Issue Topic: Memory Making and Legacy Building in Pediatric Palliative and Hospice Care

Welcome to the twentieth issue of the ChiPPS electronic newsletter. This issue of our e-newsletter offers a PDF collection of articles that are meant to illustrate the importance of memory making and legacy building in pediatric palliative and hospice care. Articles in this issue also describe a variety of ways in which memory making and legacy building can be implemented. This is, of course, merely a sampling of articles on this topic, but we believe their diversity and practicality can serve to inspire everyone involved in this type of care.

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 #20: Memory Making and Legacy Building in 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.)

The articles in this issue can conveniently be divided into 4 groups that appear here in the following order: (a) 4 articles by professional health care providers; (b) 4 articles by parents; (c) 3 articles describing photography programs at end of life; and (d) a Reader's Corner article.

Creating a Legacy: Do Items that Support Family Memories Really Make a Difference? p. 4
Lori A. Ives-Baine, RN, MN
In the keynote article for this issue, Lori describes the development of a legacy building program in the NICU at the Hospital for Sick Children in Toronto. She also gives numerous examples of ways to implement such a program and provides extensive references for those who would like to read more about this important subject.

Memory Making at the End of Life p. 10
Kelly Komatz, MD, MPH, FAAP
Kelly reinforces the previous article through her comments about a similar program in Jacksonville, Florida, with special emphasis on caring in community situations.

Legacy Building in Pediatric Palliative Care p. 11
Rebecca A. Simonitsch, MA, CCLS
Rebecca offers illustrated examples of how health care professionals can help families through attention to legacy building with children in end-of-life situations. Rebecca's examples include hand and footprints, scrapbooking, photography, and videography.

Contributions to Pediatric Palliative Care and End-of-Life Support from Child Life Specialists p. 14
Danielle Eaves, BS, CCLS, CTRS
Danielle extends the perspective of the previous article by drawing attention to some of the many ways child life specialists can contribute to memory making and legacy building in PPC.

The Decision Tree p. 16
Mark Nassutti
Mark writes candidly about his valiant efforts to bring a problem-solving matrix to bear on saving or at least extending the life of his 14-year-old son as the boy struggled with a brain tumor that ultimately took his life.

Notes Left Behind p. 20
Keith Desserich
Only after the death of their six-year-old daughter, Elena, did Keith and his wife discover that during the last months of her life Elena had very deliberately created and left behind hidden messages of love for them. Not all legacy building efforts are the work of adults.

The Legacy of Jarrett Mynear p. 22
Jennifer W. Mynear
For most of his life, Jarrett Mynear battled the cancer that eventually caused his death. Still, when he recalled how visits from volunteers with a cart of toys and trinkets had cheered him up during a stay in a Seattle hospital, Jarret took that experience and translated it into Jarrett's Joy Cart to brighten up the lives of hospitalized children who were lonely and afraid at Kentucky Children's Hospital.

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Our Daughter's Legacy
Michele Metcalf
After being diagnosed with a rare form of an aggressive liver cancer, Erin Metcalf struggled through many difficult challenges. Through it all, Erin's wish was to help other grieving children. One important contact came about when the Make-a-Wish Foundation enabled Erin to visit with the Seattle Mariners and meet, among others, Karen and Jamie Moyer. After her death, Erin's parents and The Moyer Foundation created Camp Erin in her memory, a program that serves bereaved children in multiple locations across the United States and Canada.

Now I Lay Me Down to Sleep
Tiffany Storrs
Tiffany describes the development of a program in which volunteer photographers provide no-cost remembrance portraits to families whose child will not come home from the hospital. The program has now grown to over 7,000 volunteers throughout the United States and 25 other countries serving nearly 10,000 families each year. Tiffany is explicit in identifying the many ways in which such photos are important to these families.

Everyone Has a Story
Karen Henrich
Karen offers a first-person perspective as a photographer who helped found Moment by Moment, a California network that now consists of some 200 professional photographers who offer cost-free photographs to families who have a child that has died.

Portraits of Love
Lori Sawyer
Lori's article tells about the work of a Seattle-based non-profit network of some 30 photographers who take photos of their gravely ill children and give them without charge to families. Recently, Soulumination has expanded its scope to include photos of parents who have a terminal illness to be given to their children who are under the age of 18.

Reader's Corner
Jody Chrastek, MSN, CHPN, and Donna Eull, RN, BSN, MA
Here is a brief description of the newly-published Just in Time Guide: A Primer for Pediatric Palliative Care at Home, a book that is designed to provide quick, useful, and practical information for adult hospice and palliative care nurses who are confronted with the challenge of caring for children at home.

Message from J. Donald Schumacher
NHPCO's president and CEO shares some thoughts about the continuum of care and the importance of pediatric palliative care as part of the continuum.

Items of Interest

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CREATING A LEGACY: DO ITEMS THAT SUPPORT FAMILY MEMORIES REALLY MAKE A DIFFERENCE?

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Mohammed, a critically ill newborn baby boy is dying and the nursing staff struggles to know what to do to help this family. What do we do??? In the NICU at the hospital where I work, the first thought is to help the family create memories—of a child they have only known for a short while. “Instead of a lifetime of memories, they must say hello and goodbye to their precious child in a matter of hours” (Patten, 2008).

The Palliative Care and Bereavement Program in the NICU at SickKids Hospital has been in place and growing for the past 22 years. Throughout those years, opportunities to help families create legacy have expanded from a single Polaroid photo and inked footprints to much more, supported by generous donations from bereaved families and community group.

How did the idea of legacy creation come into being in this NICU? More than 20 years ago, nurses recognized that they were caring for dying infants and their families and wanted to do better. Several staff received RTS Perinatal Grief Support training in its initial years, and took that learning to heart. Offerings included: measuring tapes, foot prints, locks of hair, photographs (Polaroid and a few 35 mm. photos of the baby on an over-bed warmer), and outfits that the baby could be dressed in and provision of basic information provided for families, which were considered our “standard of care.”

Since that time, we have enhanced what we offer to include: 3D plaster molds; painted hands and feet artwork; the opportunity to create rituals such as blessings (Anderson, 2001); naming; bathing; experiences of parenting; digital photography (sometimes up to 400 photos for a family burned onto a CD); special hand-made outfits for the infant and hand-knit blankets to wrap the baby in; embossed as well as inked hand and footprints; hand-calligraphied Certificates of Life (names, weight, EDC, length, parents’ names, DOB, DOD, hair and eye colour); videotape of parenting opportunities and rituals which are transferred onto DVD; memory boxes to place their precious items in; professional photography (www.nowilaymeddowntosleep.org or www.acpcg.org for older children); opportunities to scrapbook; personalized sibling workbooks; creation of personalized songs for dying infants (www.songsoflove.org); linkages with the Palliative and Bereavement Care Service for infants who may survive their initial withdrawal/withholding of life-sustaining medical therapy and go home or to hospice; and provision of comprehensive information for families at the time of palliation, death, and...
in the months after death (initial package, newsletters, and a variety of booklets are available in a few languages).

Is legacy creation important to do? This question was asked by Senior Management at the hospital as part of a review of the Bereavement Programs hospital-wide. This served as an excellent opportunity to review current practices and the literature available.

In reviewing the literature, it became apparent that there were no specific studies on the impact of helping families to create legacy. This review is based on single sentences or paragraphs that have been incorporated into larger studies or in guidelines/recommendations or commentaries from health care providers and families who have been impacted by the death of a child.

What is legacy? According to the Merriam-Webster Online Dictionary, legacy is a gift by will or intent by another or something received from an ancestor, often of money or items (www.merriam-webster.com/dictionary/legacy). While infants and children are not ancestors, the idea of this being an item received from the deceased supports this concept.

Why is legacy creation important? Some of the literature in perinatology and pediatrics has identified that the idea of capturing the "story" of the dying infant or child was felt to be important by families as it helped them to make sure that parents and children didn’t forget (Bryan, 1984; Johnson & Johnson, 1985; McDonald, 2002; Moules, Simonson, Prins, Anugs, & Bell, 2004; Patten, 2008; Romesberg, 2004; Schwarz, Tatzinger & Meier, 2004; Schweibert & Kirk, 2002; Shea, 2006; Woodgate, 2006). This function fits within the role of grief where the individual needs to keep the memories and connections in place (Moules, Simonson, Prins, Anugs, & Bell, 2004; Shea, 2006; Woodgate, 2006).

Legacy creation is identified as important to members of the health care team, as it is something that can be "done" when we cannot change the outcome for a family (Catlin & Carter, 2002; Daley & Limbo, 2008; Epstein, 2008; Jung, Milne, Wilcox, & Roof, 2003; Williams, 2008). Callister (2006) framed pediatric legacy work as being an important supportive intervention to assist the family in accepting the reality of the death. In the newborn population, it has been acknowledged that it is important to pay attention to the attachment and bonding issues between infant and parent, even if parenting can only be accomplished after stillbirth (Howard, 2006; Munson & Leuthner, 2007).

