network news

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icpcn
international children's palliative care network

LETTER FROM THE CHAIR

Dear Friends,

This past year has been a journey of discovery and development for the ICPCN. Discovery of the many people around the world who are passionate about palliative care for children; and of the many effective organizations, projects and models of care reaching so many children with life-limiting, life-threatening and chronic conditions; and development of the ICPCN into a recognized international partner in the field of children's palliative care and an integral part of the Worldwide Palliative Care Alliance.

The appointment of Sue Boucher one year ago, supported by a dedicated steering group representing different regions of the world, has been the catalyst for this rapid development. Having someone as committed, experienced and creative as Sue working full-time on the development of our Information service and website; connecting with organizations and individuals, and responding promptly to requests and queries, means that the ICPCN now offers a professional and up-to-date international information service.

However, we are all aware there is still much to be done and welcome suggestions, advice and comments on ways we can improve and develop further.

In the year ahead we look forward to working together with the EAPC (European Association of Palliative Care) Children's Task Force led by Dr Chantal Woods, and with Children's Hospice International and Ann Armstrong-Daily on their 20th World Congress to be held in Cape Town in September.

Each organization plays a different and essential role in promoting and developing palliative care for children, but as H.E. Ludick once said:

*"No one can whistle a symphony.
It takes an orchestra to play it."*

The children we serve and are dedicated to need each and every one of us to be a vocal advocate and committed practitioner if we want to reach our dream of palliative care for all children.

> *St Augustine of Hippo wrote: "Hope has two beautiful daughters; their names are Anger and Courage. Anger at the way things are and Courage to see that they do not remain the way they are."*

Thank you for all you do for children , and may you and your loved ones be blessed at this time and find peace, joy, hope and love in the year ahead.

Joan

Joan marches for the cause on World Hospice and Palliative Care Day

EVENTS CALENDAR: JANUARY, FEBRUARY, MARCH 2009

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

January		
14	Primary Schools and Bereavement	London, UK
16	1st International Conference on Public Health and Palliative Care	Calicut, Kerala, India
28	How to run a sibling group: Training for Professionals	Cardiff, UK
February		
3	The Challenges of Transitional Care for Children wtih Complex Needs - A Closer Look	Chorley, UK
5 - 7	German Congress on Pain Management and Paediatric Palliative Care	Recklinhausen, Germany
13 - 15	Indian Association of Palliative Care Conference (IAPC)	New Delhi, India
20 - 21	ELNEC-PPC Train-the-Trainer Programme	Sacramento, USA
25	How to run a sibling group: Training for Professionals	Manchester, UK
March		
1 - 7	Open Society Institute: Seminar on Psychiatric Aspects of Palliative Care	Salzburg, Austria
5 - 7	Palliative Medicine & Supportive Oncology 2009	Fort Lauderdale, USA
11	Siblings of disabled children - Workshop for Professionals	Exeter, UK
13 -16	World Institue of Pain (WIP) 5th World Congress	New York, USA
19	Ideas into Action (2)	Birmingham, UK
22 - 24	INCTR's 8th Meeting on Cancer in Countries with Limited Resources	Antalya, Turkey
31 - 3/4	4th South African AIDS Conference (Closing date for Abstract Submission 31 December 2008)	Durban, SA

Report from the UK

Announcement of new Academic Chair

In the UK we are about to announce a new Academic Chair post in children's palliative care to be situated at Great Ormond Street Hospital for Children. The Chair will be called the **True Colours Chair of Palliative Care for Children and Young People**. The True Colours Trust is one of the Sainsbury Family Charitable Trusts, and it is hoped that the creation of the Chair will act as a catalyst, drawing on the significant expertise around the country, and building on the commitment to make high quality paediatric palliative care universally accessible.

All 4 countries of the UK now have relevant Palliative Care Strategy issued by Government, which gives opportunities for further lobbying in relation to standards of care.

In **England,** *Better Care: Better Lives* activity is happening at local level, but there seems to have been some slowing down of activity at national level, with the arrival of a new Minister. The Ministerial post is a more senior one than previously which gives good opportunity to move Children's Palliative Care up the agenda, when it eventually gets on to the Ministerial radar. We continue to lobby to clarify the amount of funding available to health trusts to deliver the England-wide strategy for children's palliative care Better Care: Better Lives.

In **Wales**, implementation work is now beginning on the Welsh Palliative Care Strategy.

In **Scotland,** the new strategy for palliative care: Living and Dying Well uses the concepts of planning and delivery of care, and of communication and information sharing as a framework to support a person centred approach to delivering consistent palliative and end of life care in Scotland. We are still awaiting the Children's Policy document relating to specialised services.

