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LETTER FROM THE CEO

Dear Friends,

When organisations are mostly slowing down at the end of the year, the ICPCN is going through an exciting period of growth and development, thanks to the support and belief in our vision by our main funders – Tue Colours Trust, Monument Trust and the Open Society Institute. We continue to be very grateful to Dr Liz Gwyther, the Board and staff of the Hospice Palliative Care Association of South Africa who have hosted the ICPCN and continue to oversee the finances of our organisation. Without all this support, the help of the Worldwide Palliative Care Alliance, and the many hours of voluntary contributions by our steering group and scientific committee led by Dr Sue Fowler-Kerry, we would have struggled to achieve all that we have.

This has meant a significant change in the structure of the ICPCN as I have taken on the role of CEO responsible for advocacy, development and project management, including a project funded by the Diana, Princess of Wales Memorial Fund to develop children's palliative care Beacon centres and a new curriculum in Tanzania, Uganda and South Africa; Sue continues to do the magnificent job she has done as International Information Officer plus taking on responsibility for promoting palliative care within early childhood development programmes; and Dr Julia Downing, present co-vice-chair of our Scientific committee will take on the role of Education and Research Co-ordinator (part-time) from January 2011, responsible for developing an international learning course with clinical placement sites in six countries, and providing support to our strong scientific committees. All this will be supported by a part-time administrative assistant and a part-time financial officer.

Barbara Gelb and Lizzie Chambers, who were co-Vice Chairs of the Steering Committee

are now our Interim Chairs, and together with Sabine Kraft form the executive committee, and we are looking at the selection of a new Chair and Vice-Chair for the ICPCN early in 2011.

With this comes a strengthened determination to ensure that palliative care for children is kept on the agenda of large multi-national and bi-lateral agencies, government health departments, and of regional and national palliative care associations. We have an ambitious strategic plan with Information, Education, Development and Advocacy as our key objectives. We participate in all advocacy activities of the Worldwide Palliative Care Alliance and a new international advocacy coalition for palliative care. With the help of our members in different countries, we know that we can continue to expand the reach of children's palliative care to improve the quality of the lives of life-limited children everywhere.

We were delighted to receive recognition of our work from Grunenthal Pharmaceuticals in Germany who have donated €30 000 to support two of our members in developing countries, and thank them for the generosity of their staff who donated their end-of-year bonuses to provide this support.

May each one of you be blessed as you continue to work for these very valuable and vulnerable children, and may 2011 be a year when we reach many more children with palliative care and see national associations and governments recognising the need to provide palliative care for all life-limited infants, children and young people.

With my very best wishes to all,

Joan

WORLD AIDS DAY : 1 DECEMBER 2010

Source: AVERT website www.avert.org

Started on 1st December 1988, **World AIDS Day** is about raising money, increasing awareness, fighting prejudice and improving education. The World AIDS Day theme for 2010 is 'Universal Access and Human Rights'. World AIDS Day is important for reminding people that HIV has not gone away, and that there are many things still to be done.

According to UNAIDS estimates, there are now 33.3 million people living with HIV, including **2.5 million children**. During 2009 some 2.6 million people became newly infected with the virus and an estimated 1.8 million people died from AIDS.

The vast majority of people with HIV and AIDS live in lower- and middle-income countries. But HIV today is a threat to men, women and children on **all** continents around the world.



INTERNATIONAL EVENTS CALENDAR: JANUARY - MARCH 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

January		
12	Professional Boundaries Workshop	Derian House Children's Hospice, Preston, UK
20 - 21	Chronic Pain Management, 2nd National Conference	Institute of Physics, London, UK
21 - 23	International Conference on Public Health and Palliative Care	Dakha, Bangladesh
February		
11 - 13	18th International Conference of Indian Association of Palliative Care	Lucknow, India
17 - 20	The 1st Global Congress for Consensus in Child Health and Pediatrics	Austria, Vienna
March		
03 - 05	Singapore Palliative Care Conference	Biopolis, Singapore
11 - 13	Biannual Cyprus Anti-Cancer Society International Symposium	Four Seasons Hotel, Limassol, Cyprus
11 - 13	4th Pan African Pain Congress	CTICC, Cape Town, South Africa
11 - 12	Continuous Sedation at the End of Life: Ethical Perspectives (EAPC)	Ghent Marriott Hotel, Belgium
11 - 14	The Butterfly's Dream - 2nd International Children's Hospice Congress	Pécs, Hungary
24 - 25	Children's Hospices UK Conference	Birmingham, UK

Regional Round-Up of Achievements & Challenges during 2010

LATIN AMERICA

The International Confederation of Childhood Cancer Parent Organisations (ICCCPO) is a worldwide network of organisations of parents of children with cancer. Their last meeting took place in Guadalajara in September. The ICPCN was represented by Dr. Yuriko Nakashima from Mexico. Many countries like Argentina, Colombia, Ecuador, El Salvador, Dominican Republic, Panama, Mexico were present. In her report Dr. Nakashima said that there were many positive outcomes as well as an encouraging willingness to meet and work with paediatric palliative care professionals. Plans were initiated to form links or a partnership with the ALCP, ICCPO and the ICPCN.

