ChiPPS Pediatric Palliative Care Newsletter  
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Edited by Charles A. Corr, PhD, Christy Torkildson, RN, PHN, PhDc, and Maureen Horgan, LICSW

Issue Topic:  
Stand Up and Be Counted: Honoring Volunteer Perspectives in Pediatric Palliative and Hospice Care

Welcome to the twenty-ninth issue of the ChiPPS electronic newsletter. This issue of our e-newsletter offers a PDF collection of articles that explore some issues involving volunteer perspectives in providing palliative/hospice care to children and their families. Our goal in this issue is to honor and promote reflection on the many different roles of volunteers in this mode of care. Obviously, we can only suggest some of the many potential roles, but we hope that the examples and models set forth in this issue will encourage greater and more creative involvement of volunteers in appropriate ways within the broad field of pediatric palliative and hospice 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 E-newsletter Workgroup, 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 E-newsletter Workgroup, 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 christytork@gmail.com or Maureen at Horgan.Maureen@gmail.com.
Issue #29:

Stand Up and Be Counted: Honoring Volunteer Perspectives 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.)

Noah’s Poem p. 4
Scott Newport
We almost think of Scott as our "resident poet," if one can be a resident in this newsletter’s electronic format. Here Scott shares another beautiful poem, this time focused on his son, Noah, and sharing feelings about loss.

The Peace I Bring p. 5
Lauren Koski
We usually provide a 2-3 sentence preface to each piece in the newsletter; however, this is a beautiful piece that must be read to be appreciated.

Fools Rush In p. 6
Victoria Millard
Victoria brings us a wonderful clear picture of the importance and effectiveness of therapeutic clowning in pediatrics and as she states, “sometimes its effects on a scared and sick child are simply immeasurable”.

A Young Doctor Reflects on Volunteering in Pediatric Hospice Care p. 8
Michael S. Toce, MD
Michael eloquently shares how his volunteering has helped shape his practice as a physician. He offers some lessons learned about caring for children and their family members who are coping with dying and the death of a child. Although we have come a long way, his story highlights the significant gaps we continue to have in medical education.

Life as I Know It as a Pediatric Palliative/Hospice Care Respite Volunteer p. 10
Ann Fitzsimons, BS, MBA
Ann, who is our "family voice," has contributed often to our newsletters over the years. In this piece she shares herself and her experiences as a volunteer for children and families, a daunting role for one with no formal training as a healthcare provider. The following sentence sums up what we hope you take away after reading this article: “The need is great, the volunteers few, and the families of these sick/dying children are suffering. The time to volunteer is now.”

Suncoast Hospice Teen Volunteer Program p. 12
Melissa Moré, MPH
Melissa describes “the unique contributions teen volunteers can offer to pediatric patients and families.” Suncoast Teen Volunteer Program has grown from 20 to 500 and has been in existence for 17 years.

The Volunteer Program in a Children’s Hospice: The Canuck Place Experience p. 14
Leanne Freeman
Leanne provides a comprehensive overview of the volunteer program at Canuck Place, the first freestanding pediatric hospice in North America. Open since 1995, Leanne shares years of experience from which a new program or an existing program can learn.

Volunteer Training: One Program’s Experience p. 19
Christy Torkildson, RN, PHN, PhDc
As the first Program Director for George Mark Children’s House (GMCH), Christy was responsible for the development of all programs and services. In this piece she describes the process followed in developing
the volunteer programs, both adult and teen. The process can be applied to any program, whether facility or home and community based.

**Pediatric Hospice/Palliative Care Training Agenda**  
Maureen Horgan, LICSW, ACHP-SW  
Maureen shares the training agenda for the Stepping Stones program at Providence Hospice of Seattle.

**Maintaining Our Inner Light in Pediatric Palliative Care**  
Jackie Williams-Reade, PhD, LMFT  
Jackie writes about the importance of self-care. She notes that the ability “to be able to stay passionate, empathic, and resilient is the most challenging aspect of being involved in PPC.” Using her personal experiences as a provider, as a manager, and as a “consumer” she provides some provocative thoughts for us all to think about.

**Learn Healing Touch and Holistic Health Games: Life-Changing, Therapeutic, Fun, Free**  
Samuel Schoonover  
Samuel provides an overview of the services provided and games created by The TLC Holistic Health Foundation whose philosophy is “the win-win of quality one-on-one time to significantly improve their overall quality of life and create memories that last a life time.” More information can be obtained at their website that can be found in the header of the article.

**Items of Interest**  
ChiPPS customarily shares items that may be of interest to our readers.

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.
NOAH'S POEM

Scott Newport
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Noah,
Loving, caring, giving, and smart,
Brother of Evan and Chelsea,
Lover of football, ice cream, and family,

Who feels sadness when you lose someone you love,
Excitement when you get on the
Football field, joy when you’re with your family

Who needs your parents, sports, and a home
Who gives inspiration, support, and toys to the poor
Who fears losing something close to you
Heights and the end of the summer
Who would like to see earth from space
The pyramids and the world’s largest tree

Who lives in one of the only two story houses on Samoset St
And has a baby tree
Just trying to grow big
THE PEACE I BRING

Lauren Koski
SonRise Equestrian Foundation

“Guess what today is Blackie!” my handler coos softly, as she scratches the top of my head and begins brushing my forelock. There is only one guess as to what today entails, and I know that my guess will be right. My coat is soft and clean from my bath yesterday, I have been brushed for what seems like the past 4 hours, my hooves are wrapped in bright pink vet-wrap, and my “special” halter is hanging in the nearby trailer waiting to be put on. Yes, today is a George Mark day. I have come to know these days very well. As one of SonRise Equestrian Foundation’s hospice-certified miniature horses, these days have a special meaning to me. I look up at my handler and give her the best smile a “mini” could pull off and raise my head high. I know my job; today I work.