In **Northern Ireland** the implementation phase of their Strategy for children with complex health needs is progressing well.

ACT and ***Children's Hospices UK*** have been working on a number of joint initiatives,including:

Transition: a Transition Partnership has produced the first edition of a Transition newsletter and we are hosting a one day conference on transition on 29 April. There are now 14 ACT Transition Co-ordinators in post working across the UK to implement the ACT Transition Care Pathway.

Mapping: we are currently developing the next phase of our mapping initiative and will be looking to roll out the Minimum dataset and services mapping model in six targeted areas across the UK.

The Child Death Review Process which has been introduced to safeguard children by reviewing all child deaths is causing concern among children's palliative care providers as many deaths among children with life-limiting conditions are unexpected and may lead to the triggering of inappropriate rapid response procedures. We have been working to raise awareness of the need for end-of-life plans and for these plans to be well communicated, particularly with emergency/ambulance/police services.

Barbara Gelb
Children's Hospices UK

Lizzie Chambers
ACT

Romania

We finalised a project which aimed to raise standards and provide equality of care for Romanian children who are suffering from life-limiting or life-threatening illnesses, including HIV, whether at home with their families or abandoned and living in State-run institutions.

The result was that working together with local and national authorities for child protection we developed a "Minimum Standards of Care for Residential Homes" and a guideline which give specific instructions about the provision of palliative care for children living in state institutions.

The documents are now in the stage of legislative project which are to be adopted by Ministry of Social Protection.

On 7-8 November we held the 9th Conference of the Romanian National Association for Palliative Care with about 200 people from all over the country participating. It is encouraging to see more services opening every year and people wanting to learn how to start a quality palliative care service.

At present we are working on developing a National Programme for Palliative Care for Oncology. We are also trying to present the needs of children with other diseases to be introduced in The National Programmes for Rare Diseases.

Financially sustaining all our services in Hospice Casa Sperantei, and finding funds for new services. It is difficult to maintain standards in services with little resources.

by Dr Delia Birtar

South America

by Dr. Rut Kiman

Some key conferences and events that have taken place in the last few months relevant to children's palliative care in South America include the following:

- -Argentine Society of Haematology: Supportive care in paediatric cancer patients
- -Occupational Therapists Symposium
- -Participation in the 5th Argentine Meeting of Palliative care in Tucuman
- -New challenges in inclusive education
- -Paediatric Palliative Care for Nurses at the Hospital Municipal Mendez
- -Limitation of therapeutic efforts (Introduction)
- -1st paediatric palliative care course at the Hospital de Niños by Dr Ricardo Gutiérrez, Secretaria de Salud, Gobierno de la Ciudad de Buenos Aires.
- -Argentine Society of Paediatrics: Palliative Care Course on 15 November

We are writing chapters for a book on Paediatric Palliative Care with Dr Silvia Barboza. Some challenges that we face in our part of the world include the need for guidelines and recommendations, research and publication and education.

Dr Rut Kiman (third from left) and her dedicated paediatric palliative care team.

South Africa

Apart from the accepted life-limiting illnesses, it is estimated that in South Africa 6 million people are infected with AIDS and suffer from AIDS related illnesses, 250 000 of those being children. We also have 1,8 million AIDS orphans - many of whom fall into the palliative care net as a result of support offered to families of adult hospice patients.

In 2006 there were 5 sites within South Africa recognised by HPCA as providing palliative care for children. But with generous funding from the Diana, Princess of Wales Memorial Fund and PEPFAR, (United States President's Emergency Plan for Aids Relief) these 5 sites grew to 18 sites in 2007.

With stepped up funding from PEPFAR, a further 22 children's palliative care sites have been identified and will start to receive a set amount of money each month to be used for the dedicated provision of palliative care to children. This brings the total of HPCA recognised and assisted children's hospice and palliative care sites to 40.

Given this extraordinary growth and the size of the country, three Paediatric Palliative Care Officers have been employed to ensure that the expected standards of care are upheld at each of these sites.

Funding has also been earmarked for the provision of relevant training courses for their staff to be held in centres throughout the country in January and early February.