The official launch of Manual de Cuidados Paliativos INCTR Brasil took place during the Multidisciplinary Symposium and the Palliative Care Session, XII Brazilian Congress of Pediatric Oncology – SOBOPE, held in Curitiba, Brazil on 1 October 2010. One of the most important newspapers in Brazil, Folha de São Paulo, interviewed Dr. Claudia Epelman. Her interview appeared in the newspaper's Health & Science section along with an announcement about the launch of the Portuguese version of the handbook. This has helped to generate a great deal of interest in not only the handbook, but also in palliative care in general.

GUATEMALA

Dr Silvia Rivas and Dr Marisol Bustamante, the only two doctors working full time in paediatric palliative care in this country have achieved the following:

- ▶ Given approximately ten lectures on PPC in different hospitals and universities
- ▶ Provided counselling on how to start a paediatric palliative program in a national hospital in Guatemala (Hospital Roosevelt) and about how to start an outpatient service for adults for a nongovernmental organization called SEGUPAL.
- ▶ Been an active part of the medical organization for a Paediatric Hospice in Guatemala with the foundation named: "Ammar ayudando".
- ▶ Collaborated with the group of experts who were working with the federal office of opioids in Guatemala.
- ▶ Participated in the meeting for "Manual de Opioids" en Caracas, Venezuela,
- ▶ Assessed newspaper reports related to Palliative care.
- ▶ Participated in the First National meeting in Palliative Care in Guatemala held by Human Rights.
- ▶ Involved with the Organization of Ethics Committee (not research) at Unidad Nacional de Oncologia Pediatrica de Guatemala.

CHILE

RN Chery Palma reports:

Since 1987, children with the most common pediatric malignancies receive uniform standardized treatment in all of Chile. To that effect, the National Program for Antineoplastic Drugs for Children (PINDA) was founded, and is responsible for creating and supervising treatment programs for pediatric cancers and leukemia. Currently, there are 11 accredited treatment centers throughout the country, mostly in the capital, Santiago.

To celebrate World Hospice and Palliative Care Day, October 8, 2010 and the Fifteenth Day of the Program Evaluation of Cancer Pain Relief and Palliative Care, the Ministry of Health organised a drawing contest for children in hospitals, who are part of the PINDA network and who are in palliative care or have experienced pain.

Publication in the bulletin of the Children's Hospital Roberto del Rio, Santiago, on the origin of World Palliative Care Day and the work of DP and PA equipment at the hospital. The rights of children with life limiting illnesses (authored by Dr Lisbeth Quesada) were also issued to children with advanced illness.

Latin American report provided by Dr Rut Kiman

NORTH AMERICA

National Initiatives include continued education and understanding the implementation of the new legislation entitled, *Patient Protection and Affordable Care Act: Concurrent Care for Children*. NHPCO sponsors a Policy Group of State Leaders who are working through the legislation and assisting state Hospice Organization with these changes.

Educational Opportunities

The NHPCO Clinical Conference that took place in Atlanta this fall, was successful and all pediatric tracks were well attended. The Pediatric Standards document is undergoing revision, and the first module for the new Pediatric e-learning curriculum is available at www.nhpc.org

Children's Institute for Pain and Palliative Care (CIPPC) of Hospitals and Clinics of Minnesota is offering a scholarship opportunity to attend the Pediatric Pain Master Class for those practicing in undeveloped countries. For further information, please see: www.childrensmn.org/services/painandpalliativecare or email at cippc@childrensmn.org, or by phone at 612.813.6450. There is a number of pediatric education opportunities listed on this website.

Mount Ida College and the National Center for Death Education has released it's online offerings for this winter and next year, access them at www.mountida.edu/ncde. These offerings often attract registrants from all disciplines outside the United States. Courses on Bereavement, Pain Management and Spiritual Support are examples of the different educational offerings.

Report provided by Susan Huff

AUSTRALIA & NEW ZEALAND

There has been an increasing recognition by healthcare professionals in Australia and New Zealand as to the value of Paediatric Palliative Care. This, while pleasing, has often resulted in an increased clinical workload for services which has highlighted their poor resourcing and vulnerability.

