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LETTER FROM THE CHIEF EXECUTIVE

Dear Friends of Children's Palliative Care,

As we enter the run-up to the Olympic Games, I decided that a good theme for my message would be that of 'Champions'.

As part of my job I have the immense privilege of travelling to different countries, meeting wonderful champions who have developed or are developing programmes that meet the needs of life-limited children in many innovative ways, and getting to meet the wonderful children and families they serve. This last month was spent visiting Belarus, Latvia and Georgia, countries where resources are limited. In Belarus and Latvia, despite the challenges, Dr. Anna Garchakova and Dr. Anda Jansone have been very resourceful in setting up and running expert programmes that reach many children and support increasing numbers of families. Anna's vision of establishing a regional training resource with a larger In-Patient Unit for children and families, is already in the process of development.

In Georgia, under the leadership of the Open Society Georgia Foundation, plans are underway to set up a children's palliative care programme and I was very impressed by the vision and the inclusiveness of the project,

and their government's support.

On my way home I was delighted to be invited to be the guest speaker at the opening of the first children's palliative care unit in KwaZulu-Natal, at Clairwood Hospital. A partnership between the Bigshoes Foundation, the hospital and the provincial Department of Health. And, once again, led by two dynamic and resourceful ladies, Dr. Julia Ambler and Tracy Brand under the expert guidance of their visionary director, Dr. Michelle Meiring.

Each region of the world has at least one "Champion" for palliative care for children, and we need to identify and support further champions who can take palliative care services to many more children. While funds are important, money alone will not make the difference; nothing gets done without those compassionate and passionate people who put children first, care about the suffering of children and "get out there" to make a difference.

Greetings from a wintry Bloemfontein, to my fellow champions!

Welcome to Hazel Bala - Fellow from Parsons The New School for Design



We are delighted to introduce you to Hazel Bala who has come to South Africa to work with the ICPCN for six weeks as a recipient of the Open Society Foundation's Fellowship. The Fellows of this prestigious scholarship are all

graduate students in the Communication and Design and Technology Department of Parsons The New School for Design in New York.

Hazel has spent much of her time being oriented to the field of children's palliative care and has worked on various information and design projects, including looking at the design of the website, creating new banners, posters and helping the staff with social networking sites.

She has also spent time taking photographs and interviewing practitioners, primary caregivers and children in order to put together a DVD that will be worked on by a collaborative team once she is back in New York. This will be suitable to use as an advocacy tool for children's palliative care worldwide.

We are looking for ICPCN members who would be willing to participate in this project. We need interviews (using simple cell phone technology) with children's palliative care practitioners, primary caregivers (e.g. parents) and children old enough to articulate their thoughts and feelings about their condition.

If you wish to participate and contribute, please e-mail our Information Officer at: info@icpcn.co.za

INTERNATIONAL EVENTS CALENDAR: JUNE - SEPTEMBER 2012

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

June

28	High Visibility (about transition to adult services)	London, UK	www.highvisibility.eventbrite.com
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July

11	Workshop: Anticipatory Grief	Derian House Children's Hospice, UK	patricia.clarkson@derianhouse.co.uk
11 - 13	6th Annual Cardiff Conference on Paediatric Palliative Care	Cardiff University, UK	www.icpcn.org.uk
20 - 21	Children and HIV - Closing the Gap	Washington D.C. USA	
22 - 27	AIDS 2012	Washington D. C. USA	www.aids2012.org

August

27 - 31	IASP 14th World Congress on Pain	Milan, Italy	www.iasp-pain.org
27 - 30	World Cancer Congress	Montreal, Canada	www.worldcancercongress.org

September

05 - 11	7th World Research Congress of the EAPC	Trondheim, Norway	www.eapcnet.eu/
04 - 07	ANZPM 2012	Queensland, New Zealand	www.willorganise.com.au/anzspm2012/
08 - 12	14th Asian Pacific Congress of Pediatrics and 4th Asian Pacific Congress of Pediatric Nursing		
12 - 14	3rd Kenya Palliative Care Congress	Kuching, Malaysia	http://apcp2012.org/main/
17	Launch of the South African Palliative Care Network	Nairobi, Kenya	www.kehpca.org
18 - 20	HPCA International Conference	CTICC, Cape Town, South Africa	www.bigshoes.org.za
		CTICC, Cape Town, South Africa	www.hpca.co.za

6th International Cardiff Conference on Paediatric Palliative Care



The ICPCN is thrilled to be partnering once again with Cardiff University and Dr Richard Hain for the 6th International Cardiff Conference on Paediatric Palliative Care.