Many of the 40 sites have developed as an extension of the adult palliative care services that were already in existence and in response to a patently obvious need within the communities. While only 7 of these sites have In-Patient Units, others provide programmes which include home based care and/or day care centres, as well as offering numerous social work interventions such as memory work, bereavement and trauma counselling, referrals to other agencies and peer support groups. Nutritional guidance is also offered in many instances.

by Joan Marston

Meet the PPC team from HPCA in South Africa:

From left to right:
Dintletse Mojaki; Joan Marston; Maraliza Robbertze; Annanda Bothma

The True Colours Trust

ICPCN acknowledges with gratitude the funding received from The True Colours Trust for the furtherance of its work in developing paediatric palliative care worldwide

OPENING OF PAEDIATRIC PALLIATIVE CARE OFFICE OF THE GAUTENG PALLIATIVE CARE CENTRE OF EXCELLENCE, CHRIS HANI BARAGWANATH HOSPITAL, SOWETO, SOUTH AFRICA

by Dr Michelle Meiring

In Celebration of World Hospice and Palliative Care Day on 11October 2008 the Paediatric Palliative Care office of the Gauteng Palliative Care Centre of Excellence based in the Chris Hani Baragwanath hospital in Soweto, South Africa was officially opened. True to the theme of the day "Hospice and Palliative care: a human right", the opening ceremony also included a "peaceful demonstration" by a group of paediatric patients wielding placards and chanting "Pain is not a game!"

The renovation of an old pre-fabricated disused ward within the Chris Hani Baragwanath Hospital in Soweto was made possible by Mr Michael Wellsted (the uncle of a patient) who walked across the Sahara desert to raise funds for the upgrade.

The Paediatric Palliative Care office was created within what was previously used by the hospital as the paediatric gastro-enteritis unit ("drip room").

With a bit of imagination, some dry walling, a touch of brightly coloured paint and some important structural interventions, the old ward was transformed into a therapeutic space where patients suffering from non-curable conditions and their families can receive care, counseling and support. The office now boasts a meeting room, administration office, social work, doctor and psychologist's office as well as a small bathroom and kitchen facility. It also has a comfortable lounge for family counseling sessions and a play space for the children.

The offices house the Paediatric Palliative Care team of the Palliative Care Centre of Excellence which is a government/donor partnership providing palliative care services, training and research in the public health care sector in Gauteng. The Centre of Excellence is the first of its kind in Africa and was established by Dr Natalya Dynat with support from the Gauteng Department of Health.

The Paediatric team led by Dr Michelle Meiring provides a consultative service to three academic hospitals in Johannesburg and sees patients for pain and symptom control, terminal care and psycho-social support. The team also provides training for doctors, nurses and medical students in palliative care for children.

The Paediatric Palliative Care team from left to right:
Mrs Dudu Khambule, Mrs Kay McCrindle, Mrs Bridget Stark, Ms Jabulile Mahlaba, Dr Louisa Ferreira, Dr Vivi Neoh, Sister Alice Serobatse, Dr Michelle Meiring, Mrs Nonkosi Mteto

Crazy enough to walk the driest place on earth? Michael Wellstead did!!! He walked 250 km from Farafra to Bahariya Oasis situated in the Sahara Dessert over a period of 7 days.

All this to raise funds for the orphaned and vulnerable children of South Africa. Through his efforts, Michael was able to raise R50,000 from international donors. What a wonderful gesture! So many children will receive medical attention and palliative care with this money. Care that will make a world of difference in their lives. Care that will put a smile on their faces and warmth in their hearts.

ChiPPS CELEBRATES TEN YEARS

Report from the USA by Sue Huff

The National Hospice and Palliative Care Organization (NHPCO) / Children's Project on Palliative Care and Hospice Services (ChiPPS) celebrated 10 years within NHPCO. At the NHPCO Clinical conference in Dallas, Texas in October a "pediatric intensive" was held. This placed a focus on 'children's needs' throughout the conference, including a pre-conference on pain management, and a track of workshops spanning care of all ages was highlighted throughout the conference, with special recognition to ChiPPS and their accomplishments in the field. A pediatric networking session was also held. ICPCN was discussed at several pediatric workshops.

The first National Standards for Pediatric Hospice and Palliative Care are completed. NHPCO will have them available to all members of NHCPO as a Pediatric Appendix to the Adult Standards Manual in January 2009. I am now working on a lay document for parents and families of children; and also a mini version of the standards to distribute to non members. NHPCO is also revising their pediatric educational curriculum and compendium to an e-learning format on line; this project is in progress. First set of modules to be completed in Spring 2009.

Children's Hospice International World Congress was held in San Francisco, California in November. CHI continues to lobby the US Senate and House of Representatives to adapt the CHI PACC model of care for children across the USA. Seven states have waivers in place. California and New York are the next two about to enrol Children in 2009. Florida should be ready to release their first set of data on their waiver program, with cost and outcome measures.

The Initiative for Pediatric Palliative Care (IPPC) has adapted their hospital based peds palliative care curriculum, which is focused on relationship building, to fit the needs of the population of children afflicted with chronic neurological disorders. A meeting and discussion was held in Greece in November which Cynda Rushton attended.

