network news

Issue 8

December 2009

icpcn

international children's palliative care network

LETTER FROM THE CHAIR

Dear Friends,

We have had so much to celebrate this past year. Congratulations to Lizzie Chambers, the Board and staff of ACT, on celebrating 21 years of service to life-limited children. We have all benefited so much from the groundbreaking work that ACT has done and the excellent documents, discussion group and literature lists ACT provides, and we thank all involved with ACT and wish them strength in the years ahead.

This has been a wonderful and exciting year for the development of children's palliative care with new programmes and innovative projects developing in a number of countries.

We could not have achieved all we have achieved without the generous support of our involved and caring funders, the True Colours Trust and the Open Society Institute and the Hospice Palliative Care Association of South Africa has been a welcoming and supportive host to our organization.

The ICPCN Declaration of Cape Town has been signed by many organizations and individuals and in the year ahead we will be looking at ways to implement the spirit of the Declaration. We enjoyed working with Children's Hospice International to present their World Congress in Cape Town and this coming year, we are happy to collaborate with Dr Richard Hain and his team in presenting their ***Face to Face with Interface*** Conference in Cardiff in July 2010.

Our collaboration with the European Association of Palliative Care Children's Task Force is a welcome development as we need to work together if we wish to increase access to quality palliative care for children around the world, and my thanks to Dr Chantal Woods for initiating this collaboration.

Our new Paediatric Pain Special Interest Group for developing countries was the vision of Dr René Albertyn and we will have a strong Scientific Committee from the beginning of 2010; so much is happening and we are happy to see that along with advocacy and support for development we also have started to build a scientific base.

To the board of the Worldwide Palliative Care Alliance, it is a privilege to be part of your organization and we thank you for your ongoing support; to Sue Boucher and the Steering Group, many thanks for working so hard and making so much happen; and to all who are working so compassionately to make this world a better place for children with life-limiting and life-threatening conditions, congratulations on all you have done, and may you have strength to carry this work forward in the coming year.

We may have much to celebrate, but the challenge will be to reach all those children who still do not receive the benefit of quality palliative care.

Best wishes and may you experience peace and joy in this special season.

Joan

WORLD AIDS DAY : 1 DECEMBER 2009

The **Elisabeth Glaser Pediatric AIDS Foundation** made the following statement to mark World AIDS Day this year :

On **World AIDS Day**, it's time to take stock of where we are in our effort to create a generation free of HIV.

UNAIDS just released its 2009 report on the global AIDS epidemic, and the report estimates there were **430,000** new pediatric HIV infections in 2008 - a decrease of approximately 18 percent since 2001. This is great news, but the fact remains that 430,000 is a huge number, and more than half of HIV-positive pregnant women in low- and middle-income countries are not receiving the services they need to prevent mother-to-child transmission of HIV.

We're making progress toward eliminating pediatric HIV/AIDS, but it's time to drastically scale up our services. We have a treatment that is as effective as a vaccine at preventing mother-to-child transmission of HIV, yet more than **1,000** children are infected with HIV every day because their mothers do not have access to this treatment. To show our commitment to achieving a generation free of HIV, the Foundation has set a goal:

We challenge ourselves and the global community to decrease new global pediatric HIV infections by one-half between 2009 and 2013, preventing nearly a million infections in children. To achieve this goal, we will work with our partners to reach 15 million pregnant women with prevention of mother-to-child transmission services over the next five years.

Read more at **http://www.pedaids.org/home/presidentsmessage.aspx**

EVENTS CALENDAR: JANUARY - MARCH 2010

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		
11 - 5/2	Young Adult Loss: A disenfranchised population	Online Course from Mt Ida College, MA, USA
20	Midlands Paediatric Palliative Care Network study day "Are we providing holistic care?"	Legends Lounge, Villa Park, Birmingham, UK
February		
22 - 13/3	A Family Systems Perspective on Grief and Mourning	Online Course from Mt Ida College, MA, USA
23	Children with Complex Heatlh Needs: Managing the Journey	Bristol Marriot Royal Hotel, Bristol, UK
March		
07	8th International Symposium on Pediatric Pain : Sharing Knowledge with all Cultures	Fairmont Acapulco Princess, Acapulco, Mexico
08 - 12	The 8th Palliative Care Congress and International Learning Opportunity	Bournemouth International Centre, Bournemouth, UK
15 - 18	5th Latin American Palliative Care Congress	Buenos Aries, Argentina
16 - 17	ELNEC Pediatric Palliative Care Train-the-trainer Course	Pasedena, California, USA

CALL FOR ABSTRACTS - DEADLINES

11 - 14 October 2010	CHI 21st World Congress	Washington DC, USA	Call for abstracts deadline: 15 January 2010
18 - 21 August 2010	World Cancer Congress	China	Call for abstracts deadline: 28 January 2010
05 - 08 October 2010	18th International Congress on Palliative Care	Montreal, Canada	Call for abstracts deadline: 31 January 2010
29 - 30 June 2010	Respiratory Care for Young People	Derian House, Chorley, UK	Call for abstracts deadline: 31 January 2010
18 - 23 July 2010	XVIII International AIDS Conference	Vienna, Austria	Call for abstracts deadline: 10 February 2010
04 - 09 August 2010	26th IPA Congress of Pediatrics 2010	ICC, Durban, South Africa	Call for abstracts deadline: 10 February 2010
06 - 08 July 2010	Cardiff Conference in Paediatric Palliative Cae	Hilton Hotel, Cardiff, UK	Call for abstracts deadline: 01 March 2010

icpcn
international children's
palliative care network

1st ANNOUNCEMENT / CALL FOR PAPERS
5TH INTERNATIONAL CARDIFF CONFERENCE
PAEDIATRIC PALLIATIVE CARE 6 - 8 JULY 2010
"FACE TO FACE WITH INTERFACE"

CARDIFF UNIVERSITY
PRIFYSGOL CAERDYDD

> *"No man is an island, entire of itself; every man is a piece of the continent, a part of the main... any man's death diminishes me, because I am involved in mankind."* John Dunne, 1618

Care for children is never in isolation. Providing the optimum environment for the dying child in particular always means working with child, family members, and carers both lay and professional of many different disciplines. Working with others is one of our core skills; part of the stock in trade of paediatric palliative care. The definition, recognition and coordination of this team around the child is, after all, what we do.

Perhaps the greatest challenge to our skills in working together comes, not from other colleagues in palliative care, but when we come up against other specialties. On the face of it, the philosophies of paediatric and neonatal intensive care, for example, are utterly at odds with those of palliative care. On the one hand, endless interventions apparently interminably prolonging life. On the other, a philosophy of care predicated on the assumption that premature death is inevitable.