Speakers will include:

Myra Bluebond-Langner
UK Chair in PPC

The Venerable Richard Seed
Archdeacon of York

Professor Wilfred McSherry
Faculty of Health, Staffordshire University

Dr Pradnya Talawadekar
Country Co-ordinator for the CPC project in Mumbai, Maharashtra, India

Jonathan Montgomery
Chair of Hampshire Primary Care Trust and Professor of Health Care Law at the University of Southampton

Joan Marston
Chief Executive of ICPCN



For more information

Phone: +44 (0) 29 2087 5508
Email: PPC2012@cardiff.ac.uk
Website: www.icpcn.org.uk

SACPCN Launch Meeting 17 September 2012 CTICC in Cape Town



What is the SACPCN

The South African Children's Palliative Care Network, (SACPCN) has arisen out of the need to provide a forum for healthcare and other professionals as well as parents/caregivers to give input and support for an integrated approach to improve palliative care for children across South Africa.

What is the SACPCN launch meeting all about?

The launch meeting will provide an opportunity to bring leading experts in the field of PPC to a plenary session where they will share their knowledge and experiences with delegates.

Speakers include:

Dr Khaliah Johnson
Visiting fellow from Children's Hospital of Philadelphia (CHOP)

Joan Marston
Chief Executive, International Children's Palliative Care Network (ICPCN)

Dr Michelle Meiring
Clinical Director Bigshoes Foundation and Paediatric Palliative Care Lecturer, University of Cape Town

The launch meeting will provide delegates with an opportunity to give input into and identify key areas of need for both the health care professional stream and the caregiver and family streams, as well as to elect representatives to guide the institutionalization of the SACPCN. The meeting will also provide an opportunity for stakeholders to network with each other and for organisations to showcase their work.

Who should come?

The launch meeting is aimed at child health professionals such as nurses, doctors, paediatricians, social workers, allied health practitioners, spiritual leaders as well as caregivers including parents, grandparents, NGO staff and home-based care workers. The meeting will be accredited for Continuing Professional Development Points for South African participants.

Book your place

Please complete the registration form at www.hpca.co.za

How much will it cost?

Health Care Professionals R750 Parents and caregivers R500

Find out more: www.bigshoes.org.za



The two-day symposium will be held on 20 & 21 July 2012 at the Georgetown University Hotel and Conference Centre in Washington D.C Find out more at: www.teresagroup.ca

New resources from Together for Short Lives



1. Every child* and family member should be treated with respect and dignity.
2. The child and family should be offered an individual care and support package that is built around their unique needs.
3. A multi-disciplinary team should work together to support the family, and communicate with the child and family in an open and honest manner.
4. Children and families should always be listened to, and be encouraged to talk through their wishes and care choices.
5. At all stages of care, from diagnosis to death and bereavement, families should be provided with accurate and relevant information that they can understand.
6. Where possible, children should be cared for in the family's place of choice – in hospital, a hospice, or at home.
7. Emotional, psychological and spiritual support should be offered to the child, and those close to him or her.
8. Children and young people should be given the opportunity to access education and employment that is right for them.
9. The child and family's wishes concerning end of life care should be discussed and planned for well in advance.
10. Support and care should extend to all family members, friends and all those involved with the child.

*When the term 'child' is used, it refers to any baby, child or young person with a life-limiting or life-threatening condition.

info@togetherforshortlives.org.uk
Helpline: 0945 108 2201
www.togetherforshortlives.org.uk

Together for Short Lives is a registered charity, a registered care provider (1141012) and is accredited as a voluntary provider by the Care Quality Commission. The project is supported by the National Lottery. © Together for Short Lives 11 March 2012

Together for Short Lives has launched a brand new charter representing the needs of families of children with life-limiting and life-threatening conditions.