At this time in the United States, there are more efforts than ever being put into research and programming for children's hospice and palliative care needs, even though our economy is struggling and our health care systems present challenges to fund these needs. There continues to be a growing interest in the field, emphasizing on research and collecting descriptive data from programs that already exist. There are more regional, and local pediatric palliative care educational events offered.

1 December was World AIDS Day

Global HIV/AIDS estimates, end of 2007

The latest statistics on the world epidemic of AIDS & HIV were published by UNAIDS/WHO in July 2008, and refer to the end of 2007.

	Estimate
Adults living with HIV/AIDS in 2007	30.8 million
Women living with HIV/AIDS in 2007	15.5 million
Children living with HIV/AIDS in 2007	2.0 million
People newly infected with HIV in 2007	2.7 million
Children newly infected with HIV in 2007	0.37 million
AIDS deaths in 2007	2.0 million
Child AIDS deaths in 2007	0.27 million

More than 25 million people have died of AIDS since 1981.
Africa has 11.6 million AIDS orphans.
At the end of 2007, women accounted for 50% of all adults living with HIV worldwide, and for 59% in sub-Saharan Africa.
Young people (under 25 years old) account for half of all new HIV infections worldwide.
In developing and transitional countries, 9.7 million people are in immediate need of life-saving AIDS drugs; of these, only 2.99 million (31%) are receiving the drugs.

Statistics taken from the AVERT website: http://www.avert.org/worldstats.htm

RAISING THE PROFILE OF PAEDIATRIC PALLIATIVE CARE IN AFRICA

REQUEST FOR INFORMATION

To date there has been a lack of focus on palliative care for children in Africa. However, we know that there a number of key individuals and organizations who have been working hard to deliver paediatric palliative care in Africa.

Several years ago a funder commissioned a review of the status of palliative care in Africa - this went on to form a widely referenced report and served to bring a lot of additional attention to the field. However, it did not address paediatric care. We are delighted that a new review focusing solely on children has been commissioned. We hope and expect that it will have a similar effect of raising the profile of paediatric palliative care in Africa, and more important, to highlight the excellent work of those active in the field.

We need anyone who is involved in the organization, delivery, evaluation of funding of paediatric palliative care in Africa to provide us with any written materials / reports that they have.

WE DO NOT NEED YOU TO COMPLETE ANY OTHER INFORMATION – we simply want to read about what you have already written.
This could be anything from: written reports, monitoring reports, descriptions of your work, annual reports and research papers – anything that relates to what you do. The information obtained will enable us to, amongst others provide increased support, advocate for, and develop paediatric palliative care in countries in Sub-Saharan Africa.
It is of great importance that all organizations, individuals and institutions involved in providing palliative care for children are included in this review. Contributions from all organizations, individuals and institutions will be acknowledged in the final report. We are interested in any organization that provides palliative care for children with life limiting progressive illness. You might be a hospital, a hospice or a home based care service, a clinic, a community group or any other model of care. We want to make sure that we reflect you all in the report.

The success and final goal of this study (to support and develop care for the terminally ill African child), depends on obtaining as much information on existing palliative care services as possible.

PLEASE SEND YOUR RESPONSE TO:

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If you have any questions, please do not hesitate to contact:

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This work is a collaboration between:
Kings College of London (KCL)
Diana Princess of Wales Memorial Fund (DPWMF)
International Children's Palliative Care Network (ICPCN)
Hospice Palliative Care of South Africa (HPCA)
African Palliative Care Association (APCA)
University of Cape Town (UCT)
Hospice Africa Uganda
Hospice Association of Zimbabwe (HosPAZ)
University College of London (UCL)
University of the Witwatersrand Palliative Care (Wits PC)

Dr Geoff Foster wins the ICMDA Dignity and Rights to Health Award

It is with great pleasure and a deep sense of priviledge that I, on behalf of the International Christian Medical and Dental Association (ICMDA) HIV Initiative Interviewing/Selection panel announce the winner of the 2008 Dignity and Rights to Health Award.

Dr Geoff Foster, a Paediatriciain in Zimbabwe, was selected from a number of other highly regarded and most worthy nominations. The award is made annually to persons for excellence, outstanding leadership and compassion in responding to the HIV/AIDS epidemic.

We share with you the profile of Dr Foster:

He has made significant impact locally, regionally and internationally

Geoff recognized in 1987 that HIV was a devastating exploding epidemic when he saw, within a few weeks, many infants dying of AIDS at the Mutare government hospital. He began a crusade which continues through today to alert the world through publications, speaking, and demonstrating personal concern as a pediatrician in Zimbabwe. In my opinion none else has been more effective in bringing to the world's attention the plight of children affected by HIV/AIDS and break the silence and hopelessness of Paediatric AIDS.