And yet, it is often these very teams who most clearly recognise the need to work alongside paediatric palliative care specialists, and whose families could most benefit from joint working. The theme of the 2010 Cardiff Conference in Paediatric Palliative Care is: 'Face to Face with Interface'.

Call for papers is now open and abstract submissions will be welcomed in the following three categories:

1. Service evaluation/description (presentation with questions)
2. Original research (presentation with questions)
3. Workshops (longer facilitated discussions with only brief presentations)

For more information follow this link: http://www.icpcn.org.uk/events.asp?section=000100010005&sectionTitle=Events&year=2010&month=7
The deadline for abstracts is **1st March 2010**

18TH INTERNATIONAL CONGRESS ON PALLIATIVE CARE MONTREAL, CANADA

Montreal Canada, Palliative Care Conference in October, 2010 will offer a two day Pediatric Palliative Care Seminar. There will be 2 full days devoted to pediatric palliative care and the days are divided into the two themes outlined below.

Submissions for Day 1 of the Seminar (Tuesday Oct 5th) should be based on the theme of "Easing Suffering in Pediatric Palliative Care" with a focus on therapeutic modalities aimed at reducing pain & suffering of the mind, body and soul.

Submissions for the 45 minute presentation/workshops that most closely reflect the day's theme will be chosen by an author-blinded review panel; interactive sessions are preferred.

Submissions for Day 2 (Wednesday Oct 6th) should be based on the theme of "Research in Pediatric Palliative Care" with a focus on the presentation of new research findings. Submissions for the 20 minute presentations (15 minutes presentation time and 5 minutes for discussion) will be chosen by an author-blinded review panel.

Submissions for these 2 days will be reviewed specifically for inclusion in the two day Pediatric Seminar. Those not selected for presentation at the Seminar may still be accepted for presentation at another workshop or proffered paper session during the congress.

The submission deadline is January 31, 2010.

For enquiries, please contact the scientific programme department at the Congress Secretariat at : programme@pal2010.com, or 450 292 3456, ext. 228.

SAVE THE DATES

A pre-conference pediatric palliative care workshop will be presented featuring; Advanced pain and symptom management in children & Models of Care

CHI
21st World Congress
WASHINGTON D.C. USA • OCTOBER 11-14, 2010
The Future of Children's Hospice & Palliative Care: Completing the Circle of Care

L' Enfant Plaza Hotel, 480 L'Enfant Plaza, SW,
Washington DC, USA
For more information visit: www.CHIonline.org

Regional Round-Up of Achievements during 2009

UNITED KINGDOM

The partnership working between ACT and Children's Hospices UK has really borne fruit during 2009. In February we heard that £30 million funding had been awarded by the government in England for children's palliative care. This funding, together with the publication of Better Care: Better Lives, the first England-wide government strategy for children's palliative care the previous year and similar commitments by governments in Scotland, Wales and Northern Ireland means that children's palliative care has never been higher on the agenda.

PUBLICATIONS

ACT has had an extremely busy year supporting the development of children's palliative care regional networks across the UK and held a highly successful event with the leaders of these networks and the Department of Health in September. ACT has also been expanding its library of publications and produced three major new documents during 2009: the third edition of the ACT Guide to the Development of Children's Palliative Care Services, a new Family Companion to the ACT Care Pathway which aims to guide families through the maze of services; and a new Neonatal Care Pathway which aims to provide families with greater choice in the care of their baby.

Children's Hospices UK and ACT jointly produced a new framework for the development of the children's palliative care workforce, called Right People, Right Place, Right Time.

BIG LOTTERY RESEARCH FUND AWARD

At the end of the year both ACT and Children's Hospices UK heard that they had been successful in their bids to the Big Lottery Research Fund. Children's Hospices UK will be leading a major research project on transition to adult services and ACT will be leading a research project looking at how well services meet the needs of life-limited children and their families in one region of the UK. Together with the news that funding is secured for a Chair in Children's Palliative Care to be based at Great Ormond Street Hospital, this is great news for the future development of the children's palliative care sector in the UK.

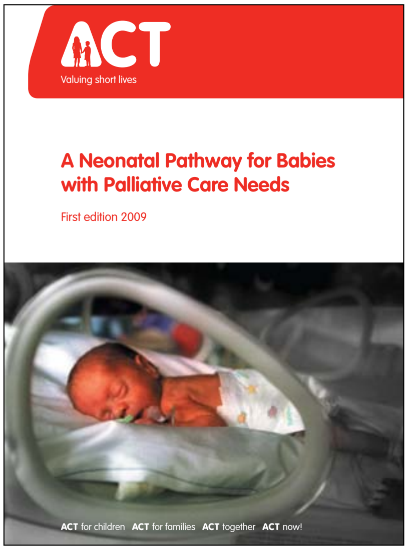
HAPPY 21ST BIRTHDAY TO ACT

To mark the celebration of 21 years, ACT's website for families and professionals **www.act.org.uk** has been completely transformed, and now includes new information for carers and families who have a child with a health condition that is life-threatening or will shorten their life. Families can now access a 'find help' search facility to help them access care, support and information at the touch of a button. The website has been re-designed to improve navigation and accessibility and includes new interactive features which will enable professional visitors to easily share their events, jobs and good practice examples. It also includes resources, tools and information to help professionals develop their skills and knowledge in delivering services to children and families. ACT was founded in 1988 as the first co-ordinating charity for the sector at a time when children's palliative care was a largely unknown discipline; with little discrete funding or dedicated services. Its vision then, as it is today, is one where every child and young person who has a life-shortening condition should be able to receive the best possible care and support.

Over the last 21 years ACT has worked hard to raise awareness of children's and families' needs; lobbied governments in all UK countries for funding and national children's palliative care policy frameworks; supported those that care for them; and helped life-limited children to have a good life and dignity in death.

Report by Barbara Gelb & Lizzie Chambers

TWO NEW PUBLICATIONS AVAILABLE FROM ACT & CHILDREN'S HOSPICES UK



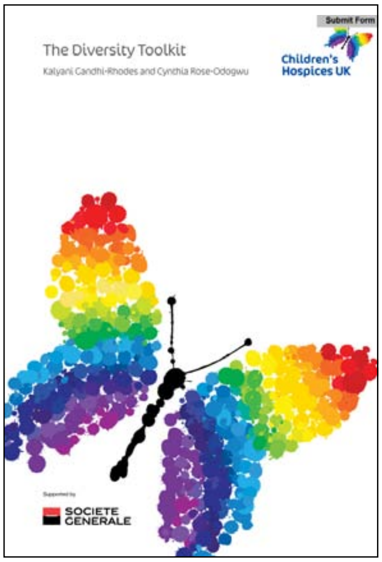
The Neonatal Care Pathway for Babies with Palliative Care Needs aims to draw together the professionals and resources needed to accompany terminally ill babies and their families along their unique care journeys. The pathway has been developed to support professionals working in maternity and obstetric services, and neonatal and children's services as they care for young babies, up to 28 days old who have life-limiting or life-threatening conditions.

