Welcome to the twenty-first issue of the ChiPPS electronic newsletter. This issue of our e-newsletter offers a PDF collection of articles that are meant to provide a variety of global perspectives on pediatric palliative and hospice care. This is, of course, merely a sampling of articles about what is being done in our field outside the United States in different countries around the world. Some of these articles reflect leadership and trend-setting in local regions, while others describe early initiatives and, in some cases, challenging work in difficult situations. We hope that the diversity of these articles, along with the successes and trials that they reflect, will be inspiring to readers of this issue.

This newsletter is produced by ChiPPS (the Children’s Project on Palliative/Hospice Services), a program of the National Hospice and Palliative Care Organization and, in particular, by NHPCO’s Communications Work Group, co-chaired by Christy Torkildson and Maureen Horgan. Archived issues of this newsletter are available at www.nhpco.org/pediatrics.

Comments about the activities of ChiPPS, its Communications Work Group, or this issue of the newsletter are welcomed. We also encourage readers to suggest topics, contributors, and specific ideas for future issues of this newsletter. Please contact Christy at torkc@sbcglobal.net or Maureen at Maureen.Horgan@providence.org.

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Issue #21: Global Perspectives on Pediatric Palliative and Hospice Care

(Click on the “bookmark” tab on the left-hand side of the PDF document for links to the following articles.)

Helen and Douglas House, Oxford, England

Sister Frances Dominica
Helen House was the first pediatric hospice house in the world opening in 1982; in 1993 it was one of 20 pediatric hospice houses all in the United Kingdom. In 2004, Douglas House opened for older teens and young adults – a bridge for the widening gap for the pediatric patient living into adulthood with life-threatening illnesses. In 2010, Helen House and Douglas House are among the 44 pediatric hospice houses in the U.K. alone, there are now two in the U.S., several in Canada and as you will read several others throughout the world and as Sister Frances so aptly says, “We are the first to say that we continue to be on a steep learning curve, with each child and young person being a unique individual.” However Helen and Douglas House have many lessons for us all.

The Emergence and Development of Children’s Hospices Across the UK: An Acorns Perspective

David Strudley, CBE, FRSA, and Emma Aspinall
Acorn’s Children’s Hospice is the largest provider of pediatric palliative and hospice care in the United Kingdom. David and Emma provide a concise overview of not only Acorns Hospice but also the development of pediatric hospice care across the U.K.

Children’s Hospice of St. Petersburg, Russia

Irene Barinoff
The first children’s hospice in Russia opened this year in St. Petersburg. Irene, a board member of the St. Petersburg-Seattle Washington Sister Churches Program provides us with a view of the dedication, need, and challenges with an American twist!

Modern Development of Pediatric Palliative Care in Belarus

A. G. Garchakova, MPH
Anna provides a detailed description of the development of pediatric palliative care and hospice in Belarus, where the country has taken an active part in determining care levels and need for their pediatric population. As Director of the first and leading pediatric hospice in Belarus founded in 1994, Anna has been involved from the beginning in the development of pediatric palliative care in Belarus.

Pediatric Palliative Care in Greece

Danai Papadatou, PhD
Danai was a founding member of the ChiPPS Steering Committee and is a respected researcher in the field of pediatric palliative care. She provides a rich overview of the challenges in developing pediatric palliative care in her home country of Greece.

Pediatric Palliative Care in Africa is Not “Salvage Work”

Ann Fitzsimons, BS, MBA
Ann is an active member of the ChiPPS Communications Workgroup as a family member representative. She is also co-Founder of Compassionate Passages, Inc. She and her Co-Founder Beth Seyda traveled to Africa to attend the 20th Children’s Hospice International World Congress. Since that visit she has returned once and plans to return again this December working with the groups in Africa to help support and promote pediatric palliative care. This article provides an overview of challenges and need for pediatric palliative care services for the hundreds of thousands children facing death on the African continent.

ChiPPS is a program of the National Hospice and Palliative Care Organization. Learn more at www.nhpco.org/pediatrics.
Hospice Association of the Witwatersrand Paediatric Palliative Care Program  p. 21
Louisa Ferreira, MBBCh (Wits), DCH (SA)
Louisa describes the work of Hospice Association of the Witwatersrand, which has been providing palliative and hospice services for over two decades in Soweto and Greater Johannesburg areas of South Africa. In 2007, the Hospice Association opened their first inpatient unit and started collaborations in order to extend services to as many children and families. The article presents challenges we all face as we strive to provide and improve palliative care services for children.

Now More Than Ever: The Importance of Pediatric Palliative Care  p. 23
Colette Cunningham, MA PPM, BA Development, RNRM
The goal of this article is to raise awareness on the need for Pediatric Palliative Care in the face of major disasters such as earthquakes. The article highlights how palliative care needs are often 'forgotten' in emergency responses. The author writes from personal experience, after spending 36 days working on Public Health in Internally Displaced People's Camps (IDPs) in the aftermath of Haiti's devastating earthquake, January 2010.

The Pro Palliative Care Unit Foundation, San Jose, Costa Rica  p. 26
Lisbeth Quesada Tristán, MD
Lisbeth was the first palliative care physician in Costa Rica. In this article, she describes the development of pediatric palliative care in her country, from the start of those services in the only Children's Hospital in the country over two decades ago.

Rights of a Child With a Terminal Illness  p. 30
Lisbeth Quesada Tristán, MD
This important document on the Rights of a Child With a Terminal Illness was first published several years ago but well merits reprinting here.

Healing With a Heart–Connection  p. 31
Jeannie Berwick
Although Jeannie is not writing specifically about pediatric palliative care, she tells of one of the native peoples in the southernmost state in Mexico, Chiapas. The Tzeltal Mayan recognize that “health” is not simply the absence of sickness, but the experience of feeling “our heart is at home.” It seems to us a very good match with the principles of pediatric palliative care!

Education: The Key to Providing Excellent Pediatric Palliative Care Internationally  p. 34
Pam Malloy, RN, MN, OCN, FPCN, Betty Ferrell, PhD, FAAN, FPCN, and Rose Virani, RNC, MHA, OCN, FPCN
End-of-Life Nursing Education Consortium was first started in the United States in 2001 to provide curriculum that could be integrated into nursing education. This goal has been far surpassed and there are now ELNEC trainers for adults and pediatrics in every state in the country and 65 foreign countries. The curriculum is interdisciplinary and fosters best practice, an identified need throughout our world.

Canuck Place Children’s Hospice: 15 years of Pediatric Palliative Care in Canada  p. 36
Hal Siden, MD, MHSC, FRCP and Fil Nalewajek, RN, BSc, MN
Hal and Fil provide an overview of pediatric palliative care in Canada. As the Medical Director and Executive Director, respectively, of the first children’s hospice house in North America they have been involved in the development of pediatric palliative care and pediatric hospice in Canada for the past 15 years and share their experience with all of us.

ChiPPer is a program of the National Hospice and Palliative Care Organization. Learn more at www.nhpco.org/pediatrics.
Reader's Corner  
Suzanne S. Toce, MD  
Here, Suzanne reviews a recent article in the New England Journal of Medicine. The article is a study of adults with a particular type of lung cancer. Its importance for readers of this newsletter lies in its emphasis on the benefits of early palliative care, either working alongside cure-oriented treatment or as the main model of care.

Items of Interest  
P. 41
When Helen House opened in 1982 we waited to see who would use it – or if anyone would use it! There was no prototype. We set criteria – new referrals should be no older than 16 and would have been diagnosed with life-shortening conditions. We were there to support families caring for their sick children at home, an attempt to be an alternative to the extended family in a culture where the nuclear family is often isolated.

We have always offered respite care, end-of-life care, and long-term family support. Through the years the vast majority of admissions have been for respite care and for care during episodes of acute illness with the need for symptom control. Kate is an example. Diagnosed at the age of 15 months with spinal muscular atrophy type II, she and her family first came to stay when she was 4 years old. Since then she has stayed with us on 54 occasions, with or without members of her family. On several occasions she has come for stepped discharge following acute episodes or surgery for which she was hospitalised. In the last two years she has always been accompanied by her faithful friend, Roo, a trained dog for the disabled.

* * *

Douglas House opened in 2004 to meet the needs of the ever increasing number of young people with progressive, life-shortening conditions who would previously have died in childhood. At Douglas House we welcome referrals from those between the ages of 16 and 35.

Strategic planning in 2009 undertaken by Helen & Douglas House identified that the organisation was evolving into a more specialist service provider, looking after increasing numbers of children and young adults who are surviving longer with often complex, acute, and unstable medical needs and frequently with changing prognoses.

As an organisation we still embrace a holistic family approach, offering short breaks. However we are now also focused on developing a service which provides specialist palliative care, investing in our medical team and nursing skill mix. The service includes increasingly complex symptom management, stepped discharge, neonatal palliative care, and end-of-life care. We are also involved in teaching post-graduate courses.

* * *

It is difficult to say whether Fred was a child or an adult. His chronological age was 16 but his role in a Romany gypsy family as the eldest of 7 children was that of an adult, both parents being illiterate and addicted to alcohol.

We met him and his family in October 2009. He had been diagnosed in 2007 after 3 years of health problems, previously thought to be a glue ear but in fact proving to be an unusually aggressive nasopharyngeal carcinoma. He underwent courses of chemotherapy and radiotherapy but relapsed in August 2007 and March 2008. He was given further radiotherapy for bony pain and came to Douglas
House on 1 October 2009, supposedly for two nights to rationalise his medication and to be in a more peaceful environment. In fact he remained in Douglas House until he died on 7 March 2010.

The problems with which Fred presented were:

- Multiple bony metastases causing complex pain
- Anxiety – contributing to his experience of "total pain." It was vital to him that we involve him in all new treatment decisions or his pain became unmanageable
- Spinal cord compression (twice treated with radiotherapy and steroids)
- Didn’t like eating “healthy” food, washing, or oral hygiene
- Support of his family including extended family and expectations around death rituals
- The healthcare professionals involved in Fred’s care were unanimous in saying it would not be possible for him to be cared for at home

It proved very difficult throughout the remainder of Fred’s life to control his neuropathic pain. He consistently defied all expectations by living longer than anyone predicted but he declined to engage in conversations focusing on his prognosis, though acknowledging it in his own way. The professional desire to achieve open communication within the family was not achieved and was probably not realistic. Fred purposefully planned to spend significant time with each of his siblings in order to leave them with some happy memories of him, the whole family spending his last Christmas together in Douglas House. The main challenge surrounding his death was to support his wishes for privacy whilst enabling his family to be with him to say their goodbyes.