Work continues on the self improvement programmes identified through the National Standards Assessment Program. Services in New Zealand and Australia were maintaining the energy being put into addressing barriers, gaps in service provision and equity of access to Paediatric Palliative Care at regional, state and national level.

The key challenge for all is gaining the appropriate level of resourcing to deal with the increasing clinical workload in an environment of static health funding and a system orientated to the health needs of adults.

Report provided by Dr Ross Drake

Regional Round-Up of Achievements & Challenges during 2010 cont.

UNITED KINGDOM

£30million for children with palliative care needs

The Coalition Government in England announced in late June 2010 that they would be giving £30million to children's palliative care in England. The purpose of the funding stream is to support projects focused on benefiting the lives of children with palliative care needs and enhancing palliative care services for children, bringing together commissioners and providers in the statutory and voluntary sectors.

Grants have now been awarded to a wide range of projects across England and the challenge is to ensure that the work is completed within the tight timescale of this financial year i.e. by end of March 2011.

As a consequence of the grant programme there is a tremendous amount of innovative work currently underway across England's children's palliative care sector and plans are in hand to ensure this work is evaluated and that the outcomes are disseminated to ensure that the whole sector – across the UK - has access to the information about the benefits of each

project. We will also look at how the benefits can be shared more globally via ICPCN and other means.

ACT and **Children's Hospices UK** are planning to work with other partners to develop an evaluation programme in order to share the learning from all the projects.

Radical changes to organisation of NHS will affect children's hospice services

Plans are underway for new legislation in England to make radical changes to the organisation and delivery of our National Health Service. The Coalition Government in England is planning to alter the way that health services are commissioned and this will affect children's hospice and palliative care services.

Currently there are 10 Strategic Health Authorities in England with Primary Care Trusts reporting to the Strategic Health Authorities. This framework is being disbanded and general practitioner medical doctors (GPs) will be undertaking commissioning of services. This will have big implications for

all children's palliative care providers, including children's hospices, and the sector is currently trying to look at ways in which we can ensure that the new system will work effectively for us. Plans also include an emphasis on choice for patients and this means that service provision for children's palliative care (as well as all other services) will be opened up to the private market, increasing competition in the sector.

Funding review

A review of the funding mechanisms for dedicated palliative care for children and adults is also currently underway. The review will make recommendations on a funding mechanism which encourages the development of community based services and supports the exercise of choice of care by care users of provider and of location of palliative care provision. The review will be completed around mid 2011.

Report by Lizzie Chambers and Barbara Gelb

SUB-SAHARAN AFRICA

One of the highlights of 2010 has been the successful implementation of The Diana, Princess of Wales Beacon Three Country Project to upscale the provision of children's palliative care in Africa. This project has seen the rollout of a pilot six-month certificate course to multi-professionals in South Africa, Uganda and Tanzania.

On 25 November, a total of 34 students from across the three countries wrote a challenging MCQ exam and participated in an OSCE (Objective Structured Clinical Examination) towards the goal of earning a Certificate of Competence in the field of Paediatric Palliative Care.

Resources & Publications for Africa

Another exciting development is the launch of the first of the range of APCA's (African Palliative Care Association) tools and manuals, to enable Africa's decision-makers and palliative care practitioners develop and deliver the best services possible to patients and their families. All of these resources have been tailored specifically to meet the needs of Africa, its resources and circumstances and are the result of continent-wide collaborations with leading experts from many disciplines. These range from handy pocket-books for busy clinicians in the field to larger manuals for office use and cover everything from the

standards needed to provide high-quality palliative care services, to how to manage pain, handle opioids or advocate successfully for policies that drive holistic care provision. All of these publications include information applicable to children and can be ordered via the APCA website at:

Another recent publication we would like to highlight is that of the *Spiritual care recommendations for people receiving palliative care in sub-Saharan Africa*. This report can be downloaded from the Cecily Saunders Institute website: <http://www.csi.kcl.ac.uk/spiritualcare.html>

The booklet, *No Secrets*, was funded by The Diana, Princess of Wales Memorial Fund and is based on a study conducted by Dr Mary Bunn at Umodzi in Malawi, which aimed to investigate attitudes towards talking to children about life-limiting illness. This booklet can be ordered or downloaded free of charge from <http://www.theworkcontinues.org/page.asp?id=1511>

With funding from the Open Society Institute Palliative Care Initiative, the ICPCN has produced the booklet: *Palliative Care for Children in South Africa, the Facts* which provides an overview of the meaning and scope of children's palliative care

in the country, the different models to be found as well as information on its phenomenal growth and development. This book can be downloaded from the ICPCN website. Go to: www.icpcn.org.uk

A new piece of research led by Dr Richard Harding at the Cicely Saunders Institute at King's College London has revealed that while the statistics continue to suggest massive need for palliative care for children, the body of research evidence needed to support its growth is still significantly underdeveloped. To download this report and find out more go to: <http://www.theworkcontinues.org>

New Appointment

Joan Marston's move into the position of CEO for the ICPCN has left a very large gap in the paediatric portfolio of the Hospice Palliative Care Association of South Africa and we would like to offer our sincere congratulations to Maraliza Robbertze, on her appointment as the National Paediatric Palliative Care Coordinator. Maraliza's background is in Social Work and she has held the position of National Paediatric Officer since January 2008. We have every confidence that she will continue to strengthen and support the good work being done in South Africa.