The charter focuses on the types of information and support families should expect to receive.

The ten statements set out in the charter are general principles that Together for Short Lives believes all organisations working in children's palliative care and disability sectors, as well as complex care services and acute settings will support.

By displaying the charter, services will be publicly showing their commitment to these core principles, and will be sending a clear message to the families they work with.

View and download the charter at www.act.org.uk/tfslcharter

Posters can be ordered in A4 or A3 format by emailing info@togetherforshortlives.org.uk or calling 0117 989 7820.



Together for Short Lives has also re-branded four family factsheets which were previously produced by ACT.

These are:

- ▶ Understanding siblings' needs
- ▶ Spiritual, religious and cultural wishes
- ▶ End of life planning
- ▶ After your child's diagnosis

These have all been re-vamped to fit with the Together for Short Lives brand and are free to download at www.act.org.uk/familyfactsheets.

For hard copies, contact susannah.woodhead@togetherforshortlives.org.uk or call 0117 989 7820.

eHospice - a free website and app with international news on hospice, palliative and end-of-life care, including children's palliative care



Palliative care news, views and inspiration from around the world

hospice and palliative care organisations worldwide.

At the touch of a button, you

Launching in October, ehospice is a free website and app that will bring you real time international news and intelligence on hospice, palliative and end of life care – delivered by regional and national

will find the latest news, commentary and analysis from across the world, bringing together the expertise and experience of the global hospice and palliative care community.

Available across web, mobile and tablet, ehospice will offer you a dynamic learning experience, including a directory of hospice and palliative care worldwide accessed via an interactive globe.

To find out more about ehospice ahead of the launch on 2 October, sign up for regular email updates by visiting:

www.ehospice.com

ICPCN eLearning module on the WHO Pain Guidelines updated

Have you completed the short course on the new WHO Pain Guidelines for persisting pain in children? You



can still do this through the ICPCN's eLearning module which can be accessed through the ICPCN website. This module has recently been

revised with new information in line with the published guidelines.

Pain assessment and management are key competencies within the discipline of children's palliative care. New guidelines were released on 1 March 2012 by the World Health Organization (WHO) on the management of persisting pain in children. Various changes have been made since the last guidelines were published, including the reduction of the three step analgesic ladder for children to a two step ladder. As well

as taking participants through the principles of pain assessment and management in children, this course will also introduce them to the new guidelines. Thus it will serve both as a course for teaching clinicians new to the area, as well as updating those who have been working in children's palliative care for a while.

Go to www.icpcn.org.uk and click on this icon or follow the link on the menu bar.



The end of an era - a sad goodbye to the wonderful 'Champions' from the Diana, Princess of Wales Memorial Fund

Champions who are very often found in the background are the visionary people working for donors to ensure that the donor funding is given where it is needed and will make a difference. It has been my privilege to work with the Diana, Princess of Wales Memorial Fund since 2001. Sadly the fund is closing down at the end of 2012 and its impact on Children's Palliative Care will be sorely missed. I would like to take this opportunity to thank the following people within the fund who have tirelessly supported the ICPCN and children's palliative care over the years.



Dr. Astrid Bonfield, the Chief Executive, is very supportive of palliative care for children and we congratulate Astrid on her appointment to head the Queen's Diamond Jubilee Fund.



Olivia Dix, who has led the Palliative Care Initiative for many years, is a true and energetic visionary who has often identified a need before people working in the field, and proposed effective solutions. Olivia has been a "forever friend" to palliative care and we know that wherever she goes from the Fund, she will make a real difference in the lives of children and adults who need support.



Laura Ross-Gakava has been a real friend to children's palliative care in sub-Saharan Africa, leading efficiently and effectively on a project to develop Beacon Centres for children's palliative care in South Africa, Uganda and Tanzania, supporting the in-country leaders or Navigators, and being forever supportive of myself as project coordinator. Laura is now working for another Foundation and we know that she carries children's palliative care in her heart.



Sally Lyon is the quiet and efficient Administrator of the Palliative Care Initiative and it has been a joy to work with Sally as she has been the calm and friendly "engine" of this wonderful fund.