A Neonatal Pathway for Babies with Palliative Care Needs is funded by the Department of Health and published by ACT (Association for Children's Palliative Care) in England, November 2009 ISBN: 1 898447 13 6 Price: £15

To order call ACT on 0117 916 6422 or email info@act.org.uk

The ***Children's Hospices UK Diversity Toolkit*** aims to equip children's hospices with the knowledge and expertise needed to provide for families from all cultures and backgrounds, no matter what their beliefs and customs. This toolkit, which is also available for organisations outside of the children's hospice sector, is intended to help organisations through:

- Developing a shared understanding of what diversity means
- Identifying current legislative requirements
- Showcasing best practice and barriers to achieving this
- Highlighting and addressing organisational challenges
- Providing a framework for planning and implementing service improvements as needed.How to order copies



The Children's Hospices UK Diversity Toolkit is available as an interactive PDF and as a hard copy folder. The toolkit is available for free to children's hospice services in the UK.

Other organisations can buy a copy of the toolkit or have access to the PDF version for £75.

Contact Sarah Hamer – sarah@childhospice.org.uk or call +44(0)117 989 7834

ROMANIA & EASTERN EUROPE

Report by Dr Delia Birtar

On the 9th and 10th of September the 10th Romanian National Conference of Palliative Care was held in Constanta, Romania and on the 22nd to the 24th of October the 12th Romanian-Hungarian reunion of paediatric oncologist.was held. At this reunion, about 75 doctors from Romania, Hungary and other Eastern European countries attended. For the first time the conference included a section on paediatric palliative care and I presented the study: Symptoms in advanced phase of childhood cancer: evaluation and approach; a study on patients who died at Hospice Casa Sperantei between 1996-2008

On the 6th of November the first Moldavian conference on Paediatric Palliative Care was held. At this conference, about 70 doctors from all the districts of Moldavia attended. We were able to encourage our colleagues from hospice Angelus in their work. Paediatric Palliative Care started there a year ago and at present they care for 22 children with cancer.

For World Hospice and Palliative Care Day, Hospice Casa Sperantei initiated an online petition for the right for palliative care in Romania. To date more than 3500 people have signed the petition.

The new publication **TAC for the 21st Century: Nine essays on Team Around the Child** (Limbrick, P. Interconnections, UK 2009) is available as a free resource in an online version to people who live outside the UK. To get the exclusive website link please send an e-mail to Peter Limbrick and tell him which country you work in.
Email: p.limbrick@virgin.net

ICPCN acknowledges with gratitude the funding received from The True Colours Trust for the furtherance of its work in promoting the development of paediatric palliative care worldwide.
www.truecolourstrust.org.uk

Regional Round-Up of Achievements during 2009 cont.

INDIA

Report by Dr Maryann Muckaden

The year 2009 started with new projects for our children palliative care patients. A Clinical Psychologist was especially employed to attend to the psychological needs of our paediatric patients, through activities involving art, puzzles, story telling, writing etc. as well as helping them share their fears and express hidden emotions.

A monthly support group for sharing as well as light entertainment for paediatric patient caregivers along with adult patients and caregivers has been a great success for the last 11 months. It has become an avenue for sharing their cancer related problems, as well as some of them being a source of inspiration for new members.

Various NGO's and individual donors offer their help through medicinal and nutritional aid / wish fulfillment / financial assistance/monthly food coupons and toys.

COMFORT BAG PROJECT

This comprises of a soft smiley pillow, soap, talcum powder, toy, napkin and bedsheet. The pillows are being made by a "Mentally Challenged Childrens Trust". This bag is given to the patients on their first visit to our clinic.

Paediatric patients are encouraged to continue their education and financial assistance is given by us. One of our female patients aged 15 years, suffering from PNET, appeared for the 10th standard public examination in March 2009 and scored a brilliant 70%. Books, umbrellas and shoes are disbursed at the start of the academic year to our paediatric patients and the children of our adult palliative patients.

WORLD HOSPICE & PALLIATIVE CARE DAY

World Hospice and Palliative Care day 2009 was celebrated by organizing a half-day seminar for the general practitioners, focusing on enhancing their skills in communication, psycho-social issues, rehabilitation, pain management and symptom control.

Ms. Priya Dutt – Member of Parliament, through her message to ICPCN has promised to support the needs of paediatric palliative patients and help organize a centre wherever possible, thereby creating palliative care awareness.

BOLLYWOOD STAR VISITS A PATIENT

The greatest Actor of our country, Shri Amitabh Bachchan fulfilled the wish of one of our 17 year old male patients suffering from PNET by visiting him at the hospice in Mumbai.

The patient described it as being "the Biggest day of his life". Sadly, the young boy passed away 10 days later.

SOUTH & CENTRAL AFRICA

Report by Joan Marston & Dr Julia Downing

A total of 45 hospices now have funded programmes for Children's Palliative Care in South Africa, some very innovative. The **Baobab** Paediatric Palliative Care Virtual Resource Centre and website is almost completed to support health care practitioners in South Africa. Dr Michelle Meiring will lead this project working with an interdisciplinary team. Discussions are also underway to get children's palliative care included in undergraduate and postgraduate training in certain universities.

THE ST NICHOLAS BANA PELE NETWORK

The St Nicholas Bana Pele Network project to develop a regional network of services for children requiring palliative care has been expanded in the Free State province. This project will develop 16 new children's palliative care programmes in the next year working with established organisations and schools. Education on children's palliative care has been provided in schools through a series of workshops.

THREE COUNTRY PROJECT

The Diana Princess of Wales Memorial Fund (DPOWMF)Three Country Project to develop Centers of Clinical Excellence in South Africa, Tanzania and Uganda began in September with the appointment of "Navigators" in each country to take training and advocacy forward. The Navigators attended the CHI World Congress, experienced palliative care in children's hospices in South Africa, and were trained in palliative care and as trainers of the new 6 month short course. The Navigators/Trainers are themselves completing the course and developing country plans. True Colors Trust have also asked to send their Zambian morphine roll-out Project manager and tutor to SA to do a CPC introductory course and spend time at Red Cross children's hospital to learn more about pain assessment.

APCA PALLIATIVE OUTCOME SCALE

APCA is continuing with the pilot for the APCA African Children's Palliative Outcome Scale. We have ethical approval in Kenya and Uganda and are still waiting for approval from South Africa and Zimbabwe. Data collection has started in Kenya and Uganda and we hope to start in South Africa and Zimbabwe in the next few weeks.