Report by Sue Boucher



Joan Marston congratulates Maraliza Robbertze on her new appointment as National Paediatric Palliative Care Coordinator for HPCA

Regional Round-Up of Achievements & Challenges during 2010 cont.

WESTERN EUROPE

Much has been happening in the field of children's palliative care all over Western Europe. Since May this year I have been coordinating the Swiss Initiative to build a Children's Hospice in Switzerland. The French are arranging a visit to a German Children's Hospice and Natasha Pedersen from *Yes to Palliative Care for Children in Norway* spent time in Germany learning about our structures, finance and how to go about developing a Children's Hospice in Norway. We are also expecting a visit from a nurse from Denmark who is keen to learn about the children's hospice movement. There are two initiatives in Austria; one of them is sponsored by the German charity *Bethe* who are also sponsoring the Swiss initiative. A further initiative has started in Teneriffa, also sponsored by the *Bethe Stiftung*.

On World Hospice and Palliative Care Day we sent out a country-wide Press Release about the ICPCN and our function in it. Many of our members reacted and congratulated us on our involvement with the ICPCN.

On 5 November we held an official Information Day with 120 professionals (doctors, nurses, clinics, children's rehabilitation units, paediatric palliative care units) in Basel, Switzerland. As the keynote speaker, I gave a presentation on the work of the ICPCN and we look forward to a growth in ICPCN membership as a result.

Other initiatives

- ▶ The second course in paediatric palliative care, in cooperation with the University Clinic for Children and the University of Social Sciences in Freiburg.
- ▶ Fundraising for a study into the necessity of children's hospice organizations in Germany
- ▶ Fundraising for children's hospices in Germany
- ▶ Lobbying for specific paediatric palliative care teams all over Germany
- ▶ Introduction of a *proof of quality label* for children's hospices in Germany

Report by Sabine Kraft

Congratulations, Sabine!

The ICPCN Steering Group and members wish to congratulate Sabine Kraft, an ICPCN Executive Board member, for being chosen to appear on a large tarpaulin covering the Victory Column in Berlin while it is under repair. This tarpaulin was draped over the Victory Column at a special ceremony on 11 August 2010.



This prestigious honour was bestowed on a select group of 204 Berlin citizens in honour of their significant contribution to the city in sports, culture, protection of the environment, and those like Sabine, in providing care and support to families and children who suffer or who are in need.

Sabine has been the manager of the National Association for Children's Hospice (Bundesverband Kinderhospiz) in Germany since 2005 and on the Steering Group of the ICPCN since 2007. We are extremely proud of her for receiving this well-deserved honour.

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Scholarships are available to applicants from developing countries for the Pediatric Pain Master Class, Minneapolis, MN, USA plus a one-week clinical practicum **Completed applications are due on 15 January 2011**

The Pediatric Pain Master Class will take place from 11 - 17 June 2011 and the practicum with the Pain and Palliative Care team from 6-9 June, 2011. Funded by The Foundation of Children's Hospitals and Clinics of Minnesota, the Children's Institute for Pain and Palliative Care (CIPPC) is offering two competitive scholarships for physicians from developing countries currently working in the field of pediatric pain and/or palliative care.

The recipients of this scholarship will be selected based on leadership abilities, commitment to moving the field of pediatric pain and palliative care forward, and attending to underserved pediatric populations. The goal of this scholarship program is to identify medical professionals who are in a position to improve acute and chronic pain management for children both in their institution and beyond (region or country).