Through caring for Fred and his family in the final months of his life the care team learnt that respecting patient autonomy is not always easy and can be at odds with conventional medical management. They realised the need to "seize the moment" when there is a window of opportunity to do something "normal." They also agreed that young adults are very unpredictable, including the way in which their disease progresses. The team was unanimous that it was a huge privilege to support Fred to die in his own way.

* * *

We are the first to say that we continue to be on a steep learning curve, with each child and young person being a unique individual. We recognize that to support them and their families we need to be in partnership with them, recognizing their expertise. The support of each family begins the day we meet them and goes on for as many months or years after the death of their young person as they may wish. The service we offer is one of friendship, practical help, and the highest standards of professional care.
THE EMERGENCE AND DEVELOPMENT OF CHILDREN’S HOSPICES ACROSS THE UK, AN ACORNS PERSPECTIVE

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In 1967 St. Christopher's Hospice was the first adult hospice to open in London, England. It was to be a further fifteen years before the first children’s hospice opened. Helen House opened in November 1982, followed by Martin House opening 5 years later in 1987, and Acorns, the third children’s hospice, opened in 1988. There are now 44 children’s hospices across the United Kingdom and more are in planning.

As children’s hospices were built across the UK they developed distinctive and unique identities: some were community based projects, others offering residential respite, a few like Acorns Children's Hospice did both, and one or two grew out of an existing adult facility. Thus the rapid growth of hospices and paediatric palliative care across the UK was largely organic with local communities and resources responding to the local needs of their children and families.

Since opening the first hospice in Birmingham in 1988, the growth of Acorns has been significant; in 22 years it has become the largest children’s hospice provider both within the UK and worldwide. Acorns’ philosophy has been to provide a needs-led rather than resource-led service; listening to the views of children and families, to understand what they perceive their service needs to be.

In keeping with other services across the UK, Acorns provides an established and respected service for children who are life limited and life threatened, offering end-of-life care, emergency care, day care, and short break support to children through our three children’s hospices. We also provide a comprehensive community service offering psychosocial support to children, their families, and siblings. This will often include home support visits with each family having an allocated worker who offers pre- and post-bereavement support, advocacy, and access to a number of social and therapeutic groups.

It is recognised that by supporting family members in this way we are promoting a healthy family and reducing the need for crisis intervention. These holistic services are available 24 hours a day, 365 days each year. This includes all school holidays. Acorns provides accessible services for all. There is a proactive commitment to ensure that all families have equal access to support from the moment of initial referral, regardless of race, creed, or background. Where, for example, English is not the first language of the child or family this is addressed by the provision of interpreting and translation services. Referral is through the child’s consultant, local hospital contact, word of mouth, or self-referral.

In all we care for almost 600 children with life-limited conditions and 800 families, including those who are bereaved. This compares with 4,000 children across the country who are cared for by our sister hospices.

Acorns works in the local communities, for the local communities. We rely enormously on charitable contributions to sustain the work we do, with less than 20% of our funding currently being provided by the UK statutory sector. In addition to being reliant on charitable funds, we are also dependant on volunteering: more than 1,600 people volunteer for Acorns. They support us in a variety of areas: they
work in our network of 45 charity shops; they assist us with fundraising; and of course they make an enormous difference to the work of the hospices. They undertake cleaning, catering, gardening, and most importantly befriending our children.

As to the future of the movement, perhaps the greatest challenge concerns the increasing numbers of children who need the support of children’s hospices and the fact that, through medical intervention, many are growing into young adulthood. It is assessed that between 6,000 and 10,000 young people will require transition care and support in facilities other than those currently available within children’s hospices. Managing this transition in a world that only understands children’s services or adult services with nothing in between will be the focus of our efforts over the coming years. Once again, Helen House has been leading the way with the building of Douglas House in Oxford. Others, including Acorns, are following with their own approaches.

In the meantime, we continue to innovate and make advances in all areas of the care and support we provide. We are very excited about the prospects for the movement but concerned too that we will be able to continue to afford the services that will be needed. In this it is encouraging to note that the UK Coalition Government has just embarked on a review of the provision of paediatric palliative care in the country with a view to ensuring the best possible care and support in the years to come. Through this, and all our combined efforts, our vision may eventually be realised that all children with life-limited and life-threatening conditions and their families will receive the care and support they need.
CHILDREN’S HOSPICE OF ST. PETERSBURG, RUSSIA

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Russia’s first Children’s Hospice, in St. Petersburg, dedicated its newly remodeled building on June 1, 2010, International Children’s Day. Government and Russian Orthodox Church dignitaries, as well as clowns, characters from Russian fairy stories, parents, and children attended the festivities, culminating seven years of dreams, dedicated hard work, and local as well as international contributions of time, talent, and financial support – an inspiring example of Church-State collaboration.

The Russian Orthodox Church had granted permission and its support to Archpriest Alexander Tkachenko to start a one-bed pediatric hospice in 2003, based on his study and experience gained as a student in 1994, in the Clinical Pastoral Education Program at Swedish Medical Center, Seattle, Washington. Increasing interest in the project by St. Petersburg government officials led to giving an abandoned orphanage building to the Hospice in 2006. In 2009, the St. Petersburg City Budget allocated 10 million dollars for a remodel of the Hospice building and for the purchase of medical equipment and furnishings. The facility now contains state of the art medical equipment, cozy bedrooms instead of hospital wards, a games room, computer room, fireplace room, pool, and small chapel. In 2010, the hospice received budgeted municipal funding of one million dollars which covers three programs of pediatric hospice activity.

The first program includes an average in-patient stay of 21 days for 18 patients. During this time, the child’s medical, emotional, and intellectual needs are met – through palliative care, family and individual psychotherapy, and provision of music, art, and play therapy. Short term stays – for family respite – are the second funded program and can accommodate a further 20 children. The main goal of the hospice stays is to construct a cheerful, supportive, cozy, beautiful environment that takes the children’s minds away from their physical discomfort, while their bodies continue to receive palliative care. Finally, funding subsidizes 4,500 home visits by mobile medical teams.

The Hospice is in the midst of hiring additional medical personnel to support the current staff of 60 people. The hope is that the children will begin to move into the Hospice facility in July, once staffing is completed.

The Children’s Hospice program in St. Petersburg provides care for over 254 terminally ill or chronically disabled children, surpassing the European Union standard of 50 hospice patients per million population.
It serves not only metropolitan St. Petersburg but also the surrounding Leningrad Region (area about the size of Maine; population about 1.6 million). The Region is divided into seven sections. Children are served primarily through at-home care, by one of the seven visiting teams of physician, nurse, caseworker, and car.

Life is difficult for the families as there are no facilities for long-term-care patients such as children with cancer, genetic diseases, muscular dystrophy, chronic diseases that prevent mobility, or those permanently disabled from auto accidents. The vast majority of children receive palliative care and other assistance at their apartments by a team of doctor, nurse, and other specialists (physical therapists, psychotherapists, social workers, dialysis personnel, etc.) employed by the Hospice. The care is provided without cost to the family and is offered without regard to religious affiliation. Aside from pain management, treatment for bed sores, and diapers, the Hospice attempts to improve the lives of the children through other means as well – providing additional food when needed and physical equipment or even a computer for some of the children.

Several Seattle-area churches from various faith traditions have sent short-term mission teams whose members have had the rare opportunity to visit inside Russian homes. These visits have provided real insight into the many difficulties the Russian families face. In addition, the Sisters of Providence have continually supported the Children’s Hospice financially.

Father Alexander has also started a “Dreams Come True” program – similar to our “Make a Wish” Foundation. Children can escape from their beds for a boat trip on the canals of St. Petersburg, or visit a museum or a special entertainment by a theater troupe, even visits to the zoo, aquarium, or Disneyland-Paris. A group of approximately one hundred volunteers, who serve without any compensation, assist the Hospice operations.

Future activities of the Hospice? The media attention to the dedication of the Hospice building has brought out the public. A second hospice is under development, funded solely through private giving. And for the original Children’s Hospice? For the short-term, focus still continues on further upgrades to the building and finding financial and supplies support so that more children may be served, as regional hospitals are not in a position to extend pediatric palliative care.

Sources:
http://www.kidshospice.ru/
http://www.fpcbellevue.org/Departments/Missions/GlobalOutreach/globalministrypartners/Russia/childrenshospice.ashx?p=1713

Model of Children’s Hospice, St. Petersburg, Russia.
MODERN DEVELOPMENT OF PEDIATRIC PALLIATIVE CARE IN BELARUS

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Palliative care for children in the Republic of Belarus began in 1994 when a charitable organization, Belarusian Children's Hospice, was founded. For the first 10 years, palliative care for children was provided exclusively by public organizations, the largest of which was Belarusian Children’s Hospice serving residents of the capital city of Minsk, as well as the territory within a radius of 250 kilometers around Minsk. From those beginnings, and following the initiative of Belarusian Children’s Hospice, six other hospices in different regions of Belarus were created in Vitebsk, Mogilev, Pinsk, Slonim, and Gomel (2). These programs now all work independently in the status of public organizations. Unfortunately, only the Belarusian Children’s Hospice, which is in Minsk, has a medical license. Children's hospice programs in the other cities provide only social and psychological help.

Since 2008, the development of palliative care in Belarus has experienced many changes which are connected to an Order of the Ministry of Health № 1010 from October 29, 2008. This document regulated the provision of palliative care provided both by governmental and non-governmental organizations, and regulated the relationship between them. In accordance with Order № 1010, three groups of children were identified as needing palliative care:

- **Group 1.** Children with hard life-limiting diseases with poor prognosis (for example cancer in the terminal stage). Palliative care is required for a limited time.

- **Group 2.** Children with chronic, progressive, life-threatening diseases for which premature death is inevitable, but treatment and controlled observation can extend their lives for a long time. Palliative care is provided from the time of diagnosis for a long time to improve the quality of life of the child and family. This group includes children with disabilities with 4 stages of loss of health, in need of constant ventilation.

- **Group 3.** Children with life-threatening conditions with uncertain prognosis (e.g., children living with the consequences of a postponed severe traumatic brain injury, the state after correction of congenital malformations, etc.). Palliative care is to be offered for a limited time to stabilize the condition until a child is removed from custody or preservation of the grounds of disability is translated into Group 2, as well as to the development of a poor prognosis, requiring a translation into Group 1.