To all the staff of the Palliative Care Initiative , we send a very big and heartfelt "Thank you" and wish you all well in the work you do in the future.

We will be forever grateful to the Diana, Princess of Wales Memorial Fund for their wise and effective grant-making that has made a real and lasting difference to children in Africa. The fund has been a fitting tribute to Diana, Princess of Wales and the ICPCN is committed to making sure that the work they have started in children's palliative care continues.

Joan Marston

Diana

Princess of Wales Memorial Fund
PALLIATIVE CARE INITIATIVE

Tiny Tim and Friends opens Maluba House in Zambia



Maluba House

In partnership with Our Lady's Hospice and the Elizabeth Glaser Pediatric AIDS Foundation, Maluba House was created for paediatric palliative care, or for children with life-limiting or life-threatening illnesses, such as HIV/AIDS, TB,

being HIV and HIV-related cancers. Paediatric palliative care through Maluba House is child-centred care and support which relieves not only the pain and difficult physical symptoms, but also deals with the child as a whole person—remembering each child has specific psychological and spiritual needs. Selected Tiny Tim and Friends (TTF) staff members were sent to Uganda for one month to study paediatric palliative care.

In our imperfect world, there are many children who suffer and die in needless pain. Until very recently, there were next to no palliative care services for children in Zambia, where even preventable pain has been accepted as a fact of life for many.

along with generous donations from Tiny Tim and Friends supporters around the world that the opening of Maluba House was made possible.



Fifteen year old Michael Mapenzi from the Kalingalinga compound in Lusaka, Zambia and whose story was featured in ICPCN's publication 'Touching Rainbows' was one of Maluba House's first patients and was able to appreciate the benefits of the beautiful new facility before he passed away earlier this year.



While working with critically ill children, it is a natural progression that Tiny Tim and Friends and our partners should be at the forefront of establishing these services for children in Zambia.

It is thanks to funding from The Diana Princess of Wales Memorial Fund, Elton John AIDS Foundation, UK based charity, True Colours Trust,

To find out more about the work being done in Zambia visit:

www.tinytimandfriends.org

cancer or severe disabilities.

Open since July 2011, "Maluba" is the local word for flower. And indeed, it does live up to its name! Walls are covered with beautiful flowers painted by the 10th grade class of Lusaka International Community School.

Since the opening around 40 children have passed through Maluba House with various diagnoses, mostly



TWO NEW CHILDREN'S HOSPICES FOR AFRICA



The Bigshoes Foundation opens the First Children's Hospice for KwaZulu/Natal, in South Africa at Clairwood Hospital in Durban



Dr Julia Ambler of the Bigshoes Foundation describes the services that will be provided by the new children's palliative care unit at the hospital

The opening speech given by Joan Marston, Chief Executive of the ICPCN

I believe that the opening of this beautiful unit, the wise and compassionate partnership could be the stimulus for KZN to look at a provincial network of palliative care services for children. The value of this unit goes far beyond the unit itself. For the children, always first and foremost, it will be a safe and child friendly haven where their condition can be assessed, and for expert treatment of pain and symptoms of the body mind and spirit. For intensive therapies, developmental stimulation and for time spent playing and enjoying normal childhood activities. A place where they can express their emotions and get help in dealing with them.

And for those children who cannot die at home to be cared for with compassion and skill, in comfort and with dignity and respect. Families can safely leave their children here while they enjoy some respite from the unending responsibilities of care. Parents,

siblings and primary caregivers, can be taught how to provide care and support and administer treatment and themselves receive counselling and support. For health care workers this unit will be a place to put knowledge into action and to learn from experts and then take that knowledge and competence back to their own organisations. The ripple effect of having such a professional centre. For the community this unit is an expression of the good in our communities and an opportunity for individuals and organisations to give of their time, talents and resources. For all who help here in any way, it will enrich your own life immeasurably.

However a unit such as this cannot work in isolation. It must be part of a continuum of care and network and train extensively to ensure children continue to receive palliative care when back in their homes and communities where they belong.