This 2-week International Scholarship includes:

- ▶ Airfare to and from Minneapolis/St. Paul.
- ▶ Hotel accommodation and meals.
- ▶ 1-week practicum with the Pain & Palliative Care Team at Children's Hospitals and Clinics of Minnesota
- ▶ 100% course tuition for the Pediatric Pain Master Class, Minneapolis, MN, USA (June 11-17, 2011)
- ▶ Ongoing mentorship

Eligibility criteria:

Physicians from a developing country who work either exclusively or largely with pediatric patients. Applicants who are currently involved in the management of children with acute and chronic/complex pain and/or in pediatric palliative care

Preference will be given to individuals (e.g. faculty member, affiliated with a medical school, teaching hospital or large children's hospital) who are interested in assuming or continuing a regional/national leadership role in the field of pediatric pain and/or palliative care

Very good command of the English language (we will prefer applicants to have undertaken a practicum, rotation, or training in an English-speaking country)

Commitment from leadership in pediatric pain and palliative care practice and education within the academic, hospital or institutional setting

For more information on the Pediatric Pain Master Class visit:
<http://www.childrensmn.org/Services/PainPalliativeCare>

Malawi



The Queen Elizabeth Central Hospital in Blantyre (QECH) is a referral hospital for cancer cases in children for the whole of southern Malawi and it is the only hospital offering chemotherapy and paediatric surgery for tumours. QECH is also the main teaching hospital for the University of Malawi's College of Medicine.

The Paediatric Palliative Care Programme, known as *Umodzi*, meaning "we are one" was established in 2002 to provide palliative care for children in Malawi and their families through developing a model of care appropriate to a hospital setting and training health professionals in palliative care.

The Umodzi team recently opened their play room at the hospital. This bright and welcoming room, equipped with colourful toys and books is staffed each day by a Play Leader who oversees the activities of the children. This play room provides an oasis and welcome play opportunities for children who are well enough to visit, and their siblings.



Umodzi see children with a wide range of illnesses and provide bereavement counselling to families. One of their biggest challenges they face is reaching their young patients once they have been discharged from hospital owing to the vast distances they need to travel and general inaccessibility due to the poor roads and difficult terrain in the rural areas. It can take an entire day to pay a visit to one or two patients and a significant percentage of their limited resources are spent on maintaining the QECH vehicles that if available, are loaned to them for this purpose.

The ICPCN is partnering with *Help the Hospices* and the Palliative Care Association of Malawi (PACAM) in a DFID funded project to scale up access to children's palliative care in Malawi. This project aims to use both the experience and expertise of the Umodzi team for the purpose of training and mentoring health professionals in Children's Palliative Care in three central hospitals in Malawi.

The project will focus on building capacity of the national associations and model children's palliative care centres in Malawi to enable them to:

- ▶ Collect evidence to influence changes in policy relating to the inclusion of CPC in health, HIV and child rights strategies
- ▶ Advocate for the removal of barriers to children's access to opioids
- ▶ Increase access to CPC training for health and social professionals in order to expand services and push to get CPC included in health worker curricula and raise awareness about the use of oral morphine to relieve pain in children.
- ▶ Raise awareness of children's rights to palliative care and relief from pain and ensure children are empowered at all stages of the project.



The Umodzi Team with Lameck Thambo from PACAM and Kate Tattersall from Help the Hospices

Throughout this five year project the ICPCN is committed to assisting with distance mentorship and accessing expertise from around the world.

With the offer of a most generous donation from the *Grünenthal Pharmaceutical Group* the ICPCN Executive has taken the decision to use part of this grant to strengthen the *Umodzi* team through the provision of a vehicle. This vehicle would enable the team members to make more home visits without having to rely on those belonging to the QEHC or spending excessive amounts of money on repairs and maintenance to these vehicles.

Some Statistics for Malawi

- ▶ Children make up more than half the population
- ▶ Infant Mortality Rate 92:1000
- ▶ 1 in 8 children die before the age of 5
- ▶ Malnutrition is widespread and almost half of children under the age of 5 have stunted development
- ▶ Maternal mortality is 984 deaths per 100,000
- ▶ Malawi is thought to have nearly 500,000 children who have lost one or both parents to HIV/AIDS, and approximately 25,000 new paediatric HIV/AIDS infections are registered every year
- ▶ 14% of reproductive age adults are infected with HIV/AIDS
- ▶ Extended family members have been overwhelmed with new demands for support to these orphaned and vulnerable children, both economically and psychosocially.



The house before renovations



The newly renovated Hospice Villa de la Esperanza

When the Foundation Ammar Ayudando were given a run-down house to use for 25 years by Rotary, there was much to celebrate. The house was badly damaged and needed a great deal of renovation work. With commitment and a great deal of enthusiasm it was lovingly rebuilt and transformed into a children's hospice and named Villa de la Esperanza.

The website at www.fundacionammarayudando.org describes the renovated building as:

"....a home-like centre staffed with specialist professionals. The green walls and open spaces produce an atmosphere of peacefulness and calm. Constructed with access for wheelchairs and equipped to provide support to patients and their families the hospice is strategically located and offers specialised care for children, no matter their financial circumstances. Also provided is care for the holistic health and well-being of patients, which include feeding, provision of medication, as well as spiritual and emotional support."