At the same time, it was decided that the children's palliative care should develop outpatient services for children for whom it is better to stay at home, except palliative care for orphaned children with serious illnesses who are in boarding institutions. To provide palliative care for children in this latter category, palliative departments at children's homes were opened. Thus, the positive point is that if the children's home previously could provide assistance only to children under 5 years old, now an orphan child in need of palliative care can receive such care throughout his or her life. At the same time, the state made attempts to establish palliative sections for children in hospitals, but it turned out that such services are not in much demand. There are at least two reasons for this: first, in Belarus there are not as many children who need palliative care (compared to adults), and, secondly, most parents do not want to stay in a hospital, and given the choice, always prefer home care.
Thus, today in Belarus there are 7 non-governmental children's hospice programs and palliative government services in children's homes. Outpatient palliative care is provided by the Belarusian Children's Hospice and clinics. The Belarusian Children's Hospice and the palliative departments at children's homes provide inpatient care to help at the end of life (“End of Life Care”). Further, in addition to the Belarusian Children's Hospice, there exists a social facility for chronically heavy children (“Respite Care”).

By 2009 in Belarus there were approximately 2.2 million children under 18 years old with about 26 thousand of these children with disabilities. According to our estimates, about 4,000 children in Belarus need prolonged palliative care. Thus, to assist those in need, a network of organizations that provide palliative care should be established. The start of creating such a network has already begun through an active civil society and the government of Belarus. For its expansion and coordination of activities at this time based on a non-governmental organization, the Belarusian Children's Hospice is creating a State Center for Pediatric Palliative Care. This center will be the organizational and methodological basis for the development of scientific services of palliative care, and will coordinate their efforts.
PEDIATRIC PALLIATIVE CARE IN GREECE

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Pediatric palliative care is slowly but steadily blooming in Greece! To understand its development, it is important to consider the social context in which health care services are provided to people who suffer and die from life-threatening conditions. Life-preservation remains a high priority for most health care professionals who assume a disease-centered approach in the care of the dying. Hospices do not exist, and home care services are available only for adults who are not necessarily dying. Palliative care is made available mostly through pain clinics, which remain symptom focused and lack an interdisciplinary approach to care.

Currently, the vast majority of children who suffer from life-limiting conditions remain hospitalized for long periods of time and spend the final days of their lives in a pediatric hospital. Until recently, there were no pediatric palliative care services available for them. Only a few hospital-based clinicians, working mostly in pediatric oncology, were sensitive to children’s and families’ psychosocial needs and tried to offer holistic care throughout the child’s illness trajectory. Comprehensive services at the end of life were lacking. Families who decided to leave the hospital and return home were left on their own to cope with the challenges of terminal care. The challenges associated with living and dying from a life-threatening illness were, nevertheless, highlighted by research studies and doctoral dissertations which explored the families’ experiences and needs.

Recently, three major projects placed pediatric palliative care into the world of pediatrics and advocated for its necessity and significance:

1. The development of the Greek Society for Paediatric Palliative Care, which was founded in 2009 with the purpose to promote the philosophy of pediatric palliative care and ensure that services and practices are provided according to standards developed by the society.

2. The 1st Panhellenic Symposium on Pediatric Palliative Care, with Greek and international experts, as well as parents, as speakers. It was held in May 2009 and was attended by clinicians, educators, health managers, and parents.

3. The development of the first and only Pediatric Palliative Home Care Service in Greece, by “Merimna,” a non-profit organization for the care of children and families facing illness and death.

"Merimna” (which means “care” in Greek) is the only organization promoting childhood bereavement support and pediatric palliative care in Greece over the past 15 years. What follows are brief descriptions of Merimna’s activities, along with perceived strengths and challenges in the development of pediatric palliative care in this country.

Founded in Greece in 1995 by an interdisciplinary team of nine health care providers and university professors, “Merimna” set as its primary goals:
The awareness-raising and sensitization of the Greek public on issues related to serious illness, death, dying, and bereavement; and

The specialized training of health care providers and educators in palliative care and bereavement support for children, adolescents, their families, and school communities.

The dissemination of information was further enhanced by Merimna’s Counseling Center. This Center has been providing over the past 12 years, free of charge, psychosocial support to children and families faced with illness and death. The Center also collaborates with schools and communities when traumatic losses and disasters occur. Children and families attending the Counseling Center benefit from individual and family counselling, while several participate in support groups for bereaved children and for bereaved parents.

In January 2010, Merimna developed the Pediatric Palliative Home Care Service. This Service is the first and only available in Greece, which seeks to cover a major gap in the care of this vulnerable and underserved population. The services offered include:

- Symptom relief for the sick child or adolescent
- Psychosocial and spiritual support for dying children and his or her family members, and
- Bereavement support for families, peers, and significant others

Members of the palliative care service include pediatricians, nurses, a social worker, and a psychologist, all with extensive and specialized training provided by the organization. To ensure continuity of care between hospital and home, they seek to establish Collaboration Agreements with three public Pediatric Hospitals and two Maternity Hospitals in the city of Athens. Such an agreement aims to facilitate the close and ongoing collaboration between Merimna’s pediatric palliative care team and hospital-based teams. It also provides opportunities to educate the hospital personnel on the principles of pediatric palliative care, and helps families make appropriate decisions at the end-of-life as they prepare for the child’s care at home. Each step in the development of this new Service is being evaluated to ascertain that the needs of children, adolescents, families, and professionals are being met in appropriate ways.

Three of the major strengths of this new Service, include:

1. Its belonging to a well-established and highly regarded organization - “Merimna” - that offers quality clinical services, provides specialized training, and conducts research in the field of childhood bereavement and pediatric palliative care.

2. The expertise, dedication, and commitment of professionals who provide pediatric palliative and bereavement services. Staff members have received in-depth training, are offered ongoing supervision, and participate in support meetings, which aim to enhance the quality of services and promote team resilience.

3. The adoption of an "open teamwork" approach which facilitates collaborations with other professionals, teams, hospitals, and schools for the benefit of children, families, and communities.

Through this approach, the Pediatric Palliative Home Care Service cultivates international collaborations for both the promotion of quality care for children with life-threatening conditions and their families in Greece and world-wide.
Three of the major **challenges** that the Service is currently faced with include:

1. The lack of knowledge and misconceptions about pediatric palliative care amongst health care professionals, which requires extensive education and training of students and professionals working in hospital settings;
2. The lack of governmental support of pediatric palliative care services which are not funded to this date; and
3. The Service’s limited funding resources, which are further restricted by the current economic crisis in Greece.

It is worth mentioning that funding resources rely exclusively on private individual and corporate donations and are secured by *The Friends of Merimna*, an association which organizes fund-raising activities in order to support Merimna’s programs.

Short term goals, include the expansion of services in order to respond to the increasing requests for home care for children and families; the education of Greek health professionals on the principles and benefits of pediatric palliative and home care; the training of volunteers to assist families in practical ways; the sensitization of the Greek society concerning seriously ill children’s right to have access to palliative home care services; and the advocacy for further development and funding of pediatric palliative care services in Greece.

Coordination of efforts between academics, clinicians, parents, and various national pediatric organizations and associations is imperative to ensure quality of care and set pediatric palliative care as a high priority in governmental health care policies and pursuits. It is the least a society can do to ensure a dignified life for children who will never grow into adulthood and for their families who will have to learn to live with such a loss.

**Links:**  
[www.merimna.org.gr](http://www.merimna.org.gr)  
[www.ppc.org.gr](http://www.ppc.org.gr)
PEDIATRIC PALLIATIVE CARE IN AFRICA IS NOT “SALVAGE WORK”

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In Africa, it is often said that palliative care is “salvage work” and not worth investing precious time and money into. But even a moment’s thought shows this to be nonsense. Our role as health care workers is primarily to relieve suffering and to protect life…There can be few things more important or valuable in life than to relieve the suffering of a child and to help the child live the life they have as fully as possible."

Dr. Justin Amery  
Children’s Palliative Care in Africa

Living in the Western World, we conceptually know there are a lot of adults and children dying in Africa, and that it is a serious problem. However, in the hectic pace of our lives and in caring for our children dying here, it’s easy to forget about it...to forget about “them,” the staggering number of children who die each year on the African continent. And what’s worse, so many of them are dying without adequate palliative care, as there are just not enough resources—financial, medicine, medical supplies, or healthcare professionals—to care for them all. The enormity of these pediatric deaths is incomprehensible, yet for the healthcare teams caring for these children in Africa, they make progress, caring for one child, one family at a time.

The Scope of the Pediatric Palliative Care Population in Africa

From Justin Amery’s book, Children’s Palliative Care in Africa, he cites the following facts and figures which help to dimensionalize the size of the population in Africa requiring pediatric palliative care:

- Nearly all child deaths occur in developing countries, with almost half of them in Africa²
- In Sub-Saharan Africa, 16% of children born alive die before their 5th birthday, nearly 9½ times higher than in the West³
- 14 countries in Africa have seen their child mortality rates increase in the last 10 years³
- HIV/AIDS accounts for up to 60% of pediatric deaths in Africa, where more than 400,000 children under 15 died of AIDS in 2003 alone⁴
- Children infected with HIV/AIDS in Uganda have a mortality rate of 54%⁵
- It is projected that by 2010, the number of children orphaned by AIDS will increase to more than 25 million in sub-Saharan Africa⁶
  - 42% of the world’s child deaths occur in Africa⁷
- Approximately 8 of 10 children dying in Africa die at home without seeing a health care provider⁸

That last statistic is sobering: 8 of 10 dying African children do not receive care from a health care provider while dying. The call to action is now and many in Africa are trying to respond. Through many individual and organizational efforts, a foundation for better care is being laid, where hopefully fewer children will die, and for those who will die, they can do so with adequate pediatric palliative care, or minimally, with at least some type of pain and symptom management.
The Barriers to Better/Any Pediatric Palliative Care in Africa

The barriers to serving this very large population of dying children in Africa are the same, yet different, in many ways from the challenges pediatric palliative and hospice care professionals face in the West. Similarities include:

- Families of dying children want their children to live…to be given every last chance at survival, and when that’s not possible, to be kept comfortable and pain-free through the dying process
- Pediatric palliative care professionals used to treating an adult population feel they lack the confidence and the skill set to provide palliative care to children (and therefore, may avoid treating them, to the detriment of the children)
- The emotional toll of caring for seriously-ill/dying children often leads to burnout and a need to step out of pediatric palliative care for self-care purposes
- Serving diverse cultures with a wide range of psychosocial issues and cultural beliefs, many of which positively (or negatively) impact the families availing themselves of care for their sick/dying child

In contrast, Justin Amery (2009) cites several barriers pediatric palliative care professionals face in Africa that may be unique to them, and the populations they serve, which include:

- The number of children who die is just infinitesimally larger in Africa than in the West
- HIV/AIDS kills so many more children in Africa than the developing world; additionally, the children with HIV/AIDS may be stigmatized or the parents/the mother may feel guilty for passing the virus to her child, both of which may result in a failure to receive health care services for the child
- There aren’t enough healthcare professionals to serve this large pediatric population, and those that do the work, often work in isolation without the benefit of partnering with colleagues to help carry the load
- The continent is so large, and the patients, so many in so many pockets around the different countries, often far from hospitals, health care centers, and home health care professionals
- Physical and human resources are so much more limited; access to medicines that are prevalent in the States may not even be available in parts of Africa and if they require refrigeration, there may not be any; even transportation to the children’s homes is sometimes impossible
- Many African countries do not have morphine available for pain management, and where it is, it is seldom prescribed adequately by the healthcare professionals caring for the children
- Due to lack of diagnostic tools/equipment and the lack of availability of medicines for chemotherapy, for example, curative treatments are usually not an option for many of the sick/dying African children
- Children may not show signs until late in the disease due to a lack of knowledge about the disease or the inability to afford access to healthcare

What’s Being Done in Pediatric Palliative Care in Africa/South Africa

There is much being done to begin to lay the framework for addressing more widespread and improved pediatric palliative care for the children of Africa and South Africa. Many of these activities are seemingly “housed” under the International Children’s Palliative Care Network (ICPCN), the Hospice Palliative Care Association of South Africa (HPCA), the African Palliative Care Association (APCA), and the Foundation for Hospices in Sub-Saharan Africa (FHSSHA) organizations, among others.
In particular, these African pediatric palliative care efforts include, but are not limited to, the following:

- An International Children’s Palliative Care Network Charter of Rights for life-limited and life-threatened children has been written to outline a proposed model for pediatric palliative care for international use, including for African children. (Editor’s note: Information about ICPCN and a copy of its Charter of Rights were published in Issue #14 [February, 2009] of this newsletter, which can be retrieved from www.nhpco.org/pediatrics.)

- Palliative care partnerships are being developed between US Hospices through FHSSA, some with palliative/hospice programs in Africa/South Africa that serve children.

- A Three Country Beacon Project has been initiated to start pediatric palliative care programs in Tanzania, Uganda, and South Africa, by building onto already existing organizations. The project involves a six-month, multi-disciplinary educational tract with two weeks of face-to-face teaching, clinical placements, competency evaluations, and a practical skill assessment.

- Funding has been received to increase access to pediatric palliative care in Malawi.

- An organization called Human Rights Watch has taken up the cause of improved palliative care for children, with Kenya identified as their initial focus. They just recently published a paper outlining some of their findings entitled: *Kenya. Needless Pain. Government Failure to Provide Palliative Care for Children in Kenya*, which is available for download via the following link: [http://www.hrw.org/sites/default/files/reports/kenya091webwcover.pdf](http://www.hrw.org/sites/default/files/reports/kenya091webwcover.pdf)

- The International Children’s Palliative Care Network has been involved in the following pediatric palliative care initiatives in Africa:
  - Development of a Guide to Children’s Hospice & Palliative Care Partnerships in the hopes of encouraging more partnerships between ICPCN members and pediatric palliative care professionals and programs around the globe. The guide can be downloaded from: [www.icpcn.org.uk](http://www.icpcn.org.uk) and then follow the link entitled “ICPCN Partnership Initiative”
  - Compilation of an ICPCN Fact Book on Children’s Palliative Care in South Africa which is close to publication

- Members of the HPCA, Joan Marston, Maraliza Robbertze, and Sue Boucher, have developed A Toolkit for Children’s Palliative Care in Africa

- The handbook, *Children’s Palliative Care in Africa*, has been written on the topic of pediatric palliative care in Africa, in particular. The handbook is downloadable from the web ([www.icpcn.org.uk](http://www.icpcn.org.uk)) or it may be purchased in hard copy from [www.hospicepalliativeareasa.co.za](http://www.hospicepalliativeareasa.co.za)

- A lack of peri-natal palliative care/hospice education and programs has been identified as one area (among many) that needs development, as there are many perinatal deaths in Africa/South Africa, and the support is limited to non-existent for the families

**Summary**

In the forward to his *Children’s Palliative Care in Africa* book, Justin Amery comments that because of all the barriers that exist to pediatric palliative care in Africa, “palliation and symptom relief are the only realistic option for most African children with advanced cancer and AIDS. This is the situation in most Sub-Saharan African countries.” So in the end, the most that can be hoped for today for these dying children is palliation of their symptoms and control of their pain. However, even this is not an easy task due to the lack of funds, lack of pain meds, lack of skilled practitioners to administer the meds, and a general lack of education on pediatric palliative care and pain and symptom management. Amery, Rose, Holmes, Nguyen, and Byarugaba conducted a study to evaluate a children’s palliative care service in resource-poor sub-Saharan Africa, with the results indicating that with the development of such a program, the benefits were many---increases in referrals, more children under professional care, more
and better morphine and chemo meds dissemination, and more compliance, for about $100/child. While some weaknesses and areas of improvement for the program were identified, the authors concluded that “affordable, nurse-led, volunteer-supported children’s palliative care services are both achievable and effective in sub-Saharan Africa.”

Much work is yet to be done, but the world is shining its light on these dying children in Africa and their plight, and efforts are underway. Elton John, in his preface to Justin Amery’s book on PPC in Africa writes, “…I applaud the publication of this book, which sets out with understanding and tenderness, the specific palliative care needs of children. It can support thousands of health workers to better care for children for whom there is no immediate cure; can give them pride and clarity in their role and can make life better for millions of children around the world.”

While Elton John applauds the publication of this book, I also applaud those healthcare professionals and volunteers in Africa/South Africa providing care for these children. It would be easy to leave and get out from under the weight of caring for and witnessing so many children dying in the direst of circumstances, but they don’t. They stay, and they do incredible work with very limited resources. It’s apparent that this is not “salvage work” for them. Let us support them in their work through more collaborative efforts, sharing of knowledge and skills, and sharing of our resources—financial and medical.

Author's Note: Ann Fitzsimons and Beth Seyda of Compassionate Passages, Inc., have made two trips to South Africa in the last year to work collaboratively with pediatric palliative care professionals in the developmental stages of their PPC programs for the children of South Africa. They are scheduled to return again in December to further help these PPC professionals move these patient-and-family-centered programs forward for the benefit of the large perinatal and pediatric populations they currently serve.

References:

3. UN ‘Millennium Development Goals Indicators Database’ (2007)
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HOSPICE ASSOCIATION OF THE WITWATERSRAND
PAEDIATRIC PALLIATIVE CARE PROGRAM

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Hospice Association of the Witwatersrand has been providing Palliative care to patients in their homes and in the Hospice In-patient Units in the Soweto and Greater Johannesburg areas for over two decades. In April 2007, Hospice Association of the Witwatersrand opened their first dedicated intensive unit for in-patient paediatric palliative care; Soweto Hospice, which is situated in Diepkloof, Soweto. This unit aims to provide holistic palliative care services for children and their families in need.

Our comprehensive Palliative care service model consists of a Paediatric Inpatient unit, Paediatric Community Home-based care, and an early childhood development centre for affected and infected children of our HIV patients. We also act as a step-down unit for our networking partner, Big Shoes Foundation, who provide Hospital-based Paediatric Palliative care services in our local government hospitals, namely Charlotte Maxeke Johannesburg Academic Hospital, Rahima Moosa Hospital, and Chris Hani Baragwanath Hospital.

Soweto Hospice receives patients from all over the region, as these patients are often accessing specialist care services from our tertiary and quaternary academic hospitals in Johannesburg, from where they may be referred to Hospice for Palliative care and in-patient symptom management. Our Hospice care is not only free to those who cannot afford our service, but also accommodates and cares for our local neighbours and children of foreigners needing our Palliative care services. Patients are also referred from the community and hospitals, local clinics, and other partnering organisations to admit children with palliative care needs into our home-based care program and unit as needed.

Our unit is named Kwa-Kgomotso, which is translated as “place of comfort.” We aim to provide comfort and loving care to each child that is admitted in our unit or seen in our home-based care program. “No end to Caring” is Hospice’s motto, and we do just that. Our 9-bed inpatient unit caters for children with life-threatening, life-limiting, and non-curable conditions, where interventions are done in a holistic manner meeting medical, psychosocial, cultural, and spiritual needs. We also realise that children will be children, and when they are starting to feel better they have a need to be developed and stimulated. Thus within the unit we also offer our children play activities, craft activities, story time, TV games, etc. We also have a playground outside with various play equipment for the children to enjoy. Our social services include helping and advocating to find resources, school placements, and stimulation programs for our patients to access once they go back into their communities.
Our care is also extended to caregivers of the children to ensure they have strong coping skills and are well educated in their children’s conditions. Drug compliance, education, and monitoring are very important, as are symptom identification, nutritional education, and social supports. We also have a food garden at our Hospice that helps both our adult and paediatric families with fresh vegetables to improve their household needs. Family support is also very important and we encourage siblings to visit, as well as for caregivers to stay with their children during their admissions as far as possible. A parent that is fully involved in the healing process of their child, and is empowered in their care, will be a much more competent carer when discharged back home into the community.

We encounter a variety of childhood illnesses and conditions; a great majority of our patients are HIV positive and may be admitted with sequelae of opportunistic infections. We also service our oncology patients admitted for control of distressing symptoms, particularly pain, as well as for terminal care. Children may also be admitted for congenital and genetic conditions that are progressive and in need for effective end-of-life care planning. Admissions for nutritional rehabilitation, antiretroviral therapy induction, and weaning of feeding tubes or oxygen, as well as respite care are also offered in our unit. Advocacy is also done with regards to palliative care procedures and treatment needed to control chronic symptoms for our patients.

Admission stays are generally between two and four weeks. Paediatric patients often stay longer than adult patients as they have more complex social needs that require intensive interventions to secure their physical and social environment before they can be discharged back to the community. Our home-based care nurses and community care workers also ensure that our patients and their families are coping and are well supported at home.

Since Soweto Hospice is a donor-funded organisation, we rely on our local hospitals and clinics to provide ongoing specialist care and allied professional care such as speech therapy, occupational therapy, physiotherapy, and dietetics. Hospice Soweto also offers bereavement support, and through our networking partners our bereaved families are able to follow a six-week program and join a support group.

Our program exists to relieve and care for patients that are struggling in their time of need. We try our best to provide and improve the individual child’s quality of life and not only quantity of life. For without quality in life, what would be a life worth living? A recent 12-year-old patient suffering from HIV complications put it simply, “I want to grow up until I die.”