APCA POCKET BOOK

Work is ongoing on the integrated pocket book for palliative care in Africa for adults and children – this is being developed along with a pocket book looking at issues around pain, which will include both adults and children.

We also hope to help in the piloting of a course on children's palliative care that has been developed in Zimbabwe called PedPal.

INITIAL NORTH AFRICAN ASSESSMENTS

We have met with people from North Africa and are in the process of trying to assess the status of palliative care, including children's palliative care, in some of the countries.

AUSTRALIA & NEW ZEALAND

Report by Dr Ross Drake

Arguably, the most significant achievement for Paediatric Palliative Care (PPC) in Australia and New Zealand (ANZ) for 2009 has been the increasing recognition of Australian state and federal governments and the New Zealand Ministry of Health of the distinct needs of children/young people and their families with life-limiting conditions. This outcome has been accomplished through, generally, quiet lobbying and advocacy over many years and has begun to result in a number of positive initiatives that will improve the care delivered to these children and their families. No small feat at a time of economic downturn and recovery.

ANZ PPC REFERENCE GROUP

The establishment of an ANZ PPC Reference Group has been a noteworthy contributor to this progression. This collection of energetic PPC healthcare workers is now recognised for their expertise and the cohesiveness of the collaboration exemplified by the development of a National Standards Assessment Program for PPC. All specialty services in ANZ are in the process of completing the program and from this will be able to identify and prioritize a work plan specific to their needs. The Reference Group has also been instrumental in securing and running a very successful PPC satellite day in conjunction with the conference run by Palliative Care Australia.

TECHNOLOGY ASSISTS INDIVIDUAL SERVICES

Advancements continue for individual services across ANZ. For the more established services development has come in the form of improving access to PPC knowledge through the use of technology such as video conferencing and web-based initiatives. Less established services have been able to achieve an increase in personnel so as to provide a more comprehensive service.

The Chinese zodiac denotes 2009 as the Year of the Ox or Buffalo and symbolizes the gaining of prosperity through fortitude and hard work. The Ox has definitely lived up to its reputation for PPC in Australia and New Zealand.

THE TRUE COLOURS TRUST SMALL GRANTS FOR AFRICA

Could your palliative care organisation make good use of a small grant? If so, APCA might be able to help. APCA is administering a small grants programme on behalf of the True Colours Trust, to support the development of palliative care in Africa, and invite hospices and palliative care providers across the continent to apply.

To find out more go to the APCA website:

www.apca.org.ug or contact Jennifer Katiake on

TrueColoursSmallGrants@apca.org.ug

Regional Round-Up of Achievements during 2009 cont.

LATIN AMERICA

Report by Dr Rut Kiman

CREATION OF A PAEDIATRIC COMMITTEE

We are very pleased to announce the creation of the Paediatric Committee within the Latin American Palliative Care Association. This took place in Caracas, Venezuela, where we met in September this year. The participants were: Dr. Sandra Flores (Colombia), Dr. Silvia Rivas (Guatemala), Dr. Yuriko Nakashima (Mexico), Dr. Carolina Kamel (Venezuela) and Dr. Rut Kiman (Argentina). Dr. Yuriko Nakashima was elected as the Chief of this Committee.

Our goals up to now are:

1. To describe experiences in PPC at a regional level.
2. To consider which are the factors that help or hinder the developments in PPC in our region.
3. To analyse future scenarios in child health and opportunities for the development of PPC.
4. To promote cooperation at regional level that will enable the sharing of activities and resources for the development of quality PPC.
5. To encourage partnering activities to share goals and projects in this field.

We also invited to participate, as representatives of their countries in this Committee: Dr. Stella Maris Binelli (Argentina), Dr. Silvia Barboza (Brazil), Dr. Lisbeth Quesada (Costa Rica), Dr. Natalie Rodriguez Zamora (Chile).

Dr Veronica Dussel, an Argentine paediatrician working in Dana Farber Institute, in Boston, USA, will be in contact with this group.

PUBLICATION OF THE BOOK "USE OF OPIOIDS"

A new book on the "Use of Opioids" supported by the ALCP (Latin American Association of PC) and The Venezuelan Association of PC has been written and will be presented during the next ALCP Congress. Two chapters within the book deal with Acute and Chronic Pain in children, and were written by Latin American professionals in the field of PPC.

PRESENT & FUTURE PROJECTS

We are working on the organization of the next ALCP Congress which is going to take place in Buenos Aires in March 2010. Paediatric Palliative Care will have an important place in this event with many Workshops, Round Tables and Conferences.

Contact has been made with local organisations such as the Argentine Paediatric Association (SAP), as Joan Marston, Chair of the ICPCN, has been invited for the ALCP Congress and this would be of great interest and provide an opportunity to spread the vision of the ICPCN. This meeting will also will help the development of the new ALCP Committee for Paediatric Palliative Care.

Dr Silvia Barboza, a Paediatrician working in the Institute for Children in San Pablo, Brazil, is the new president of the Brazilian Association of Palliative Care. This situation provides us with an excellent opportunity to spread the goals of the ICPCN in Brazil.

Within Argentina we are developing research around concepts of PPC and we are working with adult palliative care colleagues to get palliative care accepted as a Specialty in Medicine, recognised by the Ministry of Health.

CHALLENGES FOR THE YEAR AHEAD

Looking forward to some of the challenges in the year ahead, we would like to:

- make the palliative care needs of children visible for Public Health decision makers
- develop guidelines and tools which are validated for our culture
- develop and/or translate education and training materials into Spanish
- publish research and data on children with life-limiting conditions
- find the necessary funding to develop Children's Palliative Care Teams as the economic crisis has had a negative effect on donations from International organizations such as the Global Fund and others.

NORTH AMERICA

Report by Susan Huff, RN

Health Care Reform is a top priority in President Obama's administration. We await Senate and House approval for a new bill which is expected by the new year. Palliative care language is included in both versions, allowing for concurrent curative care and hospice care for children enrolled in Medicaid. We hope results lead to advantages to advance palliative care for both children and adults.

NATIONAL HOSPICE AND PALLIATIVE CARE ORGANZATION

The "Standards of Practice for Pediatric Palliative Care and Hospice" are now available from NHPCO at www.nhpco.org/pediatrics. NHPCO members may download the pediatric standards in PDF, at no charge. A printed copy of the pediatric standards is available to purchase from NHPCO's Marketplace online or by calling 1-800-646-6460.