The Hospice plans to open its doors in the last quarter of 2010 but in the meantime the palliative care team is providing a home based service, visiting and supporting the young patients in their homes."

All was going according to plan until nature stepped in, in the form of a volcano eruption and on 31 May 2010, storm Agatha, the first Pacific storm of the season, struck Guatemala. This was a huge blow to a country that was still reeling from the Pacaya volcano that had erupted just days before.

So the children's palliative care team are again working to restore the building and get back on track to open their hospice. At present they are looking for medical equipment and have begun training. They are also working towards the introduction of children's palliative care in the main hospitals of Guatemala.

With a most generous donation from the German based Grünenthal Pharmaceutical Group, the ICPCN has pledged to support the Guatemalan Children's Palliative Care team to get back on track after the devastation of the volcano and the flooding to buy much needed medical equipment.

Report from information supplied by Dr Silvia Rivas



After the flooding, everything was under water.

About the Grünenthal Group

The Grünenthal Group is an independent, family-owned international research based pharmaceutical company headquartered in Aachen, Germany. Building on its unique position in pain, its objective is to become the most patient centric company, to be a leader in therapy innovation. Altogether, the Grünenthal Group has affiliates in 35 countries worldwide. Grünenthal products are sold in more than 100 countries and approximately 4,900 employees are working for the Grünenthal Group globally.

For more information visit: www.grunenthal.com



Anandaghar – The Joyous Nest: The only Paediatric Palliative Care Centre in Eastern India caring for children infected with HIV/AIDS

“Our main objective is to get connected with as many people and organisations as possible who are working on Paediatric Palliative Care and HIV/AIDS. That will break our first hurdle of being resource constrained. OFFER (Organisations for Friends, Energy and Resources) wants to know and let others know about the works happening at Anandaghar and elsewhere in the globe”. *Kaloll Ghosh offer.kaloll@gmail.com*



An introduction

This brief introduction provides readers with an understanding of the reality of the circumstances under which our palliative care center operates.

There are very few official national estimates available on the number of children infected with HIV/AIDS in India. The reason for this lies with the policy of the National HIV/AIDS Control Programme, which is primarily focused on the adult population, particularly on the productive and reproductive age group.

An estimation by Civil Society Organisations put the figure above 300,000. In the eastern state of India, West Bengal, the picture is the same except the number has officially been put at 3,300. Yet the Government organizations such as the National Institute of Cholera and Enteric Diseases (NICED) has released a recent statistic which estimates that 6 out of every 554 children living on the streets of this more than 300 year old heritage city, Kolkata (previously Calcutta), are HIV positive. This is an alarming figure.

How it began

An 11-day old boy, abandoned on the streets, was rescued by local police and then handed over to us. On testing, he was confirmed to be HIV positive and so the need of a Palliative Care Center was realised.

The centre was named after this young boy, "Joy", which in Bengali is "Ananda" Now Anandaghar is home for 52 children and provides support to more than 110 children living at the community. The youngest child is 9 months old and the oldest, 15 years

The Government of India in association with UNAIDS has developed a model for the clinical care of children with HIV/AIDS. But our experience at Anandaghar

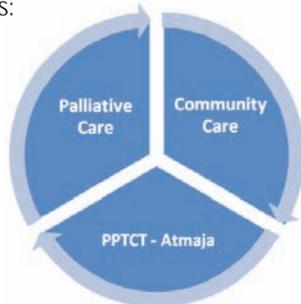
has taught us that while clinical support is required it is not a panacea for all the complications and facets relative to this condition. There has to be an overlap with family-based care, emotional care, motivation to live in a healthy manner, social protection and a constant awareness of the viral load in the blood. This makes Paediatric Palliative Care for HIV positive children a great deal more complex than it seems.

It is essential for us to raise children like Joy as members of a family. The concepts of a father, a mother, a friend, including

love for the children who are reaching puberty, cannot be covered under the umbrella of *clinical care* alone. The disease requires that all the palliative care needs are met within the affection of a family type atmosphere. Clinical care alone is not enough.

The model of care

The holistic nature of Anandaghar can be portrayed as follows:



Anandaghar, with its outreach programme within the Community, provides an array of support to children and families in need. While providing palliative care we came to realise that care and support for children with HIV/AIDS cannot solve the root or core of the problem. For an honest and comprehensive programme we are required to try to prevent *Vertical Infection* as well. That realisation provided us with the concept for the Programme called *Atmaja*, which in the classical language Sanskrit means "born out of the soul". With this in place we feel we are providing a far more comprehensive programme.