A woman with her grandson who are served by the Hospice Association of the Witwatersrand.
NOW MORE THAN EVER: THE IMPORTANCE OF PEDIATRIC PALLIATIVE CARE IN THE FACE OF A MAJOR EARTHQUAKE

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The goal of this article is to raise awareness on the need for Pediatric Palliative Care in the face of major disasters such as earthquakes. The article highlights how palliative care needs are often "forgotten" in emergency responses. The author writes from personal experience, after spending 36 days working on Public Health in Internally Displaced People’s Camps (IDPs) in the aftermath of Haiti’s devastating earthquake, January 2010.

In the aftermath of the January 12th, 2010 earthquake in Haiti, that devastated the capital, Port-au-Prince and other densely populated areas, children were badly affected. They were wounded, disabled, orphaned, or separated from their families and they are still psychologically traumatized having seen friends and relatives killed, injured, and buried under collapsed buildings. The crisis in Haiti was a child’s emergency as nearly 40% of Haiti’s population are children under the age of 14.

Before the earthquake, UNICEF stated that Haiti had the highest rates of infant, under-five, and maternal mortality in the Western Hemisphere. Diarrhoea, respiratory infections, malaria, tuberculosis, and HIV/AIDS are the leading causes of death. In addition, Haiti is the poorest nation in the Western Hemisphere with some shocking statistics (all before January 12th, 2010):

- Some 60 per cent of people, primarily in rural areas, lack access to basic healthcare services.
- Numerous schools and hospitals have closed because teachers, social workers, and health providers could not go to work for fear of violence.
- It is estimated that about 5.6 per cent of people aged 15-49 years old in Haiti are living with HIV/AIDS. This includes about 19,000 children. Antiretroviral drugs are extremely scarce.
- As many as 2,000 children a year are trafficked to the Dominican Republic, often with their parents’ support.
- Only a little over half of primary school-age children are enrolled in school; less than 2 per cent of children finish secondary school.
- Approximately 1,000 children are working as messengers, spies, and even soldiers for armed gangs in Port Au Prince (http://www.unicef.org/infobycountry/haiti.html).

These issues remain the same and in the wake of the earthquake thousands of children have lost their schools, their friends, their homes, and their families. UNICEF and other UN agencies, the Haitian Government, and International NGOs continue to work hard to ensure that children are protected and their needs are met. But what of children with special needs? Children with life-threatening illnesses, and children in need of palliative care. What happens to these children in the wake of a natural disaster? There is little evidence to suggest that this question is ever considered or asked? (Cunningham, C, Fowler-Kerry, S, 2010)

The number of children who have been orphaned, injured, and permanently maimed during the earthquake continues to be a major task for UNICEF, Save the Children, and other agencies involved in child protection and care. According to a recent BBC Panorama program (http://news.bbc.co.uk/panorama/hi/front_page/newsid_8798000/8798302.stm), UNICEF have registered 2,000 displaced children and fewer than 300 have been reunited with a parent or relative: “authorities are
still struggling to cope with thousands of children orphaned or abandoned by their parents [...]”. This poses a significant problem when a child is sick, for example suffering from HIV/AIDS. Who is there to meet their basic needs, how do they survive, and can one talk of palliative care for such children when survival to live on a daily basis is a challenge?

Apart from being orphaned, many children suffered severe injuries and according to Handicap International, there are between 2,000-4,000 amputees following the earthquake (http://www.handicap-international.org.uk) many of whom are children (estimated to be 1,000 or more); post-operative rehabilitation is still being carried out by professional teams and the fitting of artificial limbs continues. But the situation in Haiti is enormous and the rehabilitation needs massive. Trauma counselling for children as part of rehabilitation has not, for the most part, been addressed.

Notwithstanding the great need for rehabilitation, there is also a tremendous need for Palliative Care. But the question remains, how does one provide palliative care in a setting where the infrastructure for basic healthcare has collapsed? What of the psychosocial needs of children who are sick, injured, and orphaned? How are these needs met in the absence of a palliative care service or program?

The answer lies in the numerous community-based and non-governmental organizations that provide services to orphans and vulnerable children (OVCs), organizations such as Catholic Relief Services, Save the Children, Concern International, to name but a few. These organisations provide vital safety nets to the vulnerable children of Haiti. They ensure an improved quality of life especially for children with life-threatening illnesses. Therefore, perhaps without realising it, they provide palliative care to these children, given that their services provide social, physical, psychological, and spiritual support to improve the quality of life of the children in their care. This care also includes ensuring healthcare for sick children with HIV/AIDS, TB, cancer, and other life-threatening illnesses. The author can confirm this based on first-hand, eye-witnessed situations while in Haiti and from the numerous informal interviews and discussions that took place with community-based groups within the internally displaced camps.

Holy Angels Hospice & Orphanage is, to date, the only known Children’s Hospice in Haiti. The children there are severely handicapped suffering from spina-bifida, hydrocephalus, and other neurological disorders. In the aftermath of the earthquake, these children became even more vulnerable as their building was cracked and unsafe, forcing them to sleep outside without adequate shelter. However, due to the rapid intervention of an international NGO, the International Children’s Palliative Care Network (ICPCN), help was provided to the Hospice – immediate needs for food and shelter were met by Catholic Relief Services-Haiti, and other more long-term materials and equipment were provided for by a USA-based palliative care organization.

Amery et al. 2009, state that in the developing world which includes Haiti, over 75% of children with cancer suffer uncontrolled pain. Added to this is the undertreated pain of children suffering from AIDS and that of children with severe injuries and amputations, we get a glimpse of the importance of palliative care that is needed now more than ever in Haiti.

Child and counselor at Holy Angels Hospice & Orphanage.
Now more than ever, palliative care is needed in Haiti and especially for children with life-threatening illnesses. It is still not high on the list of priorities for Haiti as there are too many other competing demands. Authorities are concerned with the provision of food, water, sanitation, education, and healthcare to the 1,354 spontaneous settlement sites (camps) in Port-au-Prince that currently host 391,700 households (UN OCHA Humanitarian Bulletin, 17 August 2010).

It is the author's hope that this article has raised the awareness of the need, now more than ever, for pediatric palliative care in Haiti. Following the Haiti earthquake, ICPCN (www.icpcn.org) hosted a Forum on the need for pediatric palliative care in disaster emergency responses, but there was little response. In light of the numerous natural disasters occurring across the world—Haiti, Pakistan, and others—ICPCN would like to re-launch this Forum on Pediatric Palliative Care in Disaster Responses. If the reader is interested, please email: info@icpcn.co.za. Together, the international community of pediatric palliative care practitioners can make a difference to the children across the world in need of palliative care.
THE PRO PALLIATIVE CARE UNIT FOUNDATION, SAN JOSE, COSTA RICA

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The Pro Palliative Care Unit Foundation is an organization without aims of profit, created in 1992, under Legal Certificate no. 3-006-127309.

Its main target is to support the Palliative Cares and Pain Control Clinic at the Children's National Hospital, in San Jose, Costa Rica, created in October of 1990 to take care of children who, by the character of their disease, healing medicine does not offer any alternative, but the access to palliative medicine, that will give them during six or less months of life, a suitable professional attention, financed by the Foundation in benefit of the quality of life and pain control in this phase of their disease.

From January 2000, the Foundation widened its coverage to children with chronic diseases, that is children and adolescents in limited life conditions. At the moment more than 200 patients per month are taken care of at the Palliative Cares Clinic at the Children's National Hospital, besides their parents, brothers, and sisters.

Every year an average of 150 infants with a terminal disease enter the Children's National Hospital "Carlos Sáenz Herrera." The Children's Hospital has a unique treatment rate in Latin America and makes possible the recovery of 70% of the children, but the other 30% cannot be saved. These children, who are meant to pass away in a time that goes from one to six months, have been admitted at the Palliative Cares and Pain Control Clinic at the Children's National Hospital.

The Pro Palliative Care Unit Foundation was born as an answer to the lack of budget and clear policies of the Costa Rican social security system towards palliative care. From the beginning of the palliative care program in October of 1990, we realized that the social security system was not designed to include at-home attention of children with a terminal disease. Therefore, medical equipment like oxygen tanks, were not lent to take home.

Hence, a child who wished to remain in his or her home until the end could not do it since at certain moment of the course of his or her disease, the child had to enter the hospital for attention to his or her needs. The drama was heartrending, the child cried or shouted in fear because the hospital and its personnel were viewed like aggressors in his or her final years. Literally, children hated the hospital. Then, why force a boy or girl to die in it, when the only thing they loved was to remain at home?

In addition to this reality, we also had to handle children living in the remote countryside, whose parents did not have resources to stay in the capital city, and whom somehow had left their other children with neighbors or relatives while they went through the trauma of seeing one of their children dying.

All this complicated and painful reality, led Lisbeth Quesada Tristán, MD, to bring up the necessity of creating an institution without profit aims, to voluntarily work harvesting funds to fill these children's necessities at home and at the hospital.

ChiPPS is a program of the National Hospice and Palliative Care Organization. Learn more at www.nhpco.org/pediatrics.
ChiPPS is a program of the National Hospice and Palliative Care Organization. Learn more at www.nhpco.org/pediatrics.

Also, another painful reality that motivated the creation of the Pro Palliative Care Unit Foundation was that new positions did not exist or were very difficult to create for professionals in this field. It is important to emphasize that Lisbeth Quesada Tristán, MD, is the first professional enabled in palliative care in Costa Rica. As is already known, palliative care is developed from an interdisciplinary team and with a Bio-Psycho-Social-Spiritual vision. Personnel were needed to be contracted in order to create this team, but the social security system had no resources to do so.

Because the Children's National Hospital is unique in Costa Rica, its coverage area is ALL the country, but unfortunately the hospital does not possess sufficient vehicles to organize programmed visits on demand. How to say to a mother that a visit to her dying son in her home was not possible because there was not a vehicle for the visit? For years, Quesada Tristán, MD, and her team, some of them working voluntarily, made home visits in Quesada Tristán's vehicle assuming all the expenses by herself. She also provided medicines that the social security did not have in its basic medicine chart and that were indispensable for suitable control of pain and symptoms.

Another very painful reality to confront was that most of these patients were, and are at the present time, of limited economical resources. Many parents lost their jobs or their income was not sufficient to give their child the necessary medical equipment to take care of him or her at home. Hundreds of times during home visits the reality found was that the family and even the same patient did not have anything to eat or it was not sufficient for all. Again, Quesada Tristán, MD, and her team assumed, sometimes with or without aid from others, the nutritional demands of that family. This so painful but so regular reality in our Latin American countries made the creation of the Foundation a priority.