Below are a sample of his contributions:
A review of current literature on the impact of HIV/AIDS on children in sub-Saharan Africa (2000) by Geoff Foster and John Williamson

Where the heart is: Meeting the psychosocial needs of young children in the context of HIV/AIDS (2006)
by Linda Richter, Geoff Foster and Lorraine Sherr

Under the radar: Community safety nets for children affected by HIV/AIDS in poor households in sub-Saharan Africa (2005) by Geoff Foster

He empowers others

Geoff created an NGO called FACT-now completely led by Nationals - he remains on the board-to be a channel for resources and to advocate within Zimbabwe for HIV in children and in their mothers. He has also worked extensively with community based groups particularly those within the faith communities to bring care and prevention to the village level.

In particular he has worked with the CBO/NGO 'Farming God's Way' to bring agricultural enterprises appropriate for orphans and the poor/vulnerable to enable survival in the critical condition that Zimbabwe finds itself today.

He uses the church as his primary strategy

The church is the avenue that Dr. Foster sees as the primary strategy of delivering prevention and care to children in Africa - he has shown it can be done in the midst of complete government failure and actual policies that promote HIV spread and human degradation.

His work in HIV Prevention

Geoff with FACT, work primarily at the community level to bring programmes for HIV prevention and population survival in the absence of government/international programmes.

We thank the ICMDA HIV Initiative standing committee for its dedication to the cause of holding so prominently before us all in the ICMDA the reality of HIV/AIDS and its effects in our world.

Dr. Daryl Hackland
General Secretary (ICMDA)

PRAYERS AND SUPPORT NEEDED FOR OUR COLLEAGUES IN ZIMBABWE

An edited letter from Phil di Sorbo, Senior Technical Advisor for the Foundation for Hospices in Sub-Saharan Africa (FHSSA)

Dear Joan

Thanks for your concern. All the hospices, and their staffs, are struggling mightily. The conditions are horrific, and maintaining hope and vitality are real issues. Any reaching out to them, even to say prayers, would be supportive at this time. General messages to staff would be very welcome. You can certainly do this through Island Hospice. The people to contact are:

Executive Director is Dr Dickson Chifanga
dickson@islandhospice.zw

Chief Financial Officer is Thulani:
thulani@islandhospice.co.zw

Clinical Officer is Val Maasdorp:
verval@mweb.co.zw

Concrete financial assistance would be very helpful, if wired to the Island Hospice off shore account in Botswana (they can access this in forex).

They can use funds for special needs of staff at this time, and also for emergency relief and bereavement care (food, medicines, and counseling) for patients and families most at high risk.

As you most likely know, most hospitals and clinics have closed or are open with little or no supplies or medicines. Emergency funding can address some of the food and medicine issues. Starvation and death is all over, especially in rural areas. With the hospice expansion into the rural areas through our scale-up, Island Hospice is positioned to deliver emergency relief goods and services. In fact, we have encouraged the FHSSA partner to do so, arranged an airlift this week from Direct Relief, and are sending from FHSSA some funds to their account just for this purpose. But the needs are massive.

Warm regards always,
Phil

Full banking details for Island Hospice available from info@icpcn.co.za

Paradise Kids Supports Gold Coast Families

Theresa McEwan, Alec McEwan and Lizzie Swatland

Hi my name is Theresa McEwan and I live on the Gold Coast of Australia.

We have a local charity called Paradise Kids who support children and families experiencing grief or loss. In 2005 my 7 year old son Alec was diagnosed with an aggressive form of Multiple Sclerosis and went into Pallative care. My beautiful son went from a healthy 7 year to a very disabled child. During this time I gave up work to care for my son full time as his health continued to deteriorate. I am so grateful for this time with Alec.

"*We lived a life-time in a day*"

We lived a life-time in a day and captured many memories together. As a Mum facing the thought of losing my beautiful boy it was with gratitude that Paradise Kids was recommended to my family.

I was introduced to Lizzie Swatland who wrote a program called:

"***Illness Support Program".***

The program caters for children with a life limiting or terminal illness. Volunteers implement this program in either the hospital or at home over 7 sessions. The program takes an holistic approach with an emphasis on children understanding that they are more than their physical symptoms.

Since my son's passing I have been very fortunate to volunteer with Paradise Kids and offer support to other families in a similar situation. I have found this very rewarding and it has also helped me in my journey through healing.