This warm and inviting centre has its own voice and speaks loudly on behalf of these children and their families. Twelve year old Mattie Stepanek was the fourth child in his family to live with and eventually die from a rare form of muscular dystrophy. He wrote about colours in his anthology about 'heartsongs':

*The colour of earth is browns and greens
The colour of sky is blues and greys
The colour of hope is rainbows and sunsets
And the colour of love is people together*

May this unit be a blessing and little bit of heaven on earth for children and their families and all who come into contact with it.

Statistics for KZN

KZN has more children than any other province in South Africa (23%) and the highest prevalence of HIV in children under 15 years of age. (4.1%)

78.7% of children living in KZN live in poverty where their family earns an income of less than R552 a month (approx. US\$ 65)



Volunteers add the finishing touches to the outside mural on the new playroom, named 'Sithandeni', which means 'We love them' in Zulu.



If well enough, every child in the two paediatric wards is provided with stimulation under the supervision of a dedicated play co-ordinator and a qualified teacher. Toys are also taken to the wards for the children who are confined to bed.



A dash of colour was added to the wards and the small 'End of life' room.



The paediatric palliative care team based at Pereira Rossell Hospital Centre in Montevideo

Uruguay is a little country in the south of South America, in between Argentina on the west and Brazil in the North. It has a population of 3.3 million and an infant mortality rate of persons 7.7‰. It is unknown how many children need palliative care.

The paediatric palliative care team is based at Pereira Rossell Hospital Centre (PRHC) the national women and children reference hospital, located in Montevideo, Public Health Ministry – Universidad de la Republica.

National legislation in Uruguay has stated that it is the right to the whole population to receive palliative care but before 2004 there was no paediatric palliative care unit (PPCU) in the country. In 2004 the first PPCU inside the Intensive Care Unit PRHC was formed and in 2008 the Pereira Rossell Hospital Centre - Pediatric Palliative Care Unit (PRHC-PPCU) was implemented with assistance and for educational purposes in the Paediatrics' Department

Our Interdisciplinary, part-time/honorary team consists of two paediatricians, two paediatric residents, one oncologist, one social worker, three psychologists, two nurses and one physiotherapist.

The primary objectives of the unit are to improve the quality of health care and quality of life of hospitalized children with life-limiting/threatening conditions and to improve the palliative care competencies of paediatric staff working at PRHC.

Weekly meetings are held in order to facilitate the clinical work and for the planning of educational activities.

Patients are presented by the paediatric residents/ward staff and a systematic

clinical reasoning tool is used. After this meetings with the children and families are held as well as with specialists and the primary care physician. With input from children, family and professionals, caring objectives and support needs are defined and their implementation planned.

Our work in the field of education has included:

- ▶ Incorporation of CPC into the Paediatric Resident's curriculum
- ▶ Continuous Professional Development workshops for health workers
- ▶ Spreading CPC principles and experience in different health professional scenarios

Clinical reasoning tool for Paediatric Palliative Care

1. Does this child need Palliative Care? Why?
2. To which ACT Category does he/she belong?
3. In which stage is he/she in relation to death risk?
4. What are their main problems? Biological, psychological, social, communication, spiritual ?
5. What are the major child and family needs and preferences?
6. What are the human, materials, organisational, or management resources needed to solve the problems and satisfy needs identified?
7. To define together with the child (if possible) and the family the care objectives and action plan

To date we have worked with 165 children ranging in age between 28 days and 16 years.

Achievements

Achievements to date have included: Mandatory Paediatric Residents Course of 22 hours with a 6 month clinical rotation (So far 132 paediatric residents have passed this); Professional health workers workshops; Seven eight hour 'Introduction to PPC' workshops have been held for 210 participants from different disciplines and regions.

Participation in national congresses and scientific events including:

- Uruguayan Congress of Paediatrics
- Uruguayan Congress of Medical Psychology
- Uruguayan Congress of Paediatric Nursing
- HIV national scientific conference
- Neonatology Department conference
- Paediatrics Uruguayan Society annual meeting
- TELETON conference

Barriers

Barriers to our development include having only honorary/part time work conditions, the lack of budget for providing continued care for ambulatory and 'at home' patients as well as slow official recognition.