Since the beginning, the Foundation was born with the philosophy of serving the others. Quesada Tristán, MD, was originally contracted for only 4 hours, but she worked full time for years, understanding that if it was not thus, it would be impossible to initiate and consolidate a pediatric palliative care program. She is the one who imprints the service character on the program. This service to others philosophy has extended to the present day in such way that, without the contribution of the Foundation, the Palliative Cares Clinic at the Children's National Hospital could not work. The Foundation has contributed and continues to contribute with:

Grief-Therapy Support Group for Parents who Lost a Son or Daughter

This self-help and support group was created on October 22, 1990, as an answer to the hundreds and hundreds of parents whose children had died and did not know where to attend to elaborate a normal grief process. Initially and for years directed by Quesada Tristán, MD, the group still exists with a weekly meeting, every Monday from 6:00 to 8:00 pm, since it is impossible for parents to attend during working hours. This service was and continues to be free.

Construction of the Infrastructure within the Children's National Hospital

Initially the Hospital did not count on a place to lodge this new program, so after the "Great Day of 1994, The Children We Cannot Forget," a fund raising telethon organized by Quesada Tristán, MD, in 1994, the goal of 15 million colones (around US $35,000) was reached, making possible the construction of an office within the facilities of the Children's National Hospital, which cost ascended to 3 million colones (US $7,000 approx.). With the rest of the funds, they managed to buy a vehicle for the patient's home visits.

Professionals Hiring
Now 10 professionals are paid by the social security. The rest of the personnel who work as part of the hospital's personnel—6 professionals, a secretary, and an ambulance driver—are paid by the Foundation.

**Medicines Purchase**

During many years the Foundation bought Methadone, equipping the Hospital's Pharmacy with this strong opioid to control children's pain. The Foundation was also in charge of buying other medicines like anti-inflammatory non-steroids that the basic institution's chart did not have. This policy still remains.

**Medical Equipment Purchase**

The Foundation created a bank of medical equipment that includes: hospital beds, water and air cushions, oxygen vacuum cleaners, bidets, concentrators, oxygen tanks, oxymeters, a sterilizer, and an ambulance, among other things, that are lent to the families and their child ABSOLUTELY FREE, so that parents can take care of the child in their own home. Also, on some occasions, aid for special eatable purchases (bottoms) is given for this special form of feeding. If the Foundation does not have the specific medical equipment, then it is rented without any cost for the families.

**Food Purchase**

Since 98% of our children are of limited economic resources, the Foundation created a sponsor system. After a home visit, the team decides which are the candidates for this type of aid. Month to month, hundreds of bags of basic food items for the families and needy patients are dispatched. This includes the patient's whims.

**Programmed Visits**

The Foundation contributes with the vehicles, the driver, gasoline, lodging and meal expenses of the whole team that visit the patient in the countryside. We try to establish routes so that the greatest number of possible patients can be visited during each trip.

**Program "To Fulfill a Dream"**

Since the beginning, we understood how important was the birthday celebration to our patients, a trip, a doll, or a toy. We have organized a group of volunteers who, jointly with the interdisciplinary Clinic's team, are in charge to fulfill a dream to our patients. The hoarded satisfaction is like solid gold.

**Special Feeding Purchase**

Like Ensure and Pediasure, as well as disposable diapers in special cases.

**Maintenance of Saint Gabriel Shelter**

San Gabriel Shelter is an organized and efficient attention option for children and adolescents that is not their house nor the hospital. Children come to be evaluated, observed, and medicated, so that simple medical procedures are made as medication adjustment, and mainly, to have a good time as far as their possibilities allow them.
Customized Bio-Psycho-Social-Spiritual attention is offered for the patients, their parents, and brothers and sisters who need it. The shelter has a playroom, a sensorial stimulation room, a hydrotherapy bath, beds, and individualized attention by our interdisciplinary team, plus the volunteer team, who take care of the children and program for them activities according to their possibilities.

The group of volunteers is trained and supervised by the interdisciplinary team. Such qualification and supervision takes place on Friday afternoons.

Also individual group therapy for the patient's parents, brothers, and sisters who require it is offered. The patients and their family's meals are the shelter's responsibility, since all these are absolutely free services.

There are also programmed activities for parents, as well as for the patients, which include massages, music therapy, art therapy, aromatherapy, and hydrotherapy. Furthermore, we count on the voluntary collaboration of a retired psychiatrist. An aerobics program is offered to parents, as well as haircuts, pedicure, manicure, and massages, all this oriented to offer a breathing, resting, and relaxation space to prevent the family giving up.

The palliative care team at Children's National Hospital, San Jose, Costa Rica.
RIGHTS OF A CHILD WITH A TERMINAL ILLNESS

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I have the right to be perceived as a person with rights and not property of my parents, medical doctors, and society.

I have the right to cry.

I have the right of not being alone.

I have the right to create fantasies.

I have the right to play, because even though I am dying, I am still a child.

I have the right to behave like a teenager.

I have the right to have pain control from the day I am born.

I have the right to the truth regarding my condition. My questions should be answered with honesty and truth.

I have the right to have my needs taken care of in an integral way.

I have the right to a dignified death, surrounded by my loved ones and my special toys and objects.

I have the right to die at home and not in a hospital if I choose to.

I have the right to feel and express my fears.

I have the right to receive help for me and my parents in dealing with my death.

I have the right to feel anger and frustration because of my illness.

I have the right to object to receiving treatment when there is no cure for my illness, but quality of life.

I have the right to palliative care if I so desire.

I have the right to be sedated at the time of death if I so desire.

I have the right not to experience pain when diagnostic processes or treatments are being carried out.

I have the right that my parents understand that even though I love them very much, I will be born to a new life.
HEALING WITH A HEART–CONNECTION

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The Tseltal Maya of Chiapas, Mexico, say that when we are healthy and happy, “our heart is at home.”

Chiapas is the southern-most state in Mexico. It is also the poorest: almost 80% of the population lives in poverty. The vast majority of the poor are indigenous. CONEVAL 2009.\(^1\) Out of a population of a little over 111 million people, 43.9 lack access to basic health care. CONEVAL 2009. A report issued by the United Nations on January 14, 2010, states that life expectancy among indigenous people is on average twenty years less than that of non-indigenous.

Chiapas is home to four main Mayan populations, including the Tseltal Maya, who live in villages tucked into valleys, perched on mountains, and hidden in dense jungles in the northeastern part of the state. They have lived in the region for thousands of years. And despite the devastating impact of the Spanish Conquest and the subsequent encroachment of globalization, they continue to live much as their grandparents did.

The Tseltal Maya “cosmovision” places harmony at its center. Communities, families, and individuals are happy and healthy if they live in harmony with each other, the natural world, and the spiritual world. This concept of harmony extends to the Tseltal approach to healing. As one elder put it:

“The ladino doctor only cures symptoms; our healers cure the sickness because they harmonize what the body wants with what the heart desires.”\(^2\)

Traditional Tseltal healers employ medicinal herbs and roots available in the biologically rich environment of Chiapas, but they never see alleviation of symptoms through medicine as the only way to achieve health. Rather, Tseltal healers attend to the psychological and spiritual condition of their patients, “continually encouraging [or animating] the sick, assuring him that he is going to heal, not just by the power of herbs, but with the power of [the Spirit].”\(^3\)

For the Tseltal Maya, “Everything has a heart.” Not simply people, but all living plants and animals and even the rocks in the mountains, the water in the river, and the smoke from the hearth. And because everyone and everything has a heart, “we need to visit with them, talk with them, and wait to see if they speak to us.”\(^4\)

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\(^1\) The National Council for Evaluation of Social Development Policy (CONEVAL) is coordinated by Mexico’s Department of Social Development. It is responsible for measuring, evaluating, and monitoring the impact of all federal social assistance programs. Each year, it evaluates 170 federal programs with an average reach of 40 million people.

\(^2\) Maurer Ávalos, Eugenio, Diplomado en Lengua y Cultura Tseltal y Lengua y Cultura Nacional, p. 76, © 2006, Coordinación General de Educación Intercultural y Bilingüe.

\(^3\) Ibid.

\(^4\) Ali Modad Aguilar, Felipe, SJ, Engrandecer el corazón de la comunidad, pp. 40-41, © 1999, Centro de Reflección Teológica, AC.
This idea that everything has a heart extends to the human body as well. For example, when a Tseltal Maya healer approaches a patient suffering from fever, he asks the God (who is both Father and Mother Spirit) and the saints to grant 13 graces (the Mayan number symbolizing completion) to cool the various parts of the patient's body. The healer speaks to the patient's body:

"May your vein grow cooler! May your body grow cooler! I ask that you [Spirit] give me your cold feet, your cold hands, your cold heart...to make this body feverless! Don't go to sleep blessed vein! Don't sleep blessed body! Wake up blessed vein! Wake up, blessed body!" 5

Tseltal Maya patients suffering incurable diseases, including cancer, have few treatment options. Most are too poor to access even the minimal health care resources available in the region. Those who can, must travel to one of the small rural hospitals—often hours or even days away from their villages—where they hopefully receive pain medications to ease their suffering. The vast majority, however, stay in their villages, where traditional healers manage their physical pain with medicinal herbs, while they attend to their emotional states by "animating" their hearts. The healer convenes members of the patient's family and community. They gather around the patient, lay hands on her, whisper words of encouragement and hope, and pray at her bedside.

Over the years, many of us have traveled to Chiapas from the Seattle area and witnessed firsthand the strength of Tseltal Maya as they work together to build more just, peaceful, and healthy communities. Out of our desire to improve the lives of the Tseltal Maya in Chiapas, we established One Equal Heart Foundation, a nonprofit organization dedicated to supporting locally-led social change development in the region by funding programs that emerge from the wisdom and experience of communities and target the root causes of poverty, injustice, and environmental degradation.6

One of the programs OEH funds support is the Child Nutrition and Community Health Program, which provides materials, training, and ongoing assessment for volunteer health promoters and healers who work with families to improve nutrition and health of their communities. Currently, the staff and volunteers of the program are focused on teaching families how to improve their nutritional health by utilizing the land around their homes to grow vegetables and fruits; incorporate composting latrines to prevent contamination of ground water and rivers; and install LORENA stoves to channel smoke from cooking fires out of the house and thereby reduce respiratory illnesses. In addition, volunteer health promoters are growing medicinal plants and herbs in "living pharmacies," learning how to administer these traditional remedies to alleviate suffering, cure common illnesses, and treat wounds. Essential to the work of the Child Nutrition and Community Health Program is engaging community elders to share their knowledge and pass on their experience with traditional methods to cure illnesses and administer palliative care to younger volunteers.

