dr Nancy Hutton and Dr Khalia Johnson from Johns Hopkins Pediatric Palliative Care Program in Baltimore, Maryland. Both have been involved in nurse education in Ethiopia.



SURVEY ON GOOD PRACTICE IN HEALTH SERVICES FOR YOUNG PEOPLE AND YOUNG ADULTS IN THE UK

Supporting Health Transitions for Young People with Life-limiting Conditions: Researching Evidence of Positive Practice

A research team based at the University of York is conducting a study of good practice in health services for young people and young adults with life-limiting conditions. This includes supporting the transfer from paediatric to adult services.

The research team is very keen to hear about services which have successfully developed ways of meeting the specific needs of this group. This includes good practice with respect to: condition management including acute admissions, symptom management, psychological, social, emotional, spiritual or family support, or end of life care.

The project is adopting a case study approach and all services nominated through this call for good practice will be considered for inclusion as a case study site.

The project is interested in all types of life-limiting conditions including:

- ▶ Life-threatening conditions for which curative treatment may be feasible but can fail
- ▶ Conditions where premature death is inevitable
- ▶ Progressive conditions without curative treatment options
- ▶ Irreversible non-progressive conditions causing severe disability, leading to susceptibility to health complications and likelihood of premature death

Do you know of, or work for, an organisation/service in the UK which you believe is an example of good practice? If you do, please use this link to provide the research team with brief details (this should take no more than five minutes to complete). We would be grateful if you could submit your nominations within the next two weeks.

https://www.surveymonkey.com/s/STPEP_Call_for_good_practice

For any queries, please contact:

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