What is important to think about when creating legacy? Of prime importance is the family’s readiness to accept that these mementos may help them remember their child after their death (Daley & Limbo, 2008; Minnick, Delp, & Ciotti, 1990, p. 240; Minnick, Delp, & Ciotti, 1990, p. 2). While there is little literature to identify that creating legacy when the family does not want it is detrimental to the grief journey, the writer has been impacted by a few families who felt that these memories were not helpful but harmful to them. However, one of these few had identified that they were touched that the caregivers had wanted to help them remember their child, but that their own cultural and community norms would not allow that and we needed to respect this need. This then reinforces the need for knowledgeable, compassionate, and sensitive caregivers to be able to discuss the potential value of legacy creation, without using guilt to push the family into doing something that feels uncomfortable (Daley & Limbo, 2008, p. 2.143; Howard, 2006, p. 240; Minnick, Delp, & Ciotti, 1990, p. 25; PLIDA, 2008, p. 1-7). Privacy legislation in most jurisdictions identifies the need for transparency in this process and encourages teams to ensure that informed consent or dissent is incorporated into these discussions and documented by the caregiving team.

One of the areas that our program has excelled at has been the creation of 3D plaster molds with infants and their families, including siblings and parents (Jung, Milne, Wilcox, & Roof, 2003). These forms of legacy are very tangible for parents and allow the connection between infant and family to be visual and comforting (Brosig, 2007). For infants with anomalies in their limbs, many parents we have worked with
have wanted a special mold of that limb so that they could prove how special their baby was. We have also been questioned about making facial masks of the infants, but have not attempted this task to date.

(Unidentified mold and photo created for teaching purposes—consent had been provided, 2006)

Ink and embossed hand/foot prints allow for opportunities for legacy creation to continue into the future. Parents may use their black ink prints to create memorial tattoos, or may use them on the prayer card at a funeral. The embossed prints, which have a slight texture to them, were created when we worked with a mother who was visually impaired. One of the nurses had made embossed invitations and remembered that the texture was palpable. She obtained permission and created it for the mother, which was a precious memento that wouldn’t break like the molds could. Molds were also made with the family. These items have been discussed in several papers with identification that these are an important part of encouraging the family to come to terms with their child’s death, while still staying connected to their role as parents and their child’s too-short life (Brosig, 2007; Bryan, 1984; Daley & Limbo, 2008; Howard, 2006; Kuebelbeck, 2005; Minnick, Delp, & Ciotti, 1990; Ramesberg, 2004; WBRZ, 2009; Williams, 2008). We have extended this option with siblings and create art through water-based painted hands/feet of the family unit. This messy but permanent memento is inexpensive but very meaningful to the family.

(Photo consented by parents, 2006)

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Photography and videography has grown in our program, to include the amazing work of professional photographers through Now I Lay Me Down To Sleep (www.nowilaymedowntosleep.org). We have been working with these wonderful volunteers for the past 3 years and have been able to support some beautiful opportunities for dying infants and their families. The literature has identified that photos can be very supportive in the grief journey, especially with the newborn population, as it helps create the bond between the baby and parents, especially in situations where there has not been a great deal of time between birth and death, or there has been distance between infant and mother (Brosig, 2007; Bryan, 1984; Callister, 2006; Daley & Limbo, 2008; Epstein, 2008; Grant, 2007; Johnson & Johnson, 1985). This opportunity can also be made available to children with life-limiting illnesses through the American Child Photographers Charity Guild (www.acpcg.org).

As well, we have a high-quality digital camera, which is provided after consent is obtained, and photos are taken by team members and parents/extended family themselves. We also use a digital video camera for the same purposes and will provide the family with a printed sample of the photos through the palliative phase and death, as well as a DVD/CD of the photos and untouched videotape. Video is taken of precious moments together, baptisms, blessings, and naming ceremonies, as well as baths and times with extended families. These can be ready the next day or within a week, depending on the urgency for the family related to funeral planning.

The combination of all of these photography opportunities has been very important to many parents in the NICU as it provides the memories of their time together as well as the particulars of their baby and their story. Most of our families want their photos as soon as possible, but a few have waited a period of time and then requested them. We have developed a process within our program to keep them available for a year, just in case the anniversary of their baby’s birth and death may change their minds if they were unsure if they wanted them.

We also encourage families to take all the photos they want on their own equipment, but find that they often fill their camera cards very quickly and then use our support. Photos, as described by bereaved families, are “proof” of their child’s too-short existence, and can provide an opportunity to connect to the similarities and distinctions between infant and parents, siblings, and extended family (Callister, 2006; Daley & Limbo, 2008; Howard, 2006; Johnson et al., 1985; Kuebelbeck, 2005; Patten, 2008; Riches & Dawson, 1998; Schweibert & Kirk, 2002; Shea, 2006).

Ritual is part of legacy creation. When we perform rituals, we enable the creation of memories that often are a positive way to remember. Rituals may include naming a child; having a ceremony to bring them into their spiritual community; a first bath; a ritual circumcision; cutting of hair or a baptism/blessing or smudging ceremony. As described in a book on the use of rituals in death, Anderson (2001) identified “Rituals can help us see things in a clearer way…the symbols help us give names to those feelings, and the rituals help carry us beyond the situation to a higher understanding. They transform.” This transformation is useful in helping the bereaved to better live through their grieving or mourning experience.

Does legacy creation continue after death? Absolutely, the opportunity for families to keep their child’s memory alive is key to a “good” grief experience by most families (Brosig, 2007). There are memorial gardens (Brosig, 2007); memorial pages on social networks like Facebook; tattoos created by grieving family members to solidify their memory of the child who died; donations (Brosig, 2007) and fundraising opportunities which also provide remembrance (www.meaganswalk.com); scrapbooks to share those memories (Schwarz, Fatzinger, & Meier, 2004) and activities (candle lightings, Walks to Remember, Butterfly Releases, etc.) offered by various bereavement support networks (www.nationalshare.org; www.pbso.ca) which are too vast to capture here (Brosig, 2007). All of these opportunities can help the family to learn to live their life without their child, while still loving in absence (Attig, 2002).
Is legacy creation the right thing to do? Despite the lack of quantitative, blinded, randomized, controlled studies, legacy creation is identified as being important to many families whose children are dying and have died. The evidence is of mixed methods, with qualitative themes identified in several studies (Brosig, 2007; Callister, 2006; Epstein, 2008; Moules et al., 2004; Williams et al., 2009; Woodgate, 2006).

Recommendations for future research include studies to review the impact of legacy creation on the families over time. Rather than making this a sub-theme of a larger project it would be important to delve into the stories of these families and what has helped, and what didn’t help them in their time of grief.

Legacy creation with families before, during and after the death of a precious baby is believed to be essential support in the complex journey of grief. These memories need to be created by sensitive and caring staff, and possible parental resistance requires respect and acknowledgement. By these opportunities being supported, families can have access to what THEY need in order to grieve the loss of their child, their plans and their future.

References


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Memory making is an important task to be performed during the end-of-life care of any individual. This activity is even more important when one is facing the loss of their child. The activities inherent in memory making should cross all locations of the child’s death – whether on labor and delivery, in the intensive care unit, the general acute pediatric floors, or the emergency department, as well as at home. The Community PedsCare Program in Northeast Florida has been innovative in their approaches to ensure that families are offered the opportunity to have memories made before and after a child’s death.

The Community PedsCare Program has an active prenatal hospice program where memory making begins even before delivery. The interdisciplinary staff are called upon to assist in developing a birthing plan as well as to support family members including siblings. The expectant family is introduced to community resources including the Now I Lay Me Down to Sleep program as well as discussing memory making after the birth of their infant.

The Community PedsCare Program's strength lies in the fact that we support our children and their families in the home setting up to and through the dying phase of the child’s illness trajectory. Every staff member has access to a “bereavement” basket that is introduced into the family’s home when an imminent death is anticipated. This bereavement basket is supplied with an age- and gender-appropriate blanket, memory making supplies including color inked pads, modeling clay, heavy weight colored paper for finger, toe, hand, or foot prints that also includes a poem, room for name, date of birth and death, a disposable camera, memory boxes for locks of hair, and tissue packets, as well as a journal. Families are encouraged to use some, all, or none of these items to capture memories of their child. Our experience has been overwhelmingly positive from the families in providing these tools to them.

This concept has been carried over into the children’s hospital where supplies are kept in a common area in dedicated locked cabinet space. All the nursing units in the hospital have keys to these cabinets and the supplies are duplicates of the basket that is brought to the family in the community. Once again, the response from the families is positive in having tangible memories of their child.

It is recognized there are families for whom these memory-making activities might be: overwhelming, culturally inappropriate, or distressing. Therefore, it is important to introduce the memory-making in such a way to ensure that the family feels supported no matter what their decision is for utilizing some, all, or none of the techniques offered.

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As children and teens with life-threatening conditions receive palliative care, often they experience a variety of emotions as they absorb their situation, evaluate relationships, reflect upon life experiences, and consider what tomorrow may hold. At developmentally appropriate levels, children and teens ask significant questions such as: How can I tell my parents I know what’s happening, and I’ll be okay? How can I tell my family and friends my wishes? How will they know how much I love them? How will people remember me after I die?