The Tseltal Maya's belief that "everything has a heart" invites those of us in the Western world to consider another approach to health and healing, to see the heart-connection that links us as a call to be responsible to care for one another because we are part of one great community. In treating patients at the end of their lives or with chronic conditions, caregivers need to attend to the entire patient, both their

5 Ibid, at 80-82.

6 Programs in Chiapas operate in partnership with volunteers from the communities and are administered by the Jesuit Mission of Bachajón and the nonprofit Center for Indigenous Rights (CEDIAC).
physical and emotional/spiritual condition, and recognize that “health” is not simply the absence of sickness, but the experience of feeling “our heart is at home.”

To find out more, please visit us at: www.oneequalheart.org, or contact us at One Equal Heart Foundation, PO Box 12125, Seattle, WA 98102.
EDUCATION: THE KEY TO PROVIDING EXCELLENT PEDIATRIC PALLIATIVE CARE INTERNATIONALLY

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Healthcare providers cannot practice what they do not know. For many, once they obtain the education needed to provide excellent palliative care, “the system,” national standards, and regulations prohibit the care needed. This is frequently seen in many parts of the developing world, as it is in the United States. There are misunderstandings about opioids, lack of funds to provide technology for diagnosing and treating, and cultural misconceptions about illness and suffering. Children, the most vulnerable in any society, carry a tremendous burden of pain and suffering, due to healthcare providers lacking education and an inability to provide necessary medications and treatments.

Since 2001, the End-of-Life Nursing Education Consortium (ELNEC), a national education initiative to improve palliative care, has trained over 11,300 nurses and other healthcare professionals, representing all 50 US states, plus 65 international countries. The project provides undergraduate and graduate nursing faculty, continuing education (CE) providers, staff development educators, specialty nurses in pediatrics, oncology, critical care, and geriatrics, and other nurses with training in palliative care so they can teach this essential information to nursing students and practicing nurses. These trainers are sharing this new expertise in educational and clinical settings. ELNEC trainers are hosting professional development seminars for practicing nurses, incorporating ELNEC content into nursing curricula, hosting regional training sessions to expand ELNEC’s reach into rural and underserved communities, presenting ELNEC at national and international conferences, and improving the quality of nursing care in other innovative ways. Special attention is given to needs of children. Death rates continue to be high among children suffering from life-threatening illnesses in developing countries. Copies of the ELNEC-Pediatric Palliative Care CD-Rom are always provided to trainers doing international work. This curriculum stresses the importance of providing compassionate care to children and their families to prevent suffering and to promote assistance with bereavement needs in a culturally-sensitive manner. In addition, this curriculum addresses the importance of perinatal and neonatal palliative care.

To assist in meeting the tremendous need of educating nurses and other healthcare providers across the globe, ELNEC faculty and consultants developed the ELNEC-International curriculum in 2007, to be used specifically in developing countries. ELNEC’s primary aim is to educate nurses to improve end-of-life care, and while the initial efforts were focused in the United States, many ELNEC faculty and trainers have had opportunities to travel internationally and provide this education to nurses and other healthcare providers throughout the world. Many opportunities have been provided for trainers to use ELNEC globally. For example:
Children’s Project on Palliative/Hospice Services

- Provided two, 5-day ELNEC train-the-trainer courses to Eastern European nursing administrators and nursing faculty
- Offered an ELNEC train-the-trainer course in Tanzania with participants coming from other countries such as Rwanda, Kenya, Zanzibar, Malawi, and Zambia
- Presented an ELNEC train-the-trainer course in Nairobi, Kenya, to 49 nursing faculty and clinicians from across the country and provided in-services, using at least 1 ELNEC module, to over 700 nurses, physicians, social workers, psychologists, and chaplains in acute care facilities and hospices
- Partnered with the Hospice of San Miguel in Guantajuato, Mexico, to provide a 2-day training course for 325 nurses, physicians, social workers, nutritionists, thanatologists, and psychologists
- Supported ELNEC trainers from Seoul, Korea, in an effort to train over 340 nurses in excellent palliative care

The over-all goal in all of these efforts is to educate nurses and other healthcare professionals about excellent palliative care for children and adults. In addition, supporting their efforts to be change agents in countries where very little is known about providing compassionate end-of-life care, empowering them to work with their government to change laws that prohibit the use of opioids, and encouraging them to be leaders in promoting this care has been crucial.

Currently, ELNEC trainers and faculty have traveled to six of the seven continents, representing 65 countries. Many trainers have provided ELNEC educational courses, while others have gone as consultants to work with educators, health administrators, and community leaders to improve care of the dying in their countries. It is estimated that over 2,000 nurses and other healthcare providers have received ELNEC training internationally. Some are working on translating ELNEC into other languages and adapting it to increase the relevance to other cultures. For example, ELNEC has already been translated into Russian where nursing administrators and faculty are using the curriculum in Eastern Europe. ELNEC is also translated in Spanish (Core and Pediatric Palliative Care versions) and is being widely disseminated in Mexico, Central America, and parts of South America. Lastly, ELNEC-Japanese and ELNEC-Korean translations are being used throughout Asia. The ELNEC Project Team is currently working with a physician in Germany to translate ELNEC into German, to be used in medical/nursing school training, as well as with current practitioners throughout various countries in Europe.

The ELNEC project was initially funded by a major grant from The Robert Wood Johnson Foundation (RWJF). Additional funding has been received from the Open Society and National Cancer Institutes (NCI), the Aetna, Archstone, Oncology Nursing, and California HealthCare Foundations, and the Department of Veteran Affairs (VA). For further information about this project, go to: www.aacn.nche.edu/ELNEC
October 26, 1995 saw the opening of Canuck Place Children's Hospice in Vancouver, British Columbia. Canuck Place represented a bold step forward into the unknown, as it remained the only free-standing hospice for children in North America for the next 10 years until the opening of George Mark House in San Leandro, California.

At the time "CPCH" opened there were 6 free-standing hospices in the world, all of them in Britain; therefore much of the model of pediatric palliative care provision, processes, policies, and approaches needed to be developed in relative isolation. The impact of the development was felt in all sectors of the program: clinical care, support services, volunteer services, fund-raising, communications, and government relations.

In terms of core clinical service delivery, there were very few antecedents. Dr. Gerri Frager had established the first pediatric palliative care service in North America at the IWK Grace Health Centre in Halifax, Nova Scotia. Clinical guidelines, practice standards, educational objectives (or training for that matter) did not exist.

Phases in Hospice Development

In reflecting on the initiation, development, and growth of the CPCH we can divide into three phases, all now based on hindsight. Despite challenges and obstacles, the first five years of the hospice represented a period of consolidating the administration and programming of children's hospice/palliative care program. Clinical service was well-provided during that time, but in retrospect the major accomplishments of the hospice were operational continuity, achievement of early funding goals, development of business and program models, and fostering a stable Board and management team structure.

The second phase represents a time when we developed clinical excellence. Part of this was participation in the development of pan-Canadian Norms of Practice for Pediatric Palliative Care. These were developed by a group of PPC practitioners from across Canada. The group formed the core of what was later to become the Canadian Network of Palliative Care for Children (CNPCC), now a Network within the Canadian Hospice Palliative Care Association. Clinical excellence was also achieved with solidification of the hospice team, by taking advantage of opportunities for education, and by learning from our own increasing experience and embarking on a program of research to develop new knowledge. Solidifying our linkages with BC Children's Hospital – the provincial tertiary pediatric health center was also an important component of this phase. Establishment of a joint clinic – the Madison Clinic – at the hospital has provided a base for our inpatient consultation team, and a mechanism for us to connect to families in the often-familiar setting of the children's hospital.

The third phase is about extension of our services to other areas of this very large geographic area. From the start of the hospice we have provided service to children and families from British Columbia and the Yukon territory. The vast majority of service delivery required travel to the hospice in Vancouver – often a
flight is involved. We were able to address some of the distance issues using a toll-free number and videoconferencing for clinical care, but it did not entirely meet the need.

Our extension of services will involve several components – the building of a second hospice building in the community of Abbotsford, about 45 km east of Vancouver; a traveling consultation team with Nurses, Doctors and Counselors; and increased presence with education, support groups, and volunteers in communities on Vancouver Island and in the Interior of the province.

Service Delivery

Canuck Place has a clinical care program for children and their families living with life-limiting (also called life-threatening) illnesses, and a bereavement program for parents and siblings of a child who has died.

The Canuck Place clinical care program offers four types of admission to the hospice: respite and family support, pain and symptom management, transition to home, and end-of-life care. Additionally, outpatient clinical care at Madison clinic and inpatient consultation at BC Children's Hospice are provided.

Respite/Family Support admissions to the hospice include 24 hour care of children, on a temporary basis, to allow families time for rest and renewal. This includes nursing care, reassessment and medical management of symptoms, counseling, and therapeutic recreation services.

Pain and Symptom Management is provided when children are admitted for acute and unstable symptoms secondary to the child’s illness and/or side effects of treatments. Our current tracked response rate is 1 hour from the referral to consultation and <24 hours to admission when it is required. In addition to these urgent/emergency admissions we have found that 45% of our pre-booked Respite/Family Support admissions evolve into symptom management stays; during a Respite/Family Support stay the hospice team (Medicine, Nursing, and Counseling) often observe unaddressed or escalating symptoms.

The third admission category involves Transition to Home. When a child's needs change significantly during a hospitalization, home, community, and/or caregivers may not yet be ready to provide the necessary services or equipment. The parents as the primary caregivers may also require additional support and education. A short stay at the hospice can coordinate the transition to home.

End-of-life care or terminal care involves comprehensive services for both the children and family when the child’s death is expected to be imminent. We work closely with the hospital Intensive Care Units (Neonatal and Pediatric) around extubation and withdrawal of aggressive therapies. For some children we facilitate End-of-Life care along a continuum with Respite/Family Support, and Symptom Management as the terminal phase is highly unpredictable. Our goal, whenever possible, is to establish a single web of care across the home, hospital, and hospice settings regardless of the community in B.C. This enables the family to move between settings as their needs and energy change. A hallmark of this is careful and very active coordination of care amongst several teams – the Advanced Practice Nurses at the hospice are highly skilled at this, and it is where our Telehealth capabilities come to the fore.