Losing a child is beyond comprehension but it is Alec's memory that enables me to help others. Recently I have started working at Paradise Kids 3 days a week and it is a privilege to be able to contribute my experiences to help others.

Paradise Kids conducts grief and loss courses throughout the year catering to children of all ages. We have a hospice that accommodates 8 adults on the premises. We are committed to educating the community and implement several courses including a Palliative Care Training Program.

We are currently completing a new holiday house to accommodate children with a terminal illness and their families. During their stay the families will be offered support through counselling and the programs that Paradise Kids have to offer.

Paradise Kids is a local charity that relies on donations from the public to continue their vital work in the community.

Theresa McEwan

paradise kids

Visit the website at : http://www.paradisekids.org.au

Lizzie Swatland's Illness Support Program

In 1991 Lizzi Swatland attended and completed a Reiki seminar and through this practice has shared in many experiences of death and dying by visiting hospitals and homes and assisting people in their dying process.

In the early 1990's Lizzi attended Living with Dying Courses in Melbourne,Victoria at the Usui Reiki Centre. Over two years working in the Centre as a full time volunteer, Lizzi gained great insight and experience into the many aspects involved in healing, grief, loss, death and dying.

Due to her passion for this field of work, in 2003 Lizzi attended a Grief Counselling Training Program through the Clare College of Transformative Education and Paradise Kids on the Gold Coast.

Paradise Kids was formed in 1996 to support children suffering from major grief, loss, bereavement, life-limiting illness and trauma. To ensure the ongoing benefits to the children, support is also provided to their parents so they are better able to assist the children.

In 2003, after volunteering with Paradise Kids for 18 months, Lizzi became a team leader of the Grief and Loss Support Group and from there became the Illness Support Coordinator. Lizzi has been involved in the development and running of a new Illness Support Program which she wrote in conjunction with the existing Loss and Grief Program.

The program is run over seven sessions which takes the sick child on a journey of self discovery through their illness. The program empowers them to understand that they are more than their symptoms. The sick child has a 'buddy' who is a trained volunteer and who takes them through the program with artwork, yoga, meditation, visualization, breathe work and special rituals either in their home or hospital. We also offer counselling support to the parents and the siblings are offered the Grief and Loss Program, which is run during school term time.

Through the generosity of donors, we are now building a Family Holiday House which will allow us to accommodate families with ill children from rural and remote areas to come and holiday on the Gold Coast. Using our existing Illness Support Program as a model, we will be able to offer an extended program that will allow children and their families the much needed counselling and support while they are here, and provide them with the necessary 'tools' to help heal the heartache, when they return home. We offer ongoing support for as long as their need. During their stay with us we are also offering complimentary therapies, aromatherapy, massage and reiki. All their traveling costs etc will be covered by us and because we are a charitable organization, we are able to get tickets for the local Theme Parks.

The feedback we receive from families who have experienced the program is wonderful and they have expressed that it has been life-changing in helping the sick child cope with their illness as well as supporting the whole family in coping with the dynamics of serious illness within their family.

"…Paradise Kids gave me my confident, happy, well-adjusted child back. They taught her she is more than her illness and for that I will be forever grateful."
Ruth, mother of Bree who has Spinal Muscular Atrophy.

Contact Lizzi at: lizzi_swatland@aap.net.au

Opening of Bluebell Wood, the UK's newest Children's Hospice

On Friday September 19th 2008 the champagne flowed here at the UK's newest Children's Hospice after 9 years of research, deliberation and tireless fundraising, the first families were welcomed for care in the 'house'.

It marked the beginning of a phased opening, bringing the care in the community, which has been taken to over 70 families from across the region for the past 2 years, into the £4 million purpose built hospice near Sheffield. We estimate that there are currently over 200 families from the South Yorkshire, East Derbyshire and North Nottinghamshire area who need our support. Many of these families have been coping alone or travelling long distances for support in the past.

For those who have been supported by the care in the community service, our nursing staff have been able to offer continuity of care for children whose specialised, individual needs and likes and dislikes must be a priority. Families and nursing staff feel comfortable discussing care plans and suggesting improvements or changes for the future.

Financial cost

However, the financial cost of taking care to the families from such a vast area, whilst still finding funds to complete the build has been difficult to bear. The proposed opening date for the house was put back on a number of occasions and still the transition is a gradual one. It is impossible to simply cut off the service and move all respite, emergency and end of life care into the hospice building at a set date. With a phased opening in conjunction with the shift from home to house it is working well.

Resistance to the word Hospice

One problem we come across is inviting a family to bring their child to a hospice. The use of the word 'hospice' is conducive with end of life and many families are naturally reluctant to accept this. That is when a good relationship with the family is important and introductions need to be sensitive and carefully explained.