NEW NHPCO Pediatric Facts and Figures (2009). In addition to releasing Standards of Practice for Pediatric Palliative Care and Hospice, NHPCO has a new report, "NHPCO Facts and Figures: Pediatric Palliative and Hospice Care in America," available to download for free. The report was written by Sarah Friebert MD, NHPCO's medical consultant, and provides an overview of the landscape of pediatric palliative and hospice care in the USA for providers, policy makers, funders and the media. Additional resources on pediatric palliative and hospice care are available at **www.nhpco.org/pediatrics**.

THE LATEST ChiPPS E-NEWSLETTER IS NOW AVAILABLE

The most recent Children's Project on Pediatric Palliative/Hospice Services (ChiPPS) E-Newsletter (Issue #17; November 2009) features "Complementary Therapies in Pediatric Palliative Care." If you would like to receive the quarterly e-newsletter, please send an email message to CHIPPS2@NHPCO.org requesting to be added to the ChiPPS e-newsletter mailing list. If you are a member of National Hospice and Palliative Care Organization (NHPCO), you can go to the Communications Preferences tab in your individual member record online and "opt-in" for communications from ChiPPS. Previous issues of all the ChiPPS e-newsletters are available online at www.nhpco.org/pediatrics along with a wealth of valuable information regarding pediatric palliative care resources.

CHiPPS PEDIATRIC INTENSIVE

ChiPPS is proud to offer a pediatric intensive track as part of NHPCO's 11th National Clinical Team Conference to be held in Nashville, Tennessee, September 13 - 15, 2010.

NEW STATE INITIATIVES

CALIFORNIA

The State of California implemented their Pediatric Palliative Care Demonstration Home and Community Based Waiver on October 1st 2009. The project is called **Partners for Children** and was rolled out in 5 counties. Plans are to expand to 13 counties and serve over 1800 children in three years. Partners for Children allows for supportive services, to be provided concurrently while a child receives curative focused care.

ILLINOIS

The State of Illinois has formed The Greater Illinois Pediatric Palliative Care Coalition (GIPPCC) bringing together 6 not-for-profit community-based palliative care organizations in an effort to coordinate the development of consistent standards of care for children in the region and to coordinate the seamless referral and care of children from any of the 8 medical centers in the region.

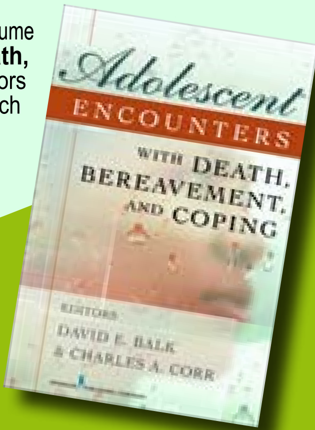
For further information, please contact Kim Downing, RN, JD [kdowning@horizonhospice.org], Mary Runge, RN, MBA [mrunge@horizonhospice.org], or David Steinhorn, MD [d-steinhorn@northwestern.edu].

NEW BOOK AVAILABLE:

CHILDREN'S ENCOUNTERS WITH DEATH, BEREAVEMENT, AND COPING

This book is edited by Charles A. Corr and David E.Balk .
Available in January 2010 from Springer Publishing Company in New York.
Toll-free telephone orders to the publisher at 877-687-7476; online to
www.springerpub.com

This will be a parallel volume to **Adolescent Encounters With Death, Bereavement, and Coping**, same editors and publisher, that was published in March 2009.



ISBN for this volume is 978-0-8261-1073-2.

SPREADING THE MESSAGE

Lessons can be learnt from the German National Association for Children's Hospices on improving exposure to palliative care services for children in other countries.

"Palliative care for the child and family shall begin at the time of diagnosis and continue alongside any curative treatments throughout the child's illness, during death and in bereavement. The aim of palliative care shall be to relieve suffering and promote quality of life.

Palliative Care seems to have become a very well known phrase – at least amongst professionals. But does it arrive at people's home - at the homes of those in need of support? Do they have a chance to use services available from the time of diagnoses onwards? Is it not our responsibility to spread the information actively in order to fulfil the ICPCN-Charter?

In Germany we have new laws implementing a right to specific palliative care for every patient but there is still no right to general palliative care. Specific care needs are made for specific situations, when there is a crisis. But what about those families who have children with life-limiting diagnosis and no urgent specific palliative care needs? Do they need support and how do we reach them? At least we should ask ourselves: do they want to be reached?

Many of the children with life-limiting conditions have a life expectancy of months or even years. Parents who are faced with a child's life-limiting diagnosis need time to accept the inevitability of premature death. During this time of growing awareness they try everything to cope with the upcoming care needs of their child. They feel that the very best that they can do for their child is not to place them in the care of others, to keep on believing in their recovery and to avoid thinking or talking about the taboo subject of 'dying'. They tend to extend themselves to the very limit and seriously neglect their personal needs. They handle care for the child, organisation of the household, and even their jobs, while trying to cope with the difficult situation in which they find themselves.

Asking for help from a hospice service is an enormous step for them to take.

Asking for help from a hospice service is an enormous step for them to take. To reach this stage, they need to have accepted that their child's illness is life-limiting and death is inevitable. But even then, there is a fear which surrounds the thought of entering a hospice. Maybe they feel like they are "giving up", perhaps they feel that it is still too early, and maybe they just want to manage on their own.

The word "hospice" is commonly understood as a service for care at the end of life. People think in terms of a few days or weeks at the end of life and in hospices for adults, with some exceptions, this is often the case. But children's hospice services offer support from the moment of diagnosis, at home and in purpose-built hospices. The purpose-built hospices offer the child and family recreational or "respite" stays when the child's condition may be quite stable. In Germany this is usually for four weeks in a year. These four weeks can be taken as a whole or split into different stays of shorter durations. And for end-of-life care, there is no time limit at all.

It is our challenge then, to reach these families sooner....

It is our challenge then, to reach these families sooner, to give them the support and the opportunity to make use of the recreational stays – certainly always presuming that the families want this support. By so doing, they also have the opportunity to meet up with other families in similar situations. This message needs to be heard in every household. We have purposely chosen to keep the word "hospice" in children's hospice work and therefore we must put every effort into making it known that children's hospices are there to offer the child and the family their support right from the time of diagnosis, throughout the entire duration of the illness and into bereavement, for as long as it is needed.

The national association of children's hospices in Germany has explicitly written down in its statutes that it is to publicise the concept of Child Hospice Work. We are taking this very seriously.
Our multi-dimensional strategies include:

1. To go to the places where we can meet these families
2. To publish articles about child hospice work in practice in non-scientific language
3. To co-operate with well-known partners and make use of the resulting publicity
4. To send out leaflets and flyers to places where parents could read them
5. To campaign in schools and offer workshops at all different educational levels
6. To spread the news using all forms of media

EXAMPLES OF SUCCESSFUL STRATEGIES

Three years ago we participated for the first time at the international fair for the disabled in Dusseldorf. This fair is one of the largest in Europe - an International Trade Fair and Congress for Rehabilitation - Prevention - Integration – Care. The products and services on display range from daily living aids, nutrition, physical care and hygiene, mobility, safety and monitoring systems to pedagogy, education, and further training, nursing and medical care, clothing, protective equipment, self-help groups and charity organisations.