While children and teens internalize or verbalize these thoughts, family members and friends also experience a whirlwind of emotions as they feel anticipatory grief, face the uncertainty of the future, comfort one another, and cherish time together. They too wonder: How will I remember them?

The ABCs of Legacy Building

Legacy building serves as an invaluable tool through which patients and caregivers alike express messages about their feelings and create tangible memories of meaningful life experiences and relationships. Utilizing legacy building techniques, children, teens, and caregivers have opportunities for self-expression, processing feelings, and communicating their wishes, needs, and love for each other. During the intimate times patients and family members share during legacy building, they often feel empowered, comforted, and supported.

Healthcare professionals have opportunities to support legacy building with families from the onset of diagnosis until the time of death as patients receive palliative care services. Child Life Specialists often have a variety of different projects and materials available for patients and families that will meet special interests. Examples of legacy building include scrapbooking, journals, videos, songs, poetry, memory boxes, and hand/foot prints. What follows are some key projects healthcare professionals can consider to offer to patients and families.

Handprints:

Hand and footprints can be done at different times during palliative care. This legacy building activity encourages communication and emotional expression. Before death, patients and caregivers may want to participate in order to share an activity as a family and to create a long-lasting memory together. When offered this project at the time of death, the majority of families want to actively participate. At that time, this legacy building activity serves as an intimate time to gather around the patient, grieve, and say good-bye. The project also promotes closure for siblings.
In experimenting with different techniques and materials, I found a popular method with families involves using canvas and acrylic paint because they clearly detail each person’s intricate and unique prints, and the project offers families an opportunity to be creative and experience a variety of emotions through this fluid medium. Materials needed include canvas in assorted sizes, acrylic paint, foam paint brushes, washcloths, and warm water to immediately remove paint. Healthcare professionals can facilitate the project by providing these appropriate materials, demonstrating helpful techniques, and encouraging family members to brainstorm together about the design for the legacy piece. Many families choose prints only from the patient, but others also may want to include their own prints on the canvas. One family created this “tree of life” together.

Three additional methods I recommend for healthcare professionals for creating handprints and footprints before or after death include:

1) “Creativity for Kids Memory Art 2 Tiles to Treasure.” This product can be ordered online through Target or Amazon.com. The tiles work well for children with small hands/feet, particularly infants. This product is advantageous because paint can easily be wiped off the tiles using warm water immediately if the prints are not optimal on the first try.

2) “Precious Hands Plaster Molding Kit” by the Webster Group. This 3D plaster kit available online can be utilized for all ages and has amazing detail to the cast. From experience, please note the initial molding time sometimes can take up to 5 minutes despite product directions. If using this product after the death of a child, I suggest letting caregivers know there is a chance it may or may not cast correctly. I recommend healthcare professionals practice using this product before patient use.

3) Pillows. Encourage a volunteer community group to make a variety of pillows made of a sturdy fabric with one side of the pillow a blank fabric. Using permanent acrylic paint, place a child’s handprints or footprints on the blank fabric and let dry. Caregivers often appreciate not only the imprint of the hands or feet, but also having a comfort object to hold with the memory of their child. Pillow designs can be geared toward different age groups or genders.

Photography:

A powerful legacy building activity that healthcare workers can provide is the opportunity to take photographs of the child and family members before or after the child’s death. Healthcare workers or volunteers can spontaneously do this project using a digital camera in the hospital or home. Various organizations comprised of photographers around the United States also provide free photography for families of children with life-limiting conditions. Moment by Moment is a non-profit organization in California composed of over 200 professional photographers that offer free portrait sessions, beautiful prints, and CDs for families of children with life-limiting conditions. Photographers take photographs in a hospital setting, home, or perhaps a favorite place of the family. Moment by Moment has been recognized by Children’s Hospital International for the amazing memories they help create for families.
Scrapbooking

Scrapbooking is an excellent therapeutic mode of self-expression for children and teens. Utilizing photos, mementos, artwork, poems, or messages from friends or family, children and teens can creatively document their life experiences. It is important for the child or teen to make personal choices regarding when and how they add to the scrapbook, such as the medium, different materials, and length. A scrapbook can be as elaborate or simple as a child or teen may choose. The scrapbook may memorialize special memories such as proms, birthday parties, science experiments, and even dreams. This legacy building project serves as a form of story-telling and processing. Caregivers also greatly benefit from opportunities to scrapbook whether it be individually or through a support group. A mother created this featured page as her 8-year-old son received hospice care for leukemia.

Important items to have available for families include paints, markers, glue, stickers, magazines, colorful scrapbook pages, and books. Target, WalMart, and Michael's Craft Store all have materials ranging from inexpensive to expensive.

Videography

Videography is often a popular legacy building tool with teens. This project provides teens with an opportunity to be creative, experience a sense of control, express wishes, and communicate feelings to loved ones. One example is a video that “Sarah,” a 17-year-old young woman with metastatic sarcoma created for her family. Sarah voiced she wanted to discontinue palliative radiation because of pain, but she feared disappointing her family. Sarah confided she wanted to tell her family she loved them and that she was aware of and at peace with her impending death. I suggested we create a video where Sarah could be the “director.” Sarah chose for each family member and close friend individually to visit her at bedside. While being filmed, Sarah shared memories with each person and both expressed their love for each other. Sarah then instructed each person to talk to the camera “as if I’m not in the room” and to talk about her. Raw with emotion, family members again expressed their love and this time their grief. Sarah also spent time cradling her infant daughter in her arms and singing to her. Finally, with the video camera propped on a table over her hospital bed, Sarah privately spoke for 10 minutes letting her family know she knew she was dying, wanted to be comfortable, and loved her family very much. Sarah asked that this 10-minute portion be shown to her family before she died so they would respect her wishes. Her family was appreciative of seeing the video because it helped them understand Sarah’s wishes and also process their grief.

Legacy building is an essential component of pediatric palliative care. It offers children, teens, and family members opportunities for celebrating life, memorializing events, and expressing emotions. Most significantly, legacy building reaches into the hearts of the patient, family, and friends and provides comfort, love, and memories.


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CONTRIBUTIONS TO PEDIATRIC PALLIATIVE CARE AND END-OF-LIFE SUPPORT FROM CHILD LIFE SPECIALISTS

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The collaboration of physicians, nurses, chaplains, social workers, and child life specialists brings much needed support to families who are in the midst of losing their child due to an end-of-life event. The role of the child life specialist brings many skills to support the family during pediatric end-of-life experiences. Child development knowledge, a family-centered approach, and skills in using play and other forms of communication with children are of paramount importance in effective bereavement support and are typical strengths of the child life professional (Brown, 2009).

As Brown (2009) notes, child life specialists have a unique opportunity to support children and families during the last weeks, days, or moments of a child’s life. Pearson (2009) stated that the presence of a dedicated child life specialist in the ICU environment helps to address the psychosocial needs of patients and families to bring balance to the highly technological medical environment. The child life specialist plays a critical role in advocating for patients and siblings during an end-of-life episode. The child life specialist is skilled in creating teaching tools that address the important components of preparation in a developmentally appropriate manner. If a family decides to take the patient home to die, these strategies should be applied if a local community pediatric palliative or hospice program exists. This is often done to assist patients, siblings, extended family, friends, and classmates through the use of age-appropriate language, photographs, medical equipment, questioning, bibliotherapy, artwork, and medical play. This preparation and support makes the good-bye process less traumatic, provides closure, and encourages better family coping through this desensitization process.

The child life specialist can assist in many ways including educating the parents on the use of developmentally appropriate language. A family’s cultural and religious beliefs must be respected and incorporated into end-of-life conversations with the patient and siblings. Some families may see the use of the words “dying” or “dead” as insensitive unless they have preparation about the necessity of specific and age-appropriate language. The child life specialist can advocate for honest, clear, concise language that incorporates the descriptions of the five senses and reinforces the permanency of death and safety of the surviving siblings. Among other things, this should involve encouraging families to avoid euphemisms, which can cause siblings to have increased confusion, stress, and what families may perceive as unusual behaviors. For example, the terms “went to sleep” and “went to heaven” may cause siblings to have sleep disturbances and discussions about how they want to go to “heaven” too.

Parents need to be educated on the importance of free play and honest discussions to help the surviving children effectively cope with the death in the months and years to follow. Grieving parents are sometimes taken aback by siblings acting out funerals, deaths, or “flying to heaven.” The child life specialist will usually provide opportunities for such play and self-expression at the time of death but will also inform the families of common behaviors to expect. It is important that parents are aware that children cope through play and not to discourage or dismiss opportunities to allow for grief processing. Families should be given bibliotherapy lists and community bereavement resources during this time.

Engaging the patient and siblings in conversation about favorite activities, toys, and memories all help to build rapport and ease anxiety throughout the dying process. The child life specialist is skilled in providing memory making activities and mementos. Pearson (2009) states that siblings need to have activities to do
while at bedside and between visits. This can be done through a variety of ways including creating dental stone hand castings, family handprint canvases, cards, photographs, scrapbooks, memory bracelets, memory boxes, and journals. These activities provide a sense of normalcy and give the siblings a "job" to do to help them feel incorporated in their brother or sister’s dying process. In addition, these legacy building items can be especially important for the developmental and concrete needs of the surviving siblings.