Our clinical experience from Anandaghar makes us aware of other important facts such as the knowledge that a good

nutritional programme supported with the regular practice of Yoga keeps the need for the intervention of ART (Anti-Retroviral Therapy) at bay. Once started on ART there still remains no other solution than to continue with it. And it is well known that ART does not come without side effects. As a result we have included Yoga and nutritional supplementation into our Palliative Care strategy. At the same time, the children at Anandaghar are regularly provided with cultural therapy, a recreational programme as well as play therapy. At Anandaghar with support from a internationally reknowned Kolkata-based dance troop, our children also participate in dance as a therapy. We have found that the use of dance has a direct relationship with them staying happy and healthy. These experiments have led us to the conclusion that the gamut of Paediatric Palliative Care for HIV/AIDS has to be wider than just medical intervention in order for it to be effective.

The call for friendship

We need collaboration, we need experience sharing and we surely need funds. **But above all we need friends.** We need supporters, we need the warmth of friendship and are thus extending our hands to all you friends.

Kaloll Ghosh
Founding Secretary

Kaloll Ghosh was awarded an Honourary Doctorate by the president of Italy and the Ashoka Foundation awarded him with the Ashoka Fellowship in recognition of his outstanding work on Children's Rights.

Find out more at: www.offerindia.org



Seen above: Children from Anandaghar celebrate Durga Puja - one of the biggest festival in West Bengal, and participate in dance therapy sessions.

RECRUITMENT DRIVE FOR *BAYT ABDULLAH* The first Children's Hospice in the Middle East



Bayt Abdullah is the first children's hospice in the Middle East. The building is almost complete and recruitment for the clinical team is now underway. We are looking for a core group of experienced, dedicated and motivated paediatric palliative care doctors and nurses to help us establish the service. We would expect our core team to be involved in education and training of local staff and assist us in delivering a high quality, sustainable service. This exciting development has been the work of a dedicated and committed team in Kuwait; KACCH (Kuwait Association for the Care of Children in Hospital) has developed child focused clinical care over the last 20 years.

KACCH is a non-governmental charitable organisation registered with the Ministry of Social Affairs and Labour in 2003. It was founded informally in 1989 to help provide optimal conditions for children and their families in hospital in order to reduce the adverse effects of hospitalisation on their development and well-being. It is funded by donations from organizations, businesses, banks, schools and individuals within Kuwait.

Under the auspices of KACCH a home care team has been delivering palliative care to children for the past 5 years. KACCH has driven forward the development of Bayt Abdullah Children's Hospice as a direct reflection of the unmet needs of children and families living with life shortening conditions in Kuwait. Bayt Abdullah (House of Abdullah) is named after a little boy who was supported by the KACCH service, enabling him to fulfil his wish of being looked after at home in the final months of his illness.

ing transfusions and chemotherapy), a rehabilitation service, outreach into existing hospital based paediatric and neonatal services and home care.

Bayt Abdullah has ten in patient suites and 10 respite chalets. This impressive and striking building is situated on a bay in the Gulf and overlooks a nature reserve; complete with Ferris wheel, tree top walkway and look out towers it has been specifically designed around the child and family.

Bayt Abdullah also houses a school room, an auditorium, a gymnasium, a mosque and a library. Ultimately we hope to be a centre of excellence providing research, education, training and support for the whole Gulf region.

To assist in the development and delivery of paediatric palliative care services, Dr Renée McCulloch and Maggie Comac (Medical and Nurse Consultants in Paediatric Palliative Care from Great Ormond Street Hospital, London) are currently living in Kuwait and working for the Ministry of Health and are happy to answer any queries.

Please email: FAO Renee or Maggie at hr@bacch.org.

Bayt Abdullah will be the centre of a highly integrated children's palliative care service. It will be free and accessible to every child and young person in Kuwait. We aim to provide an active day care unit (delivering education, psychosocial support, physiotherapy programmes, information sourcing for families and clinical care, includ-



The Respite Chalets

Recruiting now for Kuwait

The First Paediatric Hospice in the Middle East

Kuwait is leading development in paediatric palliative care in the Middle East.

Bayt Abdullah Children's Hospice is designed to accommodate the needs of children with life-limiting, life-threatening conditions and their families. The hospice has 10 inpatient beds for emergency symptom management and terminal care, 10 chalets for family respite, a large day care centre and a well established outreach team for support at home, all equipped to provide 24/7 expert care to children and young people.

The building itself is part of a continuum of care that offers children and their families the maximum freedom of choice without compromising the quality of healthcare, within a child-friendly, family-centred inter-active environment beautifully located in Sulaybikhat Bay.