Challenges

- ▶ To know the number of Uruguayan children living with life threatening-limiting conditions
- ▶ To create a national PPC network, for caring of children in all possible scenarios (home, office, hospital), in public and private settings, 24 hours/day
- ▶ To include "death management" and PPC in the curriculum of all health professions that work with children
- ▶ To achieve more complete assessment methods for educational activities
- ▶ To asses impact of CPC in children and family quality of life in order to adapt and improve professional action

We are very happy to be part of the ICPCN network!

Mercedes Bernadé

Professor of Paediatrics
PRHC-PPCU Coordinator
Uruguayan Pediatric Palliative Care Team



Map showing levels of children's palliative care provision in South America

First Children's Hospice in Germany has been Awarded the Seal of Quality

The first SEAL of Quality for a children's hospice in Olpe was awarded by the TÜV Rheinland Group, a global leader in independent testing and assessment services.

For the very first time in Germany, a children's hospice has been awarded a seal of quality. The seal was specially developed for the work of children's hospices in Germany. It guarantees reliable quality standards in a children's hospice. The global leader in independent testing and assessment services, the TÜV Rheinland, sent an auditor who investigated the structures and processes of the children's hospice in Olpe. The ambassadorship for the seal has been taken up by a German member of parliament, Mrs. Bracht-Bendt, who was also the chairwoman of the Federal intergroup child commission.

Children's hospices and children's hospice home care services support children with life-limiting diseases, together with their families. The care begins from diagnoses and continues into the time of bereavement. These organisations take care of the sick children, offer recreational support, relief and understanding and help the families to organise their day-to-day living and to develop a new perspective on life.

In 2006, the members of the National Association of Children's Hospices (Bundesverband Kinderhospiz e.V.) developed the concept of how to implement standards of quality in children's hospices. It was a challenge – taking into consideration the sensitivity of the subject as well as the highly complex structure of a children's hospice. A task team made up of leaders of children's hospices collected information on how children's hospices are structured. For example, in the case of purpose-built children's hospices there needs to be a minimum of eight beds for sick children, specially qualified palliative care professionals, a separate area for end of life care, professional bereavement support, training and supervision of the volunteers and employees. This information regarding the requirements was included in the position paper of the Bundesverband Kinderhospiz.

The idea of developing this seal of quality grew out of the need to prevent any institution calling itself a 'children's hospice' without providing the necessary services and to guarantee continuity, standards and transparent quality in children's palliative care. With the support of a special consultant agency the development of a quality handbook, which should become a guide for all institutions, was created. It has been a long, arduous and very time consuming process. But finally, in 2011, the handbook – one for purpose-built institutions and one for home-services, was finished.

The handbooks contain a description of all procedures that take place in a children's hospice. The level of the handbook is structured in the same way as the DIN ISO quality seals for companies, commonly used in Germany. We wanted something that went beyond that of the DIN ISO certification. We wanted the seal to be unique and to be specific to children's hospices. For this reason we added further criteria to the handbook. Finally, the handbook also refers to the commonly agreed structural format of children's hospices.

When a children's hospice has successfully instituted all processes and policies as set out in the handbook within its own organisation, it can apply for certification. The TÜV then audits the organisation and as the National Association of Children's Hospices, Bundesverband Kinderhospiz can award the seal of quality. The children's hospice seal is valid for three years.

Coincidentally, the first institution to attain the seal was also the first children's hospice to open in Germany. CEO of Balthasar Hospice, Rüdiger Barth says: *"We are so proud and happy, that we are now the first children's hospice with a seal of Child Hospice Quality. It is an acknowledgement of our work*



From left to right: Gero Gieseler, Quality Manager, Child Hospice Balthasar, Olpe; Sabine Kraft, CEO, National Association of Children's Hospices in Germany; Rüdiger Barth, CEO, Child Hospice Balthasar, Olpe; Olaf Seiche, CEO Business Unit Service Sector, TÜV Rheinland; MdB Nicole Bracht-Bendt, Member of Parliament, Berlin

and it gives our families even more assurance of our reliability and that they are in good and professional hands."