The death of a pediatric patient affects the entire family system. The patient’s siblings are often pushed to the side before, during, and after an impending death. This can occur for several reasons including the parents’ own inability to cope effectively and their desire to “protect” the surviving siblings. Research by Davies (1999) demonstrates the importance of sibling involvement during the dying process in order to improve their ability to cope better than their counterparts who are not present. Siblings who are not present during the death often exhibit greater emotional vulnerability and distress.

As Wolfelt (2007) points out, “Any child old enough to love is old enough to mourn.” The child life specialist can modify preparation and support based on the surviving children’s developmental levels, including siblings as young as toddlers. The child life specialist can also advocate for the siblings to be present during this time as controversy still exists in some institutions whether siblings should visit the ICU or NICU. The value of sibling involvement in this way can be seen in the following example.

A child life specialist in the hospice setting had been consulted regarding the arrival of a baby girl who was diagnosed in utero with anencephaly. The child life specialist, hospital staff, and hospice medical director collaborated to devise a birthing plan and set goals that were consistent with the family’s preferences. The child life specialist had established a relationship with the mother three months before birth to discuss memory making activities and to gather information about the siblings. The child life specialist was called when the mother went into labor and arrived as the baby was stillborn. The child life specialist helped the parents explain to the siblings in age appropriate language what was happening. The child life specialist provided memory making activities including hand and foot castings and a footprint canvas. The child life specialist also asked the almost-three-year-old brother to paint all the family members’ hands to make a family handprint canvas. The child life specialist provided him with color choices and allowed him to add his own Picasso touches, which allowed for laughter and memory making during an otherwise somber situation. The child life specialist also provided the family with local grief counseling resources as well as books, websites, and other grief tools.

References


At 14, my son Andrew knew way too much about brain anatomy. In a dimly lit conference room at Children’s Hospital in Seattle, I watched his eyes as they tracked each new brain scan image being clipped to a viewing panel. He reminded me of me watching a PowerPoint presentation by one of my subordinates. Okay. Got it. Next slide. But he wasn’t looking at a marketing plan, he was looking at his brain.

The first slide clicked into place, showing the golf ball sized tumor deep in the core of his brain. The second, taken right after his first surgery the previous July, showed a dark, finger-thick slash, the path the surgeons had edged their way through with tiny instruments to extract most – but not all – of the tumor.

Andrew stood. He held the back of a steel and plastic office chair, his brown eyes reflecting the black, white and gray images.

The third image clicked into place, captured after ten months of radiation therapy and a round of chemo. Andrew’s eyes went back and forth, back and forth. As the radiologist began to speak, Andrew picked up the chair and slammed it back down to the floor. Bang! “Fuck!”

We had a problem. I searched the gray faces of the medical team. "What do we do next?" I saw in their eyes there was no answer. My gut knew, but my mind refused to let me feel the truth. It refused to let me feel my fear.

I shifted into the most comfortable operating mode I knew: problem-solving. I’d been trained as a problem-solver, trained to see every problem as an opportunity, and this was just another problem. I could handle this. Define the problem. Develop options. Analyze the options. Make a decision and go. I was 42, I had a Stanford MBA, I had 20 years of experience, I knew how to gather facts and generate options and identify the best ones, juggling them until an intuitive flash fused them into a breakthrough solution.

I could break through walls. I just needed options.

Over the next two weeks, I networked my way to CEO’s of biotech startups testing new chemos on mice, looking for leads. I tracked down researchers who’d put drugs through early-stage clinical trials, looking for facts. I interviewed nurses who’d worked with patients in those trials, looking for the subtle details that a quantitative analysis might miss.

“Options,” I kept saying, “I need options.”

My search took me to Boston to meet with brain cancer experts with promising early-stage projects. I wanted to look them in the eyes. Maybe their eyes would reveal something they might not say on the phone.

All I got was confirmation of what Andrew’s medical team had already told me. There were five chemos to try. At best, they could slow the tumor’s growth.

Not good enough.
If the docs didn’t have a cure, I’d find one.

“I need books on brain anatomy, cancer and immune systems,” I told a Harvard Medical School librarian the next day.

“Are you a doctor?”

“No, I’m just visiting.”

She arched an eyebrow. “Are you a medical student?”

“No. I’m a dad.”

Her nod suggested she understood. She helped me gather a starter set and pointed me to a study carrel. A stack of books, a pad and pen, a cup of coffee, just like a market share report, sales updates and a whiteboard.

Brain anatomy fascinated me. It turned out cancer biology had none of the neatness that a standard tumor classification system of grades 1, 2, 3 and 4 implied. The science of the immune system intrigued me. There was something there, I just had to find it.

Pages turned. A yellow legal pad began to fill with notes about brains. My own brain suspended facts the way a juggler puts spinning plates into orbit, waiting for them to come together in that intuitive fusion that would save Andrew’s life. When I took a break for lunch, I felt excited.

Four hours later, looking at the stack of unopened books, fanning out my paltry pages of notes, and remembering that we only had months, not years, all those spinning plates came crashing down around me. I slumped over the desk, the side of my face cradled in the open brain anatomy book, and sobbed.

Another meeting back in Seattle provided a new reason to hope. In the scans, the new growth looked operable. “Operable” meant some of the tumor could be removed. The smaller the tumor, the more likely it could be killed with chemo. We had five chemos to try. Okay, let’s do the surgery, but then what? Which chemo? The medical team’s strategy: Pick one, try it, see what happens. When it no longer seems to work, try another one. This sounded like Russian Roulette in reverse, hoping to find something that might save Andrew’s life.

No. Not save his life. That was too ambitious. Something that might buy some time. Time for another time-buying treatment to emerge from the world’s research labs. Buy enough time and maybe, just maybe, a cure might come along.

But the sequence dead-ended if you got inoperable new growth.

I did the math. There were 120 possible sequences. One had to be better than the rest. Which one? I got no answer. Fine. I would find that optimal sequence. I dipped into my MBA toolkit and pulled out a decision-support technique that hadn’t seen daylight since graduation: A decision tree.

Ten days later, I met with the head of Andrew’s medical team. A man of medium height, slender, with light brown hair and a beard, he had impressed me with his gentle manner and the fact that, in our planning meetings, he focused his attention on Andrew.

Half an hour before our meeting, I snapped the cap off a black marker and began drawing the results of my analysis on the conference room’s whiteboard. At the far left, I drew a box labeled “surgery.” From
there, I drew five lines, the lines fanning out with a quiet swish, representing each of the five available chemicals. The marker’s mildly intoxicating vapor spurred me along. From each of these first lines, four smaller branches fanned out, swish, swish, swish, swish, representing the possible outcomes: Shrinkage, no growth, new growth, and inoperable new growth.

Along each of these smaller lines I wrote a number, decimal point X, the decimal point going on the board with a bump, X representing the probability of that outcome. A .2 probability means 2 out of 10 times that’s the outcome you get. The probabilities came from all the clinical trial reports on these chemicals, supplemented by phone calls and emails to question, clarify and confirm.

I popped the cap back on and snapped open the blue marker to do the next set of branches. I used green for the third, and so on until I’d filled the whiteboard.

As the doctor entered the room, I stood up in my corporate khakis and a blue Oxford shirt, with all the confidence I felt when making a presentation to my CEO. I was buttoned up.

At the whiteboard, I reviewed our options, using a pen as a pointer to tic down the list.

“Have I got them all covered?”

“Yes.” He folded his arms across his chest, his eyes intent.

I explained the decision model, where I’d obtained the probabilities and how I used them to optimize the sequence of treatments.

He nodded.

I walked him through the sequence that my analysis showed would win us the most time. Tic. Tac. Tic. Tic. I turned to him, waiting for the “Aha!”

He took a deep breath. “You know, all these probabilities you have up here, while basically correct, are essentially estimates. If I understand this model correctly, the ability to choose a best path assumes that the probabilities are highly accurate.”

He squeezed the edge of the table and leaned toward me, his voice kind and quiet. “They’re not. There’s wide variability in all of them. If you factor in that variability, what you conclude is that it doesn’t matter which path you take.”

I looked at the whiteboard. Something squeezed behind my eyes, a tingling bothered the back of my ears. There had to be an answer among the black, blue and green lines.

He looked down. “The bottom line is that Andrew’s odds aren’t terrific. We all know that. So it really doesn’t matter. Probably the biggest success factor, in my experience, is something you don’t even account for in this model. It’s Andrew’s commitment. How much does he believe in the treatment he chooses?”

I spoke the words back to him, rote training taking over, to paraphrase and show understanding, as my gut and my mind wrestled over the truth.

“Yes, that’s right,” he said when I finished.
I put the pen down with great effort. After managing a polite thank you, handshake and goodbye, I walked slowly out into the hallway. My body slackened. I saw a bench and dropped onto it, my head against the wall, eyes closed.