In our experience, people find it easier initiallly to approach the national association than to contact a children's hospice directly.

In our experience, people find it easier initially to approach the national association than to contact a children's hospice directly. Every year since then, families have taken their first step towards using the services offered by a children's hospice at the fair, where they have asked tentatively if they could be offered some support. It is as if they need the information to come from an organisation that is not too close to the hospice itself. Sadly, many of these families have been carrying this question around with them for months or even years.

This year I met a young couple struggling bravely with their fate. They are a happy family, who love their son dearly but who were feeling completely exhausted and isolated and who were struggling to make ends meet on their income as a result of having to pay for the necessary medicines for their son. Their two-year-old son, Felix, was born with a severe brain defect and now has a life expectancy of only a few months. The parents are both in their early twenties and trying their best to manage on their own. They explained to me just how desperate they feel. The mother is alone with their child all day long and they cannot sleep through the night because of the care-needs of their disabled son. They also told me that they have enormous problems getting the correct medicine for their child. It is far too expensive to buy it legally, and so they attempted to import it from a cheaper source. Now, the young father has to deal with being accused of importing illegal drugs. Their story is symbolic of the situation faced by many such families. Families in similar situations become more and more socially isolated and lack the courage to get in touch with possible support systems.


Felix with his young parents

Their story is just one of many, which is why I want to plead for children's hospices and children's hospice organisations to follow this approach. We need to be more visible and we need to let people know what is available to them and we need to offer counselling to people.

FIND STRONG PARTNERS

A powerful form of marketing is to find strong partners who are likely to have a very good media presence. An example of this is our organisation's co-operation with the **German National Football Association** to campaign on behalf of the children's hospices in Germany. This campaign will start in 2010 and will be advertised along with the World Cup. With a partner like this on board, you have a far greater chance of finding your way right into the living-rooms of the families with life-limited children.

The work of Children's Hospice must go public!

CHILDREN'S HOSPICE SERVICES IN GERMANY

There are 9 purpose-built hospices in Germany, the first was established about 10 years ago. Today, another 7 are in planning.

Furthermore, we now have around 70 volunteer child-hospice-home-services. These services operate from an agency with usually only one or two Specialists in Co-ordination and Paediatric Palliative Care (usually qualified paediatric nurses or social workers) and trained volunteers to support the families. This is a great success as only 5 years ago there were less than 20 services.

The National Association of Children's Hospices in Germany was founded in 2002. It's main objectives are:

- Achieving better public financing for children's hospice work
- To promote und publish children's hospice work
- Co-ordination and networking of child hospice work
- Development of quality standards in child hospice work
- Centre of information for all persons interested, such as families with a life-limited child, professionals, clinics, politicians and funders
- Counselling for new initiatives and support to existing organisations
- Seminars and courses on child hospice themes
- Lobbying

Author: Sabine Kraft
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Freelance Counsellor Project Management, Development and Fundraising for NGOs
Executive Board, ICPCN
Executive Director, National Children's Hospice Organisation in Germany (Bundesverband Kidnerhospiz)
Board Member, German Charity for Children's Hospices (Bundesstiftung Kinderhospiz)
Chairwoman of the Edith Heilersche Charity (Edith Heilersche Stiftung)

BUNDESVERBAND Kinderhospiz e.V.

SUPPORTING CHILDREN THROUGH INTERACTION WITH WILD ANIMALS

YEBO

Yebo is an organisation that supports children and young people with emotional and social disadvantages through primate and animal-based communication activities.
Yebo aims to relate human behaviour and feelings to that of primates, giving children the opportunity to express their feelings and family situations in a safe and non-intrusive environment. This is done with a range of creative and expressive activities. We also allow children to have direct contact with animals and wildlife to enable them to gain self-confidence and have the ability to build and sustain relationships.
Yebo is currently working with children's hospices in the UK running primate days for siblings. Feedback has shown that children appear to be able to relate their family situations of loss and trauma to similar experiences to that of primates. They appear to express their feelings about personal situations through stories and creative activities.

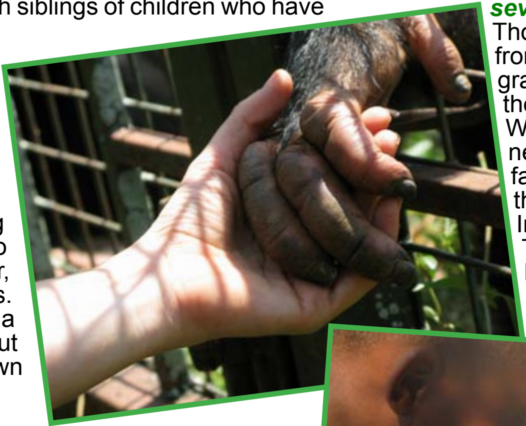
We are also running projects in South Africa focusing on children and young people who have suffered from loss or trauma and are currently looking for volunteers to help us develop this project further by working with children's hospices throughout South Africa. Children's hospices in the UK will receive a donation of £200 for every volunteer for the South African programme.

If you would like to volunteer, or for more information please visit the website www.yeboyes.org or email info@yeboyes.org

THE WORK OF YEBO

At present Yebo operates in the UK, South Africa and Uganda where we are carrying out independent research on the similarities between chimpanzees and humans and the therapeutic benefits of human-animal interaction for children. Our work aims to allow children and young people to express their feelings in a safe environment through primate and animal-based activities.

Feedback from UK hospices has shown that children are able to act out and relate family situations and feelings similar to that of a primate family. We are working primarily with siblings of children who have died or are life limited.



The day is tailored to the needs of the ages and individuals we are working with. We normally begin the day by showing the children images and videos of primates from around the world, focusing on explaining and showing them how primates are similar to humans in aspects such as behaviour, communication, feelings and emotions. This allows the children to feel a connection to the primates without being too apposing into their own feelings.

The sanctuary I worked at in South Africa was also home to disabled and sick monkeys. We relate their care to that of humans who suffer from long term illnesses. One particular monkey became very ill and could not move her legs very well. Having worked in a children's hospice I shipped from England a sensory bubble tube for the monkey, and provided her with 'hydrotherapy' which is similar to the care the brother/sister who is life-limited may be receiving. Children, particularly siblings of children with disabilites, are very receptive to this story and the pictures. We find the children 'pointing' to images and saying that their brother or sister has one of those.