Sabine Kraft, CEO of the National Association of Children's Hospices adds *"With the Children's Hospice Quality Seal we can give better direction and meaningful advice to people needing to find a children's hospice able to meet their needs."*

The National Association of Children's Hospices in Germany (Bundesverband Kinderhospiz e.V.) is the umbrella organisation for the Children's Hospices and Children's Hospice Home Services in Germany. Our focus is the quality of life of life limited children and their families.

Sabine Kraft

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Report back on first Paediatric Palliative Care Conference in Norway

In May this year the first children's palliative care conference for the Nordic countries took place in Kristiansand, Norway's fifth biggest city. The same city where palliative care for children in Norway started in 2009.

It began with a young girl of 17 years who died after a life of illness. Now her mother, Natasha Pedersen, is continuing with her daughter's life legacy through the organisation, "Yes to Units and Palliative Care for Children in Norway".

More than two years ago Natasha initiated a partnership with the Paediatric Nurses Association and the planning began for Norway's first conference on palliative care for children which they called "Not bits and pieces". The title was taken from a book by Jan Kåre Hummelvoll. The title was well suited for the focus of this important conference, namely to put palliative care for children on the government agenda. The goal for the conference was to provide a basic introduction to palliative care for children; to look at what issues we need to focus on, what has been done and what should still be done. Research was presented as well as recommendations on what is happening at the international level. The conference also focused on the need for

increased knowledge, skills and education on issues such as communication with dying children and their families as well as how to prepare health professionals to practice palliative care to children.

The conference was attended by over 204 health care professions from all over Norway, including nurses, doctors and social workers. There were also attendees from Sweden.

Both the Mayor and the head of the Health and Care Committee from the Department of Health were involved in opening the conference along with a large children's choir with over 50 children.

The conference was a great success. The evaluation showed that 95% of the participants gave very positive feedback about the conference and were inspired to do more. The conference was just the beginning and an introduction to palliative care and palliative care for children. That there is a need for more conferences in the future is now very clear. It has challenged us to continue working to achieve a more practical conference the next time and even possibly a Master class with the help of the ICPCN.

Several of the media also mentioned the conference and there was a brief interview on Norwegian radio in the early morning of the conference day. We want to thank everyone who helped, all who participated, and all who helped with practical tasks. And also a big thanks to ICPCN and Together For Short Lives for contributing, great cooperation and good advice. Also we want to give a special thanks to André Grundvig, the leader of the Norwegian Paediatric Nursing Association.



Dr Ann Edner, with Livia the labradoodle, from the only children's hospice in Sweden called Lilla Erstagården, attended the conference and gave a presentation.

Bayt Abdullah Children's Hospice in Kuwait is looking for a Medical Director, Head of Care and Director of Care

Bayt Abdullah Children's Hospice (BACCH) is one of the major projects under the Kuwait Association for the Care of Children in Hospital (KACCH).

Bayt Abdullah Children's Hospice is providing comprehensive, paediatric palliative care facility that embraces all the needs of children with life-limiting and life-threatening conditions and their families in an attractive, child friendly environment enabling them to live their lives as fully as possible for as long as possible.

BACCH is providing specialised professional palliative care service, free of charge for all children in Kuwait who meet the criteria for admission to the hospice, regardless of nationality or religion. BACCH depends entirely on donations

from individuals and organizations within Kuwait to run its operations and to provide the medical and clinical care required.

Bayt Abdullah is seeking a full time **Medical Director** of International Standing who will assume the overall responsibility for the medical component of the hospice program and lead our highly motivated and committed multidisciplinary team of professionals to achieve the highest standard of paediatric palliative care for all children in Kuwait, and their families.

The **Director of Care** is expected to plan, direct and manage the provision of paediatric palliative care for children and their families across the hospice and home-care services, working with Medical Director and other members of multidisciplinary

team and serving as a clinical preceptor for junior and senior nurses.

The **Head of Care** is expected to run clinical day-to-day operations by providing professional and clinical leadership to the palliative care team, creating an environment and culture within the care team where quality and excellence are valued and clinical practice reflects the highest standards of care for children, young people and their families.

Closing date for applications for these three positions is **1 July 2012**. To find out more about these positions and how to apply please visit their website at:

www.bacch.org