A nightmare I’d refused to acknowledge forced its way into my consciousness. I see myself hanging onto Andrew with one hand as he dangles over a void. It doesn’t matter how much I love him. It doesn’t matter how much he loves life. It doesn’t matter how smart we are or how much we try or how much we dare, our muscles will give out and gravity will win.

I watch him falling away from me, feeling utter hopelessness and despair. And shame.

“I cannot save my son.”

When I could breathe again, I sat up and wiped my face on my Oxford shirt. After revisiting every dead end of the maze we’d wandered over the past 10 months, I wandered forward in time. For how long, I wondered. Twelve, 18 months?

What could I do? Going to Boston hadn’t helped. Networking to all those CEOs hadn’t helped. The decision tree solved nothing. I’d even shouted at the sky and offered myself in exchange but nobody took the deal.

It’s up to Andrew, his doctor had said. Fine.

And then I knew. An intuitive flash fused all those failures into a new mission. I had a teenager facing death. The hardest thing for either of us was to confront and shed our fear of death. Andrew will not die afraid, I decided. This was the only way I could now protect him. I would help him get ready to die.

I had no idea how to do this. I wasn’t even sure it could be done. But I could walk with him toward his future, and talk with him. And I could try.

* * *

Mark Nassutti is a writer in Seattle.
My wife has her note. I have mine. They are tucked away in our briefcases, always with us, never out of reach. I found mine in the black backpack that we took to Elena’s wish trip. On the cover of the envelope is a lopsided purple heart, just the way Elena drew them best. On the side she wrote “DAD” in clear pink letters before sealing the envelope and hiding it in the hidden pouch of the backpack. My wife found her letter in the side pocket of her briefcase, where Elena had put it many months before. Hers too is in an envelope, with “MOM” carefully spelled out in the unsteady handwriting Elena had as the paralysis slowly set in. These are two of many letters that Elena hid for us in the last nine months of her life, some hidden between books on the bookshelf, in the corners of our dresser drawers, between dishes in the china cabinet or between photos stacked away in boxes during the construction, each note deliberately left professing her love for her family. They are constant reminders of her determination and her inspiration. She knew somehow that one day we would need them to continue. I love the heart on my letter. I yearn for her handwritten “DAD” that is written not only on my envelope but on everything from printer paper to scraps of paper around the house. Still, I can’t get beyond the envelope. The last of Elena’s letters that I read told me she was sorry she was sick. I found this letter in the drawer by my bedside two weeks after her death. I cried for the week following. I can only imagine what this letter says. Maybe it tells me she knew more than we could ever imagine, that from her original diagnosis with brain cancer to the end she understood. She understood the concealed conversations with the doctors, she understood that she would never regain what she lost, and she understood that it would ultimately take her life. But most of all, I hope that she understood that we loved her too. I only wish I had left her notes in return.

Three years later, these are the messages we remember from our daughter. Each one tells us to treasure the smaller moments in life, the passion we must keep, and most of all that she loves us. And each one is written through the honesty and compassion that only a six-year-old can possess. A life too short, but one that is changing the world.

Elena is not alone. Each day families like us and children like Elena fight diseases such as cancer and with each passing moment, they teach us how to live and the value of those simpler moments. Looking back I can’t tell you what her fifth birthday was like, what she wore, or even where we celebrated, but I will never forget the warmth of her hand as we walked together home from school. And sometimes within these smaller moments we learn the most about our children and the most about ourselves. They are not planned, particularly momentous, or even different than most days, but they are the ones that looking back I remember most.

Too often, we, as adults, forget about these moments, instead rushing to the next meeting, the next event, or even talking on our phones and in the meantime we let these moments escape. This is a lesson never forgotten by a parent that has lost a child and one we must pass on to others. To view life as a schedule or even a do-list, is to forget what you may cherish the most.

Elena’s lesson is one that today reminds not only ourselves, but also millions of people around the globe as her simple messages and notes are translated into over 20 different languages and carried by media worldwide. Yet, it is not a new message. In her own way, it is nothing but a reminder – a reminder she sought to teach us and one that today inspires others to appreciate their children. And we can never be reminded enough.
Keith Desserich's most important title is that as father. He is also an entrepreneur, author, and cancer research advocate. His and his wife’s book, “Notes Left Behind,” which is a tribute to their daughter, is a New York Times Bestseller carried worldwide. The charity it supports and inspired by their daughter, Elena, “The Cure Starts Now Foundation,” is one of the first cancer charities dedicated to a “homerun” strategy for fighting cancer that experts believe is now possible. It has over 17 locations worldwide. They also have another daughter, Gracie, for whom the book was originally written. To learn more about the book and the charity, please visit www.notesleftbehind.com or www.thecurestartsnow.org.

* * *
THE LEGACY OF JARRETT MYNEAR

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Nine-year-old Jarrett Mynear looked out the picture window of his room in the bone marrow unit. He had nothing but time to think during his 5 weeks there. For a child who had battled cancer since age 2 1/2, this was just another detour. While lying in his hospital bed, talking with his mom about all of the wonderful visitors, cards, gifts, and phone calls he'd had, Jarrett remembered something from his previous transplant at Seattle’s Fred Hutchinson Cancer Institute. He remembered the volunteers who made weekly visits to each patient with a cart of small toys and trinkets and how good that made him feel.

"Mom, I have an idea. I want to do that for the kids at KY Children's Hospital. I've been around there a long time and I know how lonely and scared some of them are and I'd like to visit them and take them a new toy, to let them know someone who understands what they're going through is thinking about them and wants to bring them a little joy."

Knowing how big his heart was, his parents, Doug and Jennifer were sure that Jarrett was very serious about making this happen and wouldn't be satisfied with just a visit or two to the children's hospital. They never ceased to be amazed at his kindness and concern for others despite a lifetime of battling cancer, losing 1/2 of a leg to it, his hair, having spent hundreds of days hooked up to IVs, having dramatically stunted growth, enduring countless scans and tests, missing out on school and living the life of a healthy kid. He often commented on how sad it was that most healthy kids take their lives for granted.

By age nine, this remarkable boy had quite a reputation for reaching out to others and showing extraordinary empathy towards other ill children. Other striking examples quickly come to mind from those who knew and loved him. At six, after receiving a dream from the Lexington Dream Factory, Jarrett took some of his birthday money and sent it with a note to the Dream Factory, telling its members how much he appreciated the dream and he wanted to help some other child have a dream granted. The next year, he requested permission from the hospital to go door to door at Halloween, passing out candy and smiles along the way. During another hospital stay, Jarrett and his mom saw a newly diagnosed three-year-old girl and her parents in the hall. She was crying because she didn't understand that she had to wear a germ mask. Jarrett told his mom he'd be right back and headed to his room, IV pole in tow. When he returned, he presented the tearful three year old with a mask decorated with bright flowers and a big red smiling mouth, telling her he'd made it just for her and how pretty she'd look wearing it. She proudly put it on, modeling it for her awestruck parents. They were touched beyond words, giving him a big, warm hug.

Having basically grown up around the hospital and clinic setting, Jarrett Mynear's positive attitude and outlook, along with his adult-like intelligence, led to requests from nurses and doctors for him to meet with newly-diagnosed children with cancer and their families to offer encouragement, support, and an example of hope.

All of these experiences led up to what is known as Jarrett's Joy Cart. That idea, hatched during his 5 weeks in the bone marrow unit, to visit the hospitalized kids and give out toys was his most shining example of caring about others. He enlisted family and adult friends he had made to help make his idea happen. On March 23, 1999, Jarrett walked confidently into a press conference to introduce his project, jockeying from radio to print to TV reporters telling them all that he just wanted to bring a little joy to the children's day and to let them know someone was thinking about them. The determination, sincerity, and charisma made him an immediate media favorite. While he and his family sorted, counted, and collected toys, word spread of this remarkable child who looked beyond his own issues to help other kids. Cameras
followed him around the halls of KY Children's Hospital as he pushed the cart full of new toys and gifts into the rooms of delighted children, many who had not had much to smile about for days. As he told the kids why he was there, family members would wipe tears, tears of joy, from their eyes. When his health would allow, Jarrett headed up his team of Jarrett's Joy Cart volunteers, making sure each cart was filled to the brim with just the right toys and gifts to please the 0-18-year-old patients.

Jarrett Mynear often said that doing something to help others, to brighten their day, was his best medicine. He didn't understand all of the media attention from Oprah and Rosie O'Donnell, the national awards such as the Prudential Spirit of Community Award and claims from many that he was a hero. Emails poured in from around the country from people who felt called to action to serve others and from those who shared that his spirit and ability to look past his own problems helped motivate them to take control of their broken lives. When asked what his wish was during his interview for the Oprah segment, "Remembering Your Spirit," he said, "I hope that people will say, 'He helped me out a lot and I'd like to do something for someone else in his name... or in his memory.'"