As construction of the hospice nears completion, we are looking for a committed, skilful, experienced workforce to deliver an excellent service based on the most up-to-date evidence based hospice and paediatric palliative care service and pain management, which includes the following positions:

Paediatric Palliative Care Specialist	Ref : MD-01
Head of Care	Ref : MD-02
Deputy Head of Care	Ref : MD-03
Head of Clinical Education	Ref : MD-04
Nurse Team Leaders	Ref : MD-05

Successful candidates will have excellent paediatric palliative care experience, communication skills, ability to work effectively within a multidisciplinary team, and strong teaching and collaboration skills.

Interested applicants can send their CVs directly to

hr@bacch.org

(indicating the reference number of the position in subject field.)

All applications and information will be treated confidentially.
Closing date for applications: 31st January 2011

Further information is available on BACCH website at www.bacch.org

ALLOW NATURAL DEATH – TE WA AROHA

Compassionate Communication in Paediatric End-of-Life Decision Making in New Zealand

Elizabeth Kubler-Ross said “It is an art to share painful news with any patient”, and “Patients often stress that it was the sense of empathy which counted more than the immediate tragedy of the news.” Many years of work as a social worker in Paediatric Oncology and Paediatric Palliative Care has confirmed the sense that discussions with families on their child’s transition to palliative care and end-of-life decision making have a profound effect upon families. Done well, such discussions are a bridge to ongoing journey for the child, the family and the health professionals who support them. Done poorly, those discussions become a very deep scar on the heart for bereaved parents.

“Done well, such discussions are a bridge to ongoing journey for the child, the family and the health professionals who support them. Done poorly, those discussions become a very deep scar on the heart for bereaved parents.”

The late Reverend Chuck Meyer worked as Chaplain at St David’s Medical Centre in Austin, Texas. The Reverend Meyer asked why we still use the terminology “Do Not Resuscitate” when we discuss dying and death with patients and their families. He suggested that people hear the “not” in “Do Not Resuscitate” and that they may not understand that “asking for a DNR does not mean that we have stopped care.” The Rev Meyer then asked why we do not use **Allow Natural Death** as an alternative when discussing end-of-life care planning.

The Paediatric Palliative Care Team at Starship Children’s Hospital in Auckland, New Zealand, began using “Allow Natural Death” when talking to families. Our experience has been that while these discussions remain very difficult, families do engage much more readily in end-of-life planning from the “Allow Natural Death perspective.” A presentation of our experience was developed and presented at conferences in The United States and at

Westmead Children’s Hospital in Sydney. Dr John Collins team at Westmead developed policy and an e-o-l form which incorporates the Allow Natural Death language. Starship Children’s Hospital gained permission from Westmead to adapt the form for use in New Zealand. One important change that was made to the New Zealand document was to ask for Allow Natural Death to be translated into Te Reo (Maori language). The title the document was given is *Te Wa Aroha* which translates to “the time of love.”

“The title the document was given is Te Wa Aroha which translates to “the time of love.”

Interestingly, we have discovered that families respond well to that simple translation of Te Wa Aroha as it speaks to the intent of end-of-life discussion which is “to prevent suffering and promote comfort, quality of life and dignity” (Parental Hopeful patterns of Thinking, Emotions and Pediatric Palliative Care Decision Making... www.archpediatrics.com).

Our experience with using the document over the past year has borne out the late Reverend Meyer’s thinking about family understanding of end-of-life decision making. Reframing e-o-l discussions with positive language appears to lead into a wider discussion about family wishes for their child, both for living the rest of the child’s life as well as for dying.

Health Professionals at Starship have welcomed the document which they are using as a guide to these difficult discussions as well as for the formal documentation of parent wishes. However, the most powerful voices we need to listen to are our families and our growing experience with the Starship e-o-l document tells us that they understand this language and more openly engage with the conversation.

Hopefully the continued use of **Allow Natural Death** in end-of-life decision making will enable parents to look back on

these conversations and recall that there was a strong “sense of empathy” which supported them to make the best possible decisions for their child and family.

Jess Jamieson
Senior Social Worker
Paediatric Palliative Care
Starship Children’s Hospital
Auckland District Health Board
New Zealand

PAIN SURVEY REQUEST

Dear colleague,

Since 2005 our pain research centre supervised by professor Dick Tibboel, collaborate with pediatric pain specialists in Cape Town, South Africa. We have encountered a number of diagnoses over there, such as meningitis and tuberculosis, that are very rare in our own continent. To further improve pain management in underdeveloped countries we feel it would be very valuable to know how you evaluate the level of pain of a number of diagnoses. We would like to invite you to the following link where you can fill in a short survey that will take only 5 to 10 minutes. We thank you beforehand for your participation,

The link to the survey is

<http://paediatric.paininventory.gizmo.com/s3/>

Yours sincerely,

Dr. Monique van Dijk, RN, PhD
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www.truecolourstrust.org.uk