The Bereavement program follows families whose child died on the hospice clinical care program. In addition, families who have experienced the loss of a child, but who were not part of the clinical care program, are able to access our bereavement services. The care is individualized and one-on-one counseling, support groups, and expressive therapies for children and teens are available. The Bereavement coordinator also oversees the annual Remembering Our Children event that brings families together.

Research and Education

ChiPPS is a program of the National Hospice and Palliative Care Organization. Learn more at www.nhpco.org/pediatrics.
Research and Education are the fourth pillar of the Hospice's Strategic Plan. By coordinating closely with the B.C. Child & Family Research Institute New Emerging Team "Transitions in Pediatric Palliative and End of Life Care," the Hospice is a core participant in an international, multi-disciplinary research program. There are numerous research activities in clinical care, biomedical investigations, psycho-social studies, and health services research.

Similarly CPCH engages in providing education at the local, national, and international level. Palliative Care Fellows (both adult and pediatric program) train at the Hospice. For Senior Residents in Pediatrics at the University of British Columbia, the Hospice is a required rotation, and 3rd year medical students attend our workshop each rotation. Canuck Place is also a primary site for the UBC inter-disciplinary course in Palliative Care.

**Canada-wide Developments**

In the last 4 years there has been significant growth in the field in Canada. Several of the major tertiary care pediatric hospitals now have fully staffed inpatient/community palliative teams, and it is considered a standard of care for this level of institution. Three communities, in addition to Vancouver, have developed children’s Hospices using different models ranging from free-standing to hospital-affiliated (Roger's House, Ottawa; LePhare (the Lighthouse), Montreal; Rotary-Flames House, Calgary.

In the next several years we anticipate further expansion of pediatric palliative care across the country with the addition of more hospital-based consultation teams and the opening of additional hospices in the larger communities.

**Conclusion**

We have been fortunate in the donor and government support we have had at Canuck Place over the last 15 years that has enabled us to undertake this great experiment in bringing specialized care to children and families who live with life-limiting illnesses. That support has not only allowed us to provide care to our community, but to help explore and establish models and processes of care that have helped influence the development of programs across the country. We hope to continue this care and innovation in opening our second children’s hospice in the Province of British Columbia in 2012 and finding innovative ways to extend our services into more communities as part of our next 15-year goal.
READER’S CORNER

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Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer

Background
Patients with metastatic non–small-cell lung cancer have a substantial symptom burden and may receive aggressive care at the end of life. We examined the effect of introducing palliative care early after diagnosis on patient-reported outcomes and end-of-life care among ambulatory patients with newly diagnosed disease.

Methods
We randomly assigned patients with newly diagnosed metastatic non–small-cell lung cancer to receive either early palliative care integrated with standard oncologic care or standard oncologic care alone. Quality of life and mood were assessed at baseline and at 12 weeks with the use of the Functional Assessment of Cancer Therapy–Lung (FACT-L) scale and the Hospital Anxiety and Depression Scale, respectively. The primary outcome was the change in the quality of life at 12 weeks. Data on end-of-life care were collected from electronic medical records.

Results
Of the 151 patients who underwent randomization, 27 died by 12 weeks and 107 (86% of the remaining patients) completed assessments. Patients assigned to early palliative care had a better quality of life than did patients assigned to standard care (mean score on the FACT-L scale [in which scores range from 0 to 136, with higher scores indicating better quality of life], 98.0 vs. 91.5; P = 0.03). In addition, fewer patients in the palliative care group than in the standard care group had depressive symptoms (16% vs. 38%, P = 0.01). Despite the fact that fewer patients in the early palliative care group received aggressive end-of-life care (33% vs. 54%, P = 0.05), median survival was longer among patients receiving early palliative care (11.6 months vs. 8.9 months, P = 0.02).

Conclusions
Among patients with metastatic non–small-cell lung cancer, early palliative care led to significant improvements in both quality of life and mood. As compared with patients receiving standard care, patients receiving early palliative care had less aggressive care at the end of life but longer survival. (Funded by an American Society of Clinical Oncology Career Development Award and philanthropic gifts; ClinicalTrials.gov number, NCT01038271.)

Who is the audience for this information? Judging by the numbers of articles in the NY Times, discussions on NPR and TV, and blog postings, this information has a very broad audience. While this is clearly about the benefits of early palliative care concurrent with standard cancer treatment in adults, all palliative care providers and administrators will be interested. As other data show that the hospice model...
of care is infrequently chosen by parents and/or providers, these data may be particularly pertinent in pediatrics.

**What is special about this article?** This article provides excellent data supporting the benefits in terms of quality of life of early palliative care. Interestingly, despite the fact that the adults receiving early palliative care had less aggressive care at end of life, the secondary outcome of survival was longer. In addition, patients receiving early palliative care more frequently had their preferences about end-of-life care documented facilitating treatment in compliance with patient wishes. What this study does not address is the potential benefits of a hospice model of care where, in general, disease oriented medical treatment is not continued.

**Where and how can I apply this information?** These data can be used to counter the argument that the palliative care team is just the death squad or that palliative care is only appropriate at end of life. The fact is that it is never too early to offer excellent palliative care in the course of a child with potential life-limiting illness or condition. These data further lend credence to the idea that there should not be a dichotomy between palliative care and disease directed care. Palliative care either integrated with disease directed medical care or as the main model of care is simply good quality care and should be the standard of care.
Items of Interest: In each issue of our ChiPPS e-newsletter, we offer additional items of interest.

1. **Pediatric Intensive at 2011 Clinical Team Conference.** NHPCO is accepting concurrent session proposals for the Pediatric Intensive that will be part of NHPCO's [2011 Clinical Team Conference](#), to be held in San Diego, California from October 6 - 8, 2011. The conference theme is "leading and innovating quality throughout the care continuum." Proposals for 60 minute presentations and 90 minute interactive sessions are invited; the deadline for submission is December 31, 2011. Poster sessions are also invited; the deadline for poster submissions is January 17, 2011. The [Call for Proposals](#) provides specific details about the conference theme and focus of the sessions being solicited. Please consider sharing your expertise at the 2011 Pediatric Intensive.

2. **NBCHPN Pediatric Registered Nurse Exam Available in March 2011.** The National Board for Certification of Hospice and Palliative Nurses has announced that the hospice and palliative pediatric registered nurse examination is available for the March 2011 testing window. The 2011 Candidate Handbook is available online and applications are accepted beginning December 1, 2010 for the pediatric registered nurse exam. For more information, visit the [NBCHPN website](#).

3. **Standards of Practice for Pediatric Palliative Care and Hospice Receive AAP Affirmation of Value.** As we have reported previously, NHPCO Standards of Practice for Pediatric Palliative Care and Hospice (Standards) have received the American Academy of Pediatrics Affirmation of Value. The Standards are a supplement to the NHPCO Standards of Practice for Hospice Programs and are designed to supplement the existing Standards and to set clinical and organizational precedents for hospice and palliative care programs providing care to infants, children, adolescents, young adults, and their families in the home, hospital, long-term care and respite setting. The Standards establish an important beginning to ensuring that children and their families receive high quality pediatric palliative care and hospice services. You can learn more about the Standards in the February 2009 NHPCO NewsLine article or by visiting the [NHPCO website](#).

   The Standards of Practice for Pediatric Palliative Care and Hospice are available in downloadable format, free-of-charge to NHPCO members and for a nominal price for all others. They can be downloaded from [NHPCO online](#).

4. **Subjects and Contributors for Future Issues of This Newsletter.** In past issues of this newsletter, we have addressed a wide range of subjects, including bereavement, sibling bereavement, self care, ill and dying teens, perinatal loss, neonatal loss, spirituality, unsung heroes in the circle of care, pain and symptom management for children with life-threatening illnesses and their families, families experiencing transitions associated with pediatric palliative care, complementary therapies, examples of programs illustrating the current status of pediatric palliative and hospice care in the United States, and memory building and legacy making in pediatric palliative and hospice care. (Please note that you can visit archived issues of this newsletter at [www.nhpc.org/pediatrics](http://www.nhpc.org/pediatrics).) For future issues, we are thinking about addressing subjects such as ethical issues and developmental considerations. If you know of good topics and/or contributors (including yourself) for any of these and/or other future issues of this newsletter, please do not be shy! Step right up and contact any of the following: Christy Torkildson at torkc@sbcglobal.net; Maureen Horgan at Maureen.Horgan@providence.org; or Chuck Corr at ccorr32@tampabay.rr.com. We will work with you!

*ChiPPS is a program of the National Hospice and Palliative Care Organization. Learn more at [www.nhpc.org/pediatrics](http://www.nhpc.org/pediatrics).*
5. **Reader’s Corner.** Our Reader’s Corner column provides brief summaries and bibliographical information about journal articles and other publications that are important and likely to be of widespread interest to individuals who are involved or interested in pediatric palliative care, but that may not be known to all readers of this newsletter. Contributions to the Reader’s Corner, like the one in this issue (see pages 39-40), include an abstract of the publication, a description of the audience for this information, comments on what is special about the publication, and suggestions as to where and how this information can be applied. We welcome suggestions for publications to include in our Reader’s Corner and/or summaries and comments on such articles following the model in this issue. Please send all such suggestions to Christy Torkildson at torkc@sbcglobal.net.

6. **Calendar of Events.** As a reminder, there is a calendar of pediatric educational opportunities on the ChiPPS section of the Web site, [www.nhpco.org/pediatrics](http://www.nhpco.org/pediatrics). ChiPPS is a program of the National Hospice and Palliative Care Organization. Learn more at [www.nhpco.org/pediatrics](http://www.nhpco.org/pediatrics). Please e-mail Christy Torkildson at torkc@sbcglobal.net to have your pediatric palliative care educational offering listed.

Please note that the opinions expressed by the contributors to this issue are their own and do not necessarily reflect the views of the editors of this newsletter, ChiPPS and its Communication Work Group, or NHPCO. We invite readers with differing points of view to submit comments or suggestions for possible publication in a future issue.

Thank you for taking time to read this issue and for any feedback that you can offer us. Providing pediatric palliative and hospice care to children, adolescents, and their family members has made great strides in recent years, even though it is certainly not always easy and still faces many challenges and obstacles. We wish you all the best in your good work. If you are not on our mailing list and received this newsletter from a friend or some other source, please send an email message to CHIPPS2@NHPCO.org requesting to be added to our mailing list. If you are a member of NHPCO, you can go to the Communications Preferences tab in your individual member record online and “opt-in” for communications from ChiPPS. Member Services will be happy to help you adjust your communications preferences; contact them at 800-646-6460. Visit the ChiPPS Web page at [www.nhpco.org/pediatrics](http://www.nhpco.org/pediatrics) for further materials and resources of interest.