Jarrett succumbed to cancer at age 13 1/2. His family and an army of volunteers have continued spreading the joy that is his Joy Cart, celebrating its eleventh year of weekly visits to over 50 hospitalized children, along with other outreach efforts in his name. When he realized that he was not going to win the battle with cancer, he asked that his family help raise money to improve conditions in the outpatient clinic where he spent over 11 years. Within 1 1/2 years, a new, state-of-the-art Pediatric Oncology Clinic opened, with a sign greeting families that reads, "Many of us were inspired by Jarrett Mynear, a boy who transcended his illness to help others." Another effort, the University of KY's DanceBlue, also benefiting KY Clinic's Pediatric Oncology Clinic and cancer research conducted at Markey Cancer Center was started because of this little boy who taught the world that spreading joy to others is the best way to help yourself. His philosophy can be summed up by this quote his mother found by Thomas L. Odem, Jr.:

"If the essence of my being has caused a smile to have appeared upon your face or a touch of joy within your heart, then in living - I have made my mark.

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For more information about Jarrett Mynear and Jarrett's Joy Cart, visit www.thejoycart.com.
OUR DAUGHTER’S LEGACY

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No parent ever wants to hear the words that their precious child has a life-limiting disease. We first heard these words in January 1998 when our youngest daughter, Erin, was diagnosed with a rare form of liver cancer. Erin had just turned 15 and was in the middle of her freshman year of high school. Not only did she hold expectations about her future, but as parents, we held the same dreams – playing varsity sports, developing her current education and higher education, participating in musical groups, social events, church functions, and so much more. The harsh realization that life as we knew it was changing was a very difficult proposition to face. What we’ve learned as even more challenging is that our lives never returned to what we previously had. Erin succumbed to her illness two and half years after being diagnosed and we now know that because of this experience there is no going back to our previous life. However, we have learned how important it is to move forward and continue to reach out and give back to others.

We were initially thrown into a new world of medical jargon and treatment side effects that required us coming up to speed rapidly in order to best support Erin as she began her treatment. To say it was a whirlwind ride would be an understatement. When I reflect back, I can honestly say it was all I could do to just keep up with each doctor visit, listening to the next set of instructions; learning how to flush a central line and administer IV nutrition and antibiotics at home. There was no time to reflect on the “bigger” picture of what all of this would mean long-term. Erin spent a lot of time in the hospital initially as her body reacted to the harsh chemotherapy drugs and she battled one infection after another. During that time, we rejoiced in the good days when she was “out of the joint,” her words for being discharged from the hospital.

Because we were initially told Erin had about three months to live we were advised that Erin should meet with the Make-A-Wish Foundation sooner rather than later. Prior to her diagnosis, Erin was a huge baseball fan and an avid fast pitch softball player. When she met with the Make-A-Wish folks, she decided she would like her wish to be a trip to Spring Training where she could meet her favorite team, the Seattle Mariners. We worked with her medical team to time a trip when it would be best between treatments and we all flew to Peoria, AZ, the end of March for Erin’s wish to come true. During this trip, Erin was invited to throw out the first pitch at a Spring Training game and that was such an honor for her! It was also arranged for Erin to meet two starting pitchers from the Seattle Mariner team: Jeff Fassero and Jamie Moyer. We spent a wonderful evening with the Fasseros and the Moyers and at the end of the dinner, Karen Moyer asked for our contact information and said that she would be in touch. True to her word, Karen and Jamie Moyer did stay in touch and often called and visited Erin after we returned to Seattle.

Erin proved to be a fighter and she battled her disease with strength and grace. It was determined that a liver transplant would be the best option for a cure after five months of intensive chemotherapy. So, in August 1998, we flew to Los Angeles where Erin underwent a successful liver transplant at UCLA. She remained in the hospital for four weeks post-transplant and we stayed in the LA area another 3 weeks until it was determined she could fly back to Seattle. During this time, I stayed with Erin and her Dad and two older sisters visited as often as possible. It was a time for the two of us to really bond and talk and I believe it was during this time that we began some of our more far-reaching conversations. Sometimes we would talk about what it would be like when she returned home and could begin resuming some normal activities like going back to school, seeing her friends, and enjoying outings with her family. Other times, we would have deep conversations about the struggles of children and adolescents going through experiences similar to Erin’s. When Erin would observe some of the younger children in the hospital going
through treatment, she would comment to me that it “just wasn’t fair” that these kids had to undergo such trials. I would remind her that her situation wasn’t exactly fair either, and she would always reply that at least she’d had fifteen years of living before she was diagnosed. She was particularly concerned for the young babies and toddlers undergoing cancer treatments. Erin always had a huge heart and was very sensitive to what other people were experiencing. I remember several times before her illness when she would come home from school and would tell me about how she would intervene on the school bus when she would see another child being picked on. She was never afraid to stand up and say what was on her mind and she had a natural quality of wanting to reach out and help others.

What began as so much hope with the chance of a cure, turned to despair when we learned just ten weeks after her liver transplant that Erin had lung metastasis and her cancer was back. This was another huge turning point in Erin’s treatment and this was when discussions of compassionate treatment began. Her doctors told us there was very little we could do in terms of aggressive treatment for fear of interfering with her post-transplant immuno-suppression therapy. The good news for Erin was that her cancer was relatively slow-growing and for the next ten months, she was able to return to school. By fall of 1999, however, she was experiencing increased back pain and that is when we learned her cancer had spread to her spine. In the next few months, she underwent two courses of radiation therapy and we began to meet with the Palliative Care team. During Erin’s final week of life, she and I discussed her life, her legacy, and how she wanted to be remembered. It was Erin’s wish to help other children in similar circumstances and it was important to her that her life not be in vain. As we struggled to cope with her impending death, I remember being inspired by her strength. In fact, it was her model of strength that carried me and our family through those very tough and trying days.

Karen and Jamie Moyer remained a constant presence in Erin’s life, visiting her at our home before her death and attending her funeral. Shortly after Erin died, the Moyers founded their foundation (The Moyer Foundation) and about a year after Erin died they approached us with a proposal. Knowing Erin’s love of children and her compassionate heart, Karen and Jamie proposed a children’s bereavement camp in Erin’s memory and suggested it be named Camp Erin. We were immediately excited about this type of legacy that would have so much meaning for everything Erin believed in. The first camp was held in 2002 through a partnership with the hospice organization that cared for Erin. Since then, The Moyer Foundation launched a fundraising campaign to help expand Camp Erin nationally, bringing hope and healing to children in more communities each year. Today, with 36 camps in 23 states, and one in Canada, Camp Erin is the largest bereavement camp in the country serving more than 2,500 annually.

Through Camp Erin, Erin’s wish to reach out and help other children who are grieving the loss of a mother, father, sister, brother or other close family member is being fulfilled. It has been rich and rewarding work for me and my family. Erin’s Dad has a saying that feels so appropriate which is “healing through service.” We have learned through our experience that by reaching out and choosing to walk toward the light that we can take a tragic experience and carry on our daughter’s memory in a positive and helpful way. We feel doubly rewarded when we attend camp and are able to experience first-hand the transition that these children go through during their brief time at camp. Part of our attendance at camp includes telling the story of Erin and explaining some of the symbolism behind the camp’s logo of a great blue heron and shooting star. These stories also contribute to keeping Erin’s legacy alive by sharing who she was as a person with all the campers. I continually feel Erin’s presence as I interact and observe the various camp activities and I know she would be so proud.

Wikipedia’s definition of a legacy or legacies is “. . . what someone or something is remembered for or what they have left behind that is remembered, revered or has impacted current events and the present day.” To me, Camp Erin is one way that we have been fortunate enough to keep Erin’s dreams alive and carry on her spirit. However, there are so many ways to uphold our children’s dreams that can be incorporated into everyday traditions.

ChiPAPS is a program of the National Hospice and Palliative Care Organization. Learn more at www.nhpco.org/pediatrics.
Erin’s faith was hugely important to her and she openly talked about her beliefs with her family and friends. I do believe that her strong faith is what kept her going for more than two years and also gave her inner peace when it became apparent that death was inevitable. We had some rituals that we practiced while Erin was alive with prayer and meditation and she had special candles that she would light frequently. She especially liked to have candles lit in her room when she went to bed at night so that she could pray and meditate to the candlelight. Erin knew that I would insure that the candles were extinguished once she was asleep, but this gave her peace and it was a simple request to honor. We still have a very special liturgical candle that we call “Erin’s candle” and this candle is lit often in our home especially when we have family gatherings to signify Erin’s presence with us. In fact, her sisters insist that this candle travels with us if we celebrate holidays in someone else’s home as it is an important part of Erin’s legacy.

Another way I honor Erin’s memory is by serving as a parent advisor to the Pediatric Advanced Care Team (formerly the Palliative Care Consulting Group) at the hospital where Erin was treated. It is such an honor for me to participate in the monthly training of residents on the Hematology/Oncology service where we hold discussions about how to present bad news and hold difficult conversations with families. In this way, I do feel that Erin would be pleased to know that I am directly working with the young physicians taking care of patients with life-limiting diagnoses.

In conclusion, there are multiple ways to honor and preserve our children’s memories through rituals, story-telling, and community-based actions. For me and our family, it is important to keep Erin’s spirit alive. I have found that in speaking with other bereaved parents we have a commonality of wanting to share stories of our children and never tire of talking about our children. Finding meaningful ways to keep these memories alive is a wonderful way to promote the legacies of our loved ones.