It is a shame there is no word other than hospice to describe our support. It is more than just respite, although quality respite care is an invaluable source of support throughout the lifetime of many of the children referred to a children's hospice.

One of the first parents to use Bluebell Wood, Jon Sparks explains what this means to him and his family...

Sam's story

"We were both active, working, parents with an energetic two year old daughter, Freya, who had never been ill. Rona's pregnancy with our second child had been normal and we had just started decorating the attic which we had converted to make another bedroom for our expanding family. As soon as Sam was born we knew things were not right. It took another six months, including two stays in Intensive Care and many nights where we lived as a family in rooms above the hospital, for the doctors to discover just how 'not right' things were. Finally, Sam was diagnosed as having an incredibly rare metabolic disorder called 'I Cell' disease. It is a progressive condition that offers no hope of recovery. Sam will die, perhaps in a year or two or perhaps much sooner.

Somehow, Sam is a happy smiling baby but one that needs 24 hour care - which has left us exhausted. Freya, now three, has adapted to a house filled with oxygen pipes, masses of specialised medical equipment and nurses. She understands that her little brother is going to die; that her daddy has to be taken to hospital in an ambulance because his heart is poor and that he is often too tired to play with her. Freya understands her mummy can't go to work because she needs to look after Sam and she understands we can't go on holiday like her friends at nursery do.

Except now we can. Bluebell Wood has allowed us to all come away together and all rest and play together. Freya loves the toys, dresses, musical instruments, soft play and the attention. Sam is in safe hands and sees us whenever we want and we have lay-ins and our meals made for us! For the first time in over a year Rona has had enough sleep I have remembered that we never finished painting the attic. It's been so much more than a holiday and we can't wait to come back!"

It is fantastic to walk around the building and hear children's voices, drums and tambourines blasting out from the music room – directly beneath the Chief Executive's Office and laughter from the Spa Pool and that's just as often from the parents as the children. The building is full of life and fun, love and lots of exhausted but satisfied members of staff.

Bluebell Wood has benefited enormously from the advice and experience of other Children's Hospices for which we are extremely grateful. Ensuring we can fund the hospice in the present climate is a worry, especially as almost all money is from voluntary donations. But we are hoping that the general public will be as warm and generous as in the past especially when they see how these amazing families are benefiting from some well deserved rest, reassurance and special care.

For more information visit www.bluebellwood.org

ADI'S STORY (1990 - 2008)

Lessons learned by the team at Rachel House

Adi was a 17-year old boy with a brain tumour. He was the fifth child of Cucu and Edik, from a family of 7. On 30th August, Rachel House was contacted for assistance by a family Edik is working for as a gardener. The family had paid for Adi's medical expenses including treatment, surgery and hospitalization until such time the doctors announced that there was nothing else that could be done for Adi and that he should be taken home.

On Sunday, 31st August, a social worker and a nurse from Rachel House visited Adi's home to conduct an initial assessment. We found Adi in a semi-comatose state, lying in the middle of the living room of a small and humble home, cared for solely by Yumi, Adi's 20-year old sister.

We discovered that Adi had been blind since 10th August, a day before the surgery he had undergone to drain the fluid from the brain area at RSPAD. Post surgery, he spent 3 weeks in the hospital before being sent home on 29th August with little hope of living beyond 1 week. At home, Adi was being fed through a feeding tube ("NGT"), which by the time we arrived, had been blocked by food items which Yumi did not know how to flush out. During the first visit, we found other complications such as the high temperature (from possible infections), swollen legs and the need for adult-sized pampers.

> The journey with Adi in the following few weeks taught us many valuable lessons, all of which have led us to closely review and re-evaluate the premises of our services.

Caregiver limitation

Although we tried to equip Yumi with as much caregiver's knowledge as possible, the fact that she was the sole caregiver made it difficult for her to execute the tasks in a way that would provide Adi with the level of care he needed in order not to suffer. For example, Yumi was not able to move Adi as often as he would have needed to be moved in order to avoid bedsores developing (by the time he died, Adi had open bedsores and wounds on his back and around the spine area, which led to other more serious complications such as infections, fever etc.)

Limited facility at home

As fluid was building up in Adi's chest in his final days, we brought an electrically powered suction tube to the house to drain the fluid. Unfortunately, due to the low voltage available in the house, we were not able to perform the procedure.

Total absence of help from neighbours

A factor that we never expected to witness was the absolute absence of assistance from the neighbours. In fact, Yumi and her family were shunned by them because of Adi's illness. Was this due to fear borne out of a lack of understanding of the illness?