We also focus on primate families having bereavements or illness in their troops by telling them how primates are removed from their homes due to things like deforestation. This is is a safer way of communicating to the children and also gives a subtle educational message about conservation. Next we put the children into 'primate groups' such as chimpanzees, orangutans, vervets, gorillas etc and ask them to make puppets of each monkey/ape in the group that they would wish to be, for example, the mum, dad, brother or sister who is ill and ask them to give the puppet a 'feeling' such as sad,happy,angry, etc.

We then ask the children to think of a story about a situation that has happened to the primates in the wild and how they feel about the situation and finally ask them to perform their play to the group.

The children are supported by carers from the hospice organisations and the staff and volunteers from Yebo as the children are looking at sensitive issues. Yebo provides volunteers and staff with in-depth training on all these subjects.

A CASE STUDY:

WORKING WITH THOMAS AND VINCENT

This is just one example of the many children who have suffered severe traumas in their lives.

Thomas and Vincent are two 12 year old boys who suffer from muscular dystrophy and who lived at home with their grandparents. Their grandparents had cared for them since they were young due to the loss of their parents from an illness. With a disability such as muscular dystrophy the two boys needed 24 hour care from their grandparents and would in fact sleep in their grandparents' bed to enable them to care for their needs during the night time.
In the middle of the night, two gunmen broke into their home. They saw the grandparents but not the boys as they were lying quietly and did not move. The gunmen shot and killed the grandparents and Vincent and Thomas were left to lie in the bed with their slain grandparents until they were found the next day.
They now live at a boarding school for special needs children in South Africa and were so traumatised after the incident that they found it very difficult to speak, and would not communicate with the teachers or carers.

HOW YEBO HELPED THE BOYS

The two boys worked with the volunteers from Yebo on various communication activities, where they were able to communicate their feelings through non-verbal forms of expression, using primate-based activities. This is where we work with the children to relate human feelings and emotions to that of primates. The children responded very well to the activities and began communicating their feelings and needs more to their teachers and people that were caring for them. They were also able to visit an animal sanctuary, where, for the first time in their lives, they were able to have contact with wildlife and where they got to experience meeting and interaction with animals.

Lisa Davies
Founder and Manager
www.yeboyes.org

YES TO PALLIATIVE CARE AND UNITS FOR CHILDREN IN NORWAY

Andrea with her mother, Natasha Pedersen

Family exercise time!

Andrea with her younger sister, Isabell

An inspirational story of one mother's determination to bring palliative care to the children of Norway so that other parents and families can feel supported and cared for in the future.

We live in a technological world where medical equipment and aids will only get better and more advanced. Luckily, most people do not get to know anything about this as they do not have a child with an incurable illness. However, although the number of deaths have drastically reduced, every year there are 600 children who die in Norway from a serious illness.

> **Many people believe that the longer one lives with a serious illness, the easier it is to be prepared for death. This is not true!**

Nobody can be fully prepared for death, and especially not that of one's own child. Following many of my own experiences as a parent, a previous health-worker and a priest, I have observed that there is a lack of assistance for that group of children and their families. The purpose of the organisation, **Yes to Pallliative Care and Units for Children in Norway** is first and foremost to bring our case and our needs to the fore.

NATASHA'S PERSONAL EXPERIENCE

We do not know what tomorrow brings, and being fortunate to have been a mother for 17 years to a child with multiple handicaps who has lived with one foot in the grave, I have experienced this fact with both mind, body and soul. I have experienced unnecessary suffering and stress simply due to a lack of knowledge. To provide a worthy and dignified end for a child's life is very difficult as the fear of the unknown is always there! A child's death will always be difficult, but without knowledge and support, it becomes far more difficult than it needs to be.

> **The death of a child touches us deeply as human beings.**

When one waits for death, sorrow is great and one suffers anticipatory grief. I may have the knowledge about death as a priest and a care-giver, but this has not helped me a great deal in the daily life of my family. One is first and foremost a mother, a relative, and a human being. It is hard when, after years of treatment and focusing on correcting and preventing conditions, suddenly you have to put all your energy into focusing just on the child and not so much on her treatment. It confronts us as adults , as parents and has health workers. That a child shall die is against nature, and it involves many strong feelings in us.

Andrea, who is my mentor and daughter, has now lived a long life with uncertainty hanging over her. In the spring of 2008, the decision was made not to put Andrea on life-support. Even though we have lived so long with a sick child, this was a very difficult process for us to go through, involving many meetings and much heart searching. Three doctors at the hospital and Andrea's primary doctor prepared, together with ourselves, a plan to allow the rest of her life to be as easy as possible. The plan gave us reassurance about when things should happen, and the changes that would occur. Now, here we are, one year later, and Andrea is still with us with seven different diagnoses, two of which are fatal. The State Hospital told us this autumn 2009 that her life and her health are untreatable and getting worse. This touches us deeply and now we have arrived at the most difficult stage in Andrea's life. We know that she is about to die, she has been close many times, and all the medical alarms are showing red. We feel so helpless and know that all we can do now is to fight to ensure that she receives a worthy and dignified end to her life.

MOTIVATION TO START THE ORGANISATION

While a great deal is known about adult palliative care, particularly for those suffering from cancer, there is not enough knowledge about how children who have untreatable illnesses feel in Norway. And the differences and variations in the diagnoses of these children are huge. Many children are unable to talk; some are blind or deaf and have enormous challenges communicating. These children require extra help from those around them, health workers, family, doctors and other professionals. They need help to see, listen and touch, and for someone to just BE there. We, who have worked with language, know that non-verbal language is amazingly strong.

ANDREA'S LEGACY

Andrea now holds the last baton, and we are fighting to get a bureaucratic system to help us establish an organisation so that children who are dying are able to receive good quality palliative care from trained health care workers. The idea for such a group grew in me throughout this process over many years and many sleepless nights! To lose that which is the dearest to you, your own child, is heartbreaking. We have begun this group for our own benefit as well as for all the others who suffer as we do. It is most unlikely that we will get the help and support we need for our own child, but we know that it is still important for those who will come later. This will be Andrea's legacy to the children in Norway.

www.palliativbarn.com

Natasha Pedersen
Just a mother and founder of **Yes to Palliative Care and Units for Children in Norway**

AN UPDATE ON PROGRESS IN NORWAY SINCE NATASHA FIRST WROTE THE ABOVE ARTICLE

Many good things have happened in a short time - the progress is amazing! We have been in contact with many people and other organisations in Norway. Our Facebook group has reached 4600 members since 25 October. We have been making brochures and cards, getting paying members and a website. Many organisations within healthcare wish our organisation a warm welcome and are happy that this issue on palliative care for children is finally on the agenda. There are two palliative care organisations in Norway for adults, mostly cancer patients. Paediatrics and paediatricians are not represented in either of these organisations. Neither of them has contacted us, despite emails sent to them, but we are not giving up! Several newspapers have run articles on us, one magazine with 1 million readers has given coverage to our organisation and will be on sale in February. Now we are working with finances and have been in contact with several people and are also compiling statistics on how many children in Norway need palliative care. One firm has given us advertising to have on our cars, so soon many cars will have our logo on them.