* * *

ChiPPS is a program of the National Hospice and Palliative Care Organization. Learn more at www.nhpco.org/pediatrics.
NOW I LAY ME DOWN TO SLEEP

Tiffany Storrs
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“Remembrance and ritual are both healthy and necessary for a bereaved parent...really for anyone that grieves. For a parent, memorializing validates their child’s life and their death.”
– Geri Nelson, NILMDTS Bereavement Advisor

Legacy Building

It was a cold winter’s night in Denver, Colorado on February 10, 2005, when Cheryl Haggard (Now I Lay Me Down to Sleep co-founder) and her husband Mike made the heart-wrenching decision to take their precious son off life-support. Baby Maddux was born a mere 6 days earlier with a life threatening condition called myotubular myopathy. Knowing that the memories of her son would be few and fleeting, Cheryl requested that local photographer Sandy Puc’ (Now I Lay Me Down to Sleep co-founder) capture final moments of Maddux’s short stay on Earth. Sandy Puc’ was the name of the photographer whose signature Cheryl had seen on the portraits of healthy newborns in the hospital where Maddux was born.
Those tender portraits documenting Maddux’s eternal connection with his family inspired both Haggard and Puc’ to team up and form a non-profit organization that provides no-cost remembrance portraiture to families whose babies will never come home from the hospital. Realizing that most parents in these circumstances are left with only a mental photograph, Haggard and Puc’ conceived the vision behind the **Now I Lay Me Down to Sleep Foundation** ([www.NILMDTS.org](http://www.NILMDTS.org)) in March 2005, just 6 weeks after baby Maddux’s session. Unbeknownst to Cheryl at that point in time, her loss would help millions of grieving parents experiencing early infant loss.

Five years later, membership has grown from a skeleton crew of just four people, to more than 7,000 volunteer photographers in the United States and 25 international countries. NILMDTS serves approximately 9,850 families a year.

When birth and death coincide, the heartache is universal. For many, the loss feels insufferable. How to hold on and let go. How to honor their precious baby, and how to preserve their legacy.

“One mother’s loss has turned into a memorial to her son (Maddux), by giving permission to other families who are experiencing the death of a newborn that it is okay to remember, it is okay to not forget,” said NILMDTS Bereavement Advisor Geri Nelson. “Remembrance and ritual are both healthy and necessary for a bereaved parent…really for anyone that grieves. For a parent, memorializing validates their child’s life and their death,” added Nelson.

When babies lives are cut short, NILMDTS gently steps in to help keep memories alive when the “unthinkable” happens. To grief-stricken parents, the notion of photographing their baby may not immediately occur to them. Our mission is to introduce remembrance photography to bereaving families. NILMDTS wholeheartedly believes that “there is no foot too small that it cannot leave an imprint on this world.”

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Memory-making is the core of our existence as an organization. The healing properties received from remembrance portraiture are vast and include the following:

- A picture helps the family confirm the existence of their baby’s life and to confront the reality of their child’s death.

- A picture shows parents exactly how the baby looked so they do not have to rely on memory or the memory of impressions developed while in a state of shock and numbness.

- A picture gives parents a way to share their baby with others. A photograph can be an important factor in preventing unhealthy denial, especially for families who did not actually witness their baby’s death, or choose not to see their infant after death.

- A picture may be the only tangible memory of their baby. This can be very comforting to parents who do not want to forget and fear they can’t or won’t remember. Preserving final, precious memories can never be recovered once lost.

- A picture provides a way to get in touch with the positive aspects of remembrance and assists parents to recall their precious babies.

NILMDTS gifts are displayed in a variety of ways including: nightstands, hallways, office desks, and wallets. All in all, these portraits serve to substantiate the importance of their babies' lives, validate their existence, build their legacy, and keep their memories alive.

NILMDTS photographers understand that families will cherish their portraits until the end of their days and that their talent behind the lens translates into a priceless gift for a family in need.

**About Now I Lay Me Down to Sleep**
For information on how to find a participating photographer, visit [www.nowilaymedowntosleep.org](http://www.nowilaymedowntosleep.org). The red “Find a Photographer” link on the homepage connects families with scores of volunteers located within a 50-mile radius of a hospital’s zip code.

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EVERYONE HAS A STORY

Karen Henrich
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As a photographer, through my lens I capture images of children. When you look at the photos I take, you see children through my eyes. You see freckles, bruises, tears, and giggles, but it is through the eyes of the children themselves that we see what is truly important. To see the world through the eyes of a child is to see a world filled with wonder, joy, excitement, love, purity, peace, curiosity, and the celebration of simple moments. I believe that all children are full of such wonder, no matter if they are healthy or ill.

Five years ago I began a non-profit, focused on capturing portraits for families that have a child with a potential life-limiting illness. Now, with a cadre of over two hundred professional photographers in California, we capture precious images of more than 600 families each year. Together, we have discovered that the spirit of a child does not hide in their illness. Through our lenses, when pointed at these courageous children, we capture a spirit that radiates hope, courage, and an unbreakable connection with their families. We capture those wonderful moments that will provide indelible memories to share with others. The images captured are used by families in a variety of ways and are always expressed to be one of their most cherished possessions.

Moment by Moment receives our referrals through the children’s hospitals all throughout in California. Typically our referrals come from Child Life Specialists or Social Workers, but we also have physicians that refer families. The photographer meets the family at the bedside or in the community setting (a family’s home, the photographer’s studio, or a park). The families are not asked to pay anything and receive the session with the professional photographer and after the session a CD of all images and prints from the sitting.

The first question people often ask us is, “Why take portraits for a family during such a difficult time when their child is sick?” What we see is, more than ever, the families want to document and celebrate what they have this day, this moment.
I am more grateful for every moment, every day I experience as I work with these families. After each shoot, I am grateful, on this day, I did not have to comfort my own child in the confines of hospital walls. I am grateful on this day I did not have to meet with a team of specialists, who—no matter how much training they have—cannot tell me for certain that my child will be “fine.” I am grateful to be on the outside, as a photographer, capturing memories of children who make an indelible mark on this world, although here for perhaps only a short while.

I go home from each shot and tell my own two boys how much I love them. They typically respond with, “Mom, we love you more.” I explain that cannot possibly be true! And again, I am grateful—grateful for this little ritual with my children and the moments we have to share it.

For more information please visit the website, www.momentbymoment.org.

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PORTRAITS OF LOVE

Lori Sawyer
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It begins with a phone call. More often than not, the call comes from Seattle Children’s Hospital, but not always. Calls have come from Providence Hospital, other medical centers around the region, friends of a family in need, or sometimes even from the family itself. There are times when the call is urgent, time is short, and there is no time to wait. In almost every such instance, a Soulumination photographer has dropped everything to answer the call. But many times, thankfully, there is the promise of more time and thus begins a series of conversations to plan for the perfect timing and venue in which to capture the priceless and irreplaceable gift of memories.

Soulumination is a small, Seattle non-profit founded by Lynette Huffman-Johnson, a professional photographer. The mission of Soulumination is to “celebrate the lives of children and parents facing life-threatening conditions by providing professional photographs—free of charge—of these special individuals and their families. The life-affirming photographs of Soulumination are an enduring, positive record of the child’s brief life, and provide a loving legacy for the children of parents lost to terminal illness.”

Soulumination grew out of a series of personal experiences that, when linked together over time, brought Lynette Johnson to the realization that there was a unique, unmet need in the Seattle area. Over twenty years ago, Lynette watched one of her dearest friends cope with the loss of her infant son. Then, nine years ago Lynette was both honored and saddened to take photographs of her niece, Lanie, who was stillborn. Both experiences left a deep impact on Lynette and became the seeds of inspiration that would later grow into an ever-growing gift of compassion.

Soulumination was officially founded five years ago and since then has grown to include 30 volunteer, professional photographers from the Seattle area. The foundation has served over 500 families and continues to see growth each year, as more people are made aware of its existence and the beauty Soulumination has to offer. When the foundation began it was focused solely on providing photographs to families with a child who was gravely ill. Two years ago the mission was expanded to include families in which a parent, with children under the age of 18, is terminally ill.
The staff and photographers of Soulumination take great care in determining the best location for each shoot to take place. If the child is strong enough, the family might come to the studio at Soulumination for their photo session. If not, a photographer will make arrangements to travel to the family’s home or to the hospital where the child is being cared for. Often it takes several tries before the shoot can take place. Sometimes the child unexpectedly requires new tests or procedures, or an important family member can’t be present, and so the photo session is always graciously rescheduled. Everyone at Soulumination will tell you repeatedly that their aim is to place the family’s needs and comfort as their highest priority.

Every family, every child, and every photo shoot is unique. When death is imminent, Soulumination photographers enter into that sacred time as a quiet observer always mindful of the privilege of being witness to such an intimate moment. During photo sessions where the child is strong, where there is hope of more time, there is very often laughter and joy but always the poignancy or recognizing that a precious child is very, very ill. When photographing a terminally ill parent, Soulumination photographers strive to capture the essence of the family in the hopes that this will provide the children visual, tangible memories for the years ahead when their parent is no longer with them.