Accessibility

Adi's home is 2 hours and 45 minutes away from central Jakarta. It is a huge distance to cover given our limited resources (manpower etc). We repeatedly found ourselves struggling with having to arrange for Adi to be taken to the nearest hospital in Bogor (on potholed roads) for the change of NGT and catheter, for suction of fluid from his chest and other complications that we could not manage, either due to the distance or due to operational license limitations.

Adi's last days highlighted to us the serious need for an in-patient unit to cater for children like him who live too far away for our home care team to access, and those who live in too destitute a situation to allow for proper care to be administered in order that the process of death can be eased and made less horrifying for the patients, and for those around them.

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The launch of Rachel House was featured in our previous ICPCN newsletter and is the first Children's Hospice Programme in South Jakarta.

Psychological Strains Of Full-Time Nursing Staff In Children's Hospices

Results of a nationwide pilot study in Germany

Authors:
Dina Philipp (Dipl.-Psych)
Prof. Dr. Christian Loffing (Dipl.-Psych)

This study by D. Philipp and Prof. Dr. C. Loffing is dedicated to these very helpers, namely to the full-time nursing staff and family assistants of the children's hospices.

The children staying in a children's hospice and their families find themselves in a psychologically and physically extremely difficult situation, which shakes their foundations. In this phase of life - which is the final one for the children - all those supporting and caring for the children and their families also need a lot of strength and courage. This study by D. Philipp and Prof. Dr. C. Loffing is dedicated to these very helpers, namely to the full-time nursing staff and family assistants of the children's hospices. With the support of the Bundesverband Kinderhospiz e.V. (German National Association of Children's Hospices) six of the (in 2007) eight existing children's hospices could be included in this pilot study.

The aim of the study

The aim of the study was the recording of the prevailing psychological strains as well as their coping strategies and the resources which are required to enable staff members to work in a children's hospice on a long-term basis. The main as well as the secondary questions examined were:

- if the full-time nursing staff and the family assistants differed from the standard random sample concerning their strain and relaxation, their work-related behavioural and emotional pattern and
- how they personally experience dying and death.

The random sample of the main study consisted of 87 persons aged between 21 and 60 years. Apart from quantitative data of the employees, qualitative data was collected; this was done with half-standardized interviews as well as with questionnaires to the managers of the participating children's hospices.

The Results

The evaluation of the hypotheses showed that - referring to "social tension" and "emotional strain" – the examined random sample differed significantly from the corresponding standard random sample.

These results could be interpreted as factors of risk, because the staff members suffered more often from arguments and quarrels within the team as well as from anger, anxieties or loneliness.
It was found that the examined random sample showed a significantly higher ability for distance and a significantly lower willingness to overexert oneself.

Furthermore, highly significant results became evident in a much lower distinctness in the subtest "Fear of the death of important persons in your life" among nursing staff and family assistants of children's hospices compared with the standard.

The qualitative results supported the fact that social tension, conflicts, lack of exchange and information were the greatest strain for the employees – after insufficient working and organizational conditions. Referring to working and organizational conditions, the main factors of strain were lack of structure, unorganized procedures and undefined areas of responsibility as well as unreliable working hours.

The nursing of the children and the partly difficult dealing with the families were given third and fourth position in the ranking of strains. Also bad communication by the experts and staff shortages were considered to be sources of strain, but not social tension or structural conditions.

For coping with stress the employees mainly demanded changes in the interpersonal area, as for example team work, open communication and discussion as well as mutual respect. As far as structures were concerned, the nursing staff and family helpers mainly needed reliable working hours, unambiguous areas of responsibility, agreements and lucidity.

For themselves the employees wished – among others – more compensation as well as more esteem from colleagues, managers and society in general.

As far as required changes were concerned, the most frequently mentioned aspects were team meetings and activities, and also possibilities of self-reflection, relaxation and reduction of stress.

Supervision, which was top priority for the experts, was only given fifth position by the staff. As a consequence, recommendations for the areas "team", "leadership", "communication and agreements", "structure and scheduled arrangements" as well as "offers" could be developed. Here the focus was – among others – concentrated on team development, transparent communication, esteem, flexible leadership, unambiguous distribution of assignments as well as a good work-life-balance.

The results and recommendations of this pilot study can only be a first step towards the further development of work in children's hospices and for a better stress-coping strategy of the employees. This study could contribute a first, important step towards a further professionalization of work in children's hospices and the preservation of health of the nursing staff – people who are urgently needed.

For further information as well as insight into the complete study you are welcome to contact Dina Phillipp at this address: dina.philipp@gmx.de

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The ICPCN is part of the Worldwide Palliative Care Alliance

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

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