We have received wonderful support from both **Children's Hospice International** and the **ICPCN** who have given us valuable information and knowledge. CHI has offered us the rights to use their literature and have it translated into Norwegian. We ***will*** make a difference for all the life-limited children and their families in Norway. National research policy measures are our main goal and we will start to provide courses on palliative care for children in the fall. We are determined to do whatever is needed to get our work recognised. Our organisation is looking forward to even more progress in the year 2010 and is very proud to be a part of the ICPCN.

Natasha Pedersen
CEO and founder of **Yes to palliative care and Units for Children in Norway**

Christmas in Bethlehem

Christmas, Bethlehem, infants and a loving caring family is a familiar story for many of us. As Christmas approaches I am in Bethlehem to reconnect with the Sharif family. Four years ago I met Yahia Abu Sharif and his wife Reema Abu Sharif, at the Maher Center in Bethlehem. In 2001 their son, Maher, a bright, funny, engaging boy aged twelve, died after a long fight with cancer. They decided to use their experience and help other families whose children had a diagnosis of cancer.

Yahia and Reema were alone in coping with the roller-coaster of emotions and complicated decisions that all cancer stricken families face. Using their experience Yahia and Reema established a center to support these families in a way that they themselves would have valued. The parents named it the **Maher Center** in memory of their son.

In addition to the many stresses for families affected by cancer, life in Israeli-occupied Bethlehem brings more problems. Effectively strangled by the 8 metre concrete wall that surrounds Bethlehem, daily life is difficult and unpredictable due to the complex system of passes, permits, and the fragmentation of the West Bank.

Cancer treatment may be free but patients and their families face many difficulties which include:

- The travel to hospital appointments is expensive. (65% of Palestinians are unemployed) Yahia told us of a recent case where a teenage boy was unable to afford 100 NIS ($20 approx.) for each journey to get Chemotherapy treatment, and had died.
- There may be road closures, (there are 617 in the West Bank-OCHA-2009UN Office of Humanitarian Affairs) and long waits at check- points.
- Permits to travel have a time limit and are only granted when a hospital appointment has been made. They are only valid for one day, making it difficult for parents to stay overnight.
- The hospitals don't accommodate parents for overnight stays while their child receives treatment.
- Fathers must accompany their wives as it would not be acceptable for a woman to travel alone. Since treatment may involve 8 chemotherapy sessions over a year this would represent a year's lost wages for the family.
- There are no PET Scanners in Palestine

THE ESTABLISHMENT OF THE MAHER CENTER

The Maher Center was established in 2003 through the efforts of volunteers, parents, social-work students and medical personnel. Initially, the Beit Jala hospital gave Yahia a room where children undergoing treatment could play and study. Volunteers painted the space with bright,cheerful colours and equipped it with toys, paints, TV and films, and low tables and chairs. It soon became apparent that adolescents with cancer also needed age-appropriate support, so a nearby house was leased, and equipped with computers for young patients and local teenagers. This social interaction helped break down the stigma surrounding cancer, normalize their situation and increase understanding about the disease. The Center also produced a handbook for parents explaining medical procedures, the choices available, and above all, letting parents know they were not alone.

Yahia writes,
"With the help of so many wonderful, dedicated volunteers, we created a special place that did many special things, such as:

- helping children with cancer feel they are 'normal', and providing them with recreational activities, fun events like birthday parties and theatre, and the ability to continue their studies,
- providing parents and family members with psychosocial support, guiding and counselling about how their child's cancer is affecting both the child and the family, and helping parents and family members with their fears, sadness, anger and grief.
- providing training and professional development to volunteers in order to increase their skills in the area of childhood cancer and palliative care, and
- raising awareness in the community about cancer, what it is, and how it affects the child and the whole family.

FORCED TO CLOSE

Despite all this good work and a long legal battle, the Maher Center is now being forced to close but Yahia and his dedicated group of volunteers intend to continue the work and he is currently looking for new premises. There is an urgent need for continuity and to renovate a new Center to keep and improve the mission of the Maher Center.

Christmas 2008

I wish all of you a very Happy Christmas. Like all Palestinians I am hoping for Peace in the New year, but it must be a just peace.

Gaie Delap

The author, Gaie Delap has worked in Palestine as an Ecumenical Accompanier with The World Council of Churches. She is a Quaker who lives in Bristol, UK and regularly visits Palestine.

If you would like more information or to support the Maher Center, please contact Yahia at yabusharif@yahoo.com or Gaie at gaiedelap@yahoo.co.uk

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WORLD'S FIRST COMPREHENSIVE STUDY OF PALLIATIVE CARE RECEIVED BY CHILDREN AND YOUNG PEOPLE

A partnership between researchers at the University of Leeds and Martin House Children's Hospice has resulted in the world's first comprehensive study of palliative care received by children and young people. The new data will help health authorities plan palliative care resources more effectively as the research shows, for the first time that children, young people and their families may need the care and support provided by a hospice for varying amounts of time, in some cases for more than 20 years.

Lead researcher from the University's Paediatric Epidemiology Group, Lorna Taylor commented that one of the most interesting results is the length of survival time for children and young people, indicating this service is concerned with much more than the end of life care associated with an adult hospice. Over a 20 year period 1,554 children from birth to 19 years were referred to Martin House. Of the 89.5% accepted, the average survival time was more than five years.

With funding from Martin House and using a unique archive, started in 1987, the research team had access to more than two decades of data, on all children referred to the hospice up until May 2008.

Whilst palliative care for children and young people is a growing speciality, up to now there has been little available information to help health authorities plan and prioritise future resources effectively. Following the recommendations of a report published in 2007, highlighting the lack of available information, the UK Department of Health has identified research in palliative care services for children and young people as a priority.

Jan Aldridge, Consultant Clinical Psychologist at Martin House explained that part of their role at Martin House is to be a resource to the wider community so that health professionals and families from all social and ethnic backgrounds know they are there and what they do.

The research study took two years and was undertaken in partnership between the University of Leeds and Martin House.

Follow this link to access a pdf copy of the research:
http://adc.bmj.com/cgi/rapidpdf/adc.2009.158774v1

Hospice Palliative Care Association of South Africa
no end to caring

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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