After the photo session, along with all of the photographs taken, the families receive the negatives and an archive quality CD of all of their photos. Soulumination gives over complete ownership of the photos to the family. No photo is ever shared as part of Soulumination publications, materials, or education events without the written consent of the family. Families are also given a beautiful, handmade tri-fold album with a selection of photos inside, as well as a larger handmade photo album. Both the tri-folds and the photo albums are handcrafted by volunteers, many of whom are Soul parents, friends, or family members. They will tell you that after having received the gift of Soulumination themselves they felt compelled to help provide that same gift to others. Mothers are also given a lovely silver charm bracelet with their child’s photo. The mission of Soulumination is not only to provide professional photographs to families facing an unimaginable loss, but to do so in a way that truly honors the beauty and unique blessing of each and every child and family.

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There is no quantifiable way to measure the impact of photos on a family’s experience of grief and healing. But the hundreds of comments, cards, emails and thoughts that have been expressed to Soulumination from family members and friends demonstrate that what they are offering is indeed of great value. Many parents have shared that while they want to believe their memories will never fade and they will always remember every expression and touch, the reality is that the human mind is not nearly so infallible. Photographs preserve those precious moments in a way that mere memory cannot. The outpouring of gratitude from families who have received Soulumination’s photographic gift is all the evidence needed to confirm that their mission is necessary and valuable.

Photographs will not cure any disease. They may never change history in any monumental way. But they can capture a person, a smile, a touch, a moment in time, in a way that can make all the difference for a family faced with the unimaginable task of having to say good bye, far too soon.

For more information about the work and mission of Soulumination, and to view photos of the many Soul children and adults, go to www.soulumination.org.

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

Jody Chrastek, MSN, CHPN
Donna Eull, RN, BSN, MA

Just in Time Guide: A Primer for Pediatric Palliative Care at Home
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The Hospice and Palliative Nurses Association asked us to write a guide for adult hospice and palliative care providers to help them better care for kids at home. It has been identified that often it is difficult to identify hospice/palliative care programs that are comfortable caring for children, so they wanted a quick resource that could be used in the field.

SUMMARY
When you are asked to care for a child this afternoon!- A Just in Time Guide.

“I could never take care of a dying child…..we are just not prepared for kids.” Hospice staff caring for adults often express these feelings when asked to provide end-of-life care for a child and his or her family at home. Yet these same hospice staff are the very ones who have the compassion, skills, and intuition to walk with the families at this most difficult of times. As one mother said, “I just want someone who knows what death looks like to be with me and help me. I have never seen death before.” Who better to do this than hospice staff?

There are definite differences and skills that are needed for caring for children and educational resources are available. But what if there is no time before this afternoon to take a course or review the one you did two years ago?

This guide is intended to provide quick, useful, and practical information to adult hospice and palliative care nurses as they prepare to care for children at home. It is designed to be used along with the Pediatric Pain and Symptom Management Algorithm for Palliative Care book written by Linda Wrede-Seaman. The goal is to build on the skills and expertise hospice nurses already have, and help them become kid competent and kid-friendly. This guide is a practical pocket reference for providers in the field. It also provides resources for further contacts, education, and supports.

This guide is an easy reference for common scenarios, such as first visit tips and developmental considerations when working with children and their families at end of life.

Not only can you care for kids at end of life, with help of this guide you can do it well!

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A MESSAGE FROM DON SCHUMACHER ON THE CONTINUUM OF CARE

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On August 2, I opened NHPCO’s conference, Developing the Care Continuum, with a discussion about the importance of hospice and palliative care in the continuum of care. I wanted to share just a few thoughts with the readers of the ChiPPS newsletter.

I think many people would agree that the US healthcare system is quite fragmented – hence the importance of creating a continuum that includes hospice and palliative care. This must include pediatric palliative care.

Pediatric care has always been near to my heart and as quality-driven providers, we should be able to support the needs and/or assist in care coordination of all those coping serious and life-limiting illness – this includes children, adolescents, and their family members.

I recognize that pediatric palliative care is something many providers feel uncomfortable offering, but it is something we should understand more fully. We must expand our skill set and explore what resources are available to families in the communities we serve. I commend the work of the Children’s Project for Palliative/Hospice Services in developing new tools and resources to move the field forward.

Pediatric palliative care was specifically addressed in the health care reform legislation passed this year. This was a provision that NHPCO strongly lobbied for. The law allows children who are enrolled in either Medicaid or CHIP to receive hospice services without foregoing curative treatment related to a life-limiting illness. This should provide for a more seamless continuum.

When there is a seamless care continuum, providers work together to develop a coordinated plan that addresses all the needs of the patient and family caregivers. Those of you involved in pediatric palliative care know all too well that the needs of these seriously ill young people and families encompass physical, emotional, social, spiritual, nutritional and financial as well as practical and logistical needs. Care and services should be coordinated by professionals who understand the range of options available and appropriate in each situation.

I also want to stress that the concept of the care continuum is not – indeed, cannot be – solely geared to hospice providers. I know there are many hospice professionals working with ChiPPS but there are many others representing a range of provider types and disciplines, and we all must be involved with the development of the care continuum. Working together towards the creation of a seamless continuum will require us to collaborate and partner in a more expansive way than we’ve ever seen in the hospice community.

I believe that every single hospice provider needs to offer non-hospice palliative care. If you do not, somebody else will. Hospices are the experts in serious and life-limiting illness in their communities and they must be leaders in developing a seamless continuum of care. So what I’m hoping is that hospices in the United States, in addition to the wonderful things they already do providing care in the last months of life, will become more visible and available as providers of or experts in pediatric palliative care.

Thank you for all you do to advance care for young people and their families.

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Items of Interest

In each issue of our ChiPPS e-newsletter, we offer additional items of interest.

1. **NHPCO’s 3rd Annual Pediatric Palliative Care Intensive.** ChiPPS is proud to offer the 3rd annual pediatric intensive track as part of NHPCO’s 11th National Clinical Team Conference to be held in Atlanta, GA, September 13 - 15, 2010. The Pediatric Intensive will offer sessions that enhance provider and professional capacity to meet and exceed these standards and ensure that staff have the education needed to confidently care for seriously ill children and their family caregivers. More information will is available at [www.nhpco.org/ctc2010](http://www.nhpco.org/ctc2010).

2. **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, and examples of programs illustrating the current status of pediatric palliative and hospice care in the United States. (Please note that you can visit archived issues of this newsletter at [www.nhpco.org/pediatrics](http://www.nhpco.org/pediatrics).) For future issues, we are thinking about addressing subjects such as global perspectives on pediatric palliative care, 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!

3. **Reader's Corner.** Contributions to the Reader’s Corner, like the one contained in this issue, 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

4. **Standards of Practice for Pediatric Palliative Care.** Working with the ChiPPS workgroup, NHPCO has published the *Standards of Practice for Pediatric Palliative Care and Hospice*, which 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 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. The *Standards of Practice for Pediatric Palliative Care and Hospice* are available free to NHPCO members and for a nominal price for all others. They can be downloaded at: [http://www.nhpco.org/i4a/pages/index.cfm?pageid=3409](http://www.nhpco.org/i4a/pages/index.cfm?pageid=3409).

5. **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). Please e-mail Christy Torkildson at torkc@sbcglobal.net to have your pediatric palliative care educational offering listed. Here are some representative offerings:

   • **Pediatric Palliative Care Intensive** at NHPCO’s 11th National Clinical Team Conference to be held in Atlanta, GA, September 13 - 15, 2010. Visit [www.nhpco.org/ctc2010](http://www.nhpco.org/ctc2010) for more information.
• **18th International Congress on Palliative Care.** October 5-8, 2010 - Palais des Congrès, Montréal, Canada

• **Center to Advance Palliative Care Annual Conference** with a pediatric track will be: October 21-23, 2010, Pointe Hilton Tapatio Cliffs Resort, Phoenix Arizona. For more information: [www.capc.org](http://www.capc.org)

• **The District of Columbia Pediatric Palliative and Children’s Institute of Pain and Palliative Care, Children’s Hospitals and Clinics of Minnesota present; Pediatric Pain Medicine and Management of Distressing Symptoms in Palliative Care: A four-day intensive workshop** at the Washington Marriott, Washington, DC, Sunday, October 31 (welcome reception) - Thursday, November 4, 2010. For more information, call 202-895-0191 or e-mail info@dcppcc.org.

• **The District of Columbia Pediatric Palliative Care 4th Annual Pediatric Palliative Care Conference.** November 5 & 6, 2010 in Washington D.C. For more information call 202-895-0191 or e-mail info@dcppcc.org

• **Pregnancy Loss and Infant Death Alliance (PLIDA) and Association of SIDS and Infant Mortality Programs (ASIP);** November 4-7, 2010; Washington, DC. For more information: [www.perinatalbereavementconference.org](http://www.perinatalbereavementconference.org).

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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 1-800-646-6460. Visit the ChiPPS Web page at [www.nhpc.org/pediatrics](http://www.nhpc.org/pediatrics) for further materials and resources of interest.

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