As we head over to the house, I am already on the job. I remind myself of my manners and mentally prepare myself with every step. When the door opens, I am immediately hit with the clean, sterile smell, but also the serenity of the environment. Volunteers and nurses come up to greet me with bright smiling faces, and sunlight illuminates the building from its many windows. The “clip clop” of my hooves echo quietly in the hallway, beckoning families to peer out the doors of their rooms. “Mama, Mama! It’s Blackie!” One little boy excitedly whispers to his mother, bouncing up and down. I am quite the celebrity.

I clip clop down the entire length of the hallway until I get to the very last room. My handler instructs me to stand patiently as she speaks with the nurse and the family in the room. Behind their hushed voices, I can hear the quiet whirring of the machines. Through their legs, I can just see the beginnings of the tubes and wires. And in my heart I can feel the heaviness of not only the past few days, but the past years as well. I know what I must do.

At my handler’s order, I solicitously make my way into the room. A pint-sized hand rests on the edge of the bed, curled slightly to compensate for the IVs. I examine the frail skin and noticeable veins and my heart drops. I brace myself, and look up. Damp curls plastered to her forehead frame an oval face, her dark eyelashes rest softly against her clammy, pale cheeks, and she sleeps fretfully- stirring often. With a burdened heart, I move closer, rest my head in the crook of her arm and stay very still. All I want to do is give her a hug and take away the pain; this is the closest I can come to that. I close my eyes along with hers and wait.

My ears prick up, hearing a sharp intake of breath. I turn to see the child’s mother with glistening eyes, grasping her husband’s arm. I look up to the little girl to see her wearily smile down at me, her beautiful green eyes now open and alert. She is tired and fading fast, but she is happy and content. Her mother succumbs to tears. She kisses the child’s head before kissing my own, and for a moment the room is relieved of the past years of suffering. Instead, hope has flooded in. I remain where I am, afraid to move and change the atmosphere of the room, and I lay there until she has closed her eyes for the last time, finally at peace.
FOOLS RUSH IN

Victoria Millard
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“Clowning enables the opening up of avenues of communication with patients that the medical staff doesn’t succeed with or doesn’t know how to connect with. When a clown arrives, he uses skills that open up gates, cross boundaries, and reach places that most people don’t allow themselves to go to in a hospital setting. Clowning engages in different areas than any other paramedical field.” Herzl Tziony, University of Haifa, Israel, which offers a Bachelor’s Degree in Medical Clowning.

As Dr. La Foo, I worked as a “clown doctor” for eleven years at Seattle Children’s Hospital, as part of the Childlife Department’s specialists in therapeutic play. One of my partners was Dr. Bonky, a little clown about a foot shorter than myself who always seemed to get the children on her side and get the better of me. Working in pairs was a great joy, but sometimes, two clowns were too many. This is the story of how one day I stood back and marveled at the skill of my colleague and the unique effectiveness of the therapeutic clown.

As we were making our rounds on the medical unit, we were told by a nurse that one little girl was extremely upset, screaming and crying. “Medical staff haven’t been able to get in her room. Why don’t you see if you can?” she asked.

As we walked by the room, we could hear the little girl, about five years old, screaming at the top of her lungs. She sat surrounded by many family members, who were unable to soothe her. Bonky did not hesitate to take the plunge, to use the clown arts of exaggeration and excess to break through the ordinary way of doing things. Risking failure, rejection, and possibly offense, she ran into the room screaming just as loudly as the little girl, asking if she could please use the bathroom, she just had to go! Her desperate frenzy distracted the little girl. She stopped crying, and stared at Bonky. Bonky pleaded. Then the little girl nodded her head yes. Bonky ran in the bathroom, making a lot of noise, then ran back out with ten feet of toilet paper trailing out of the back of her skirt. She was still frantic.

“Have you got your sink to wash my hands!” she said. “Is that okay?” The little girl, with an astonished look on her face, nodded yes. Bonky turned around to wash her hands at the sink, humming a little tune and wiggling her behind in time to the music, causing the toilet paper to swish back and forth. She dried her hands and turned toward the patient’s bed. Spotting a teddy bear, she exclaimed, “Oh, I’m afraid of bears! Does he bite?” The girl shook her head no.

Bonky approached the bear, closer and closer, overcoming her fear enough to pet it, and find that he was safe. She introduced the bear to everyone in the room, who were invited to hug the bear and not be afraid. As the bear hugged and kissed everyone, the little girl smiled. The bear then decided to rub and kiss the top of daddy’s bald head. The little girl laughed.

Bonky presented the little girl with the bear, who held it tightly, as Bonky thanked her profusely for the use of her bathroom, and said good-bye.

The short clown routine seems very simple. It does not require advanced circus skills or scientific medical knowledge. It is, however, an example of another kind of skill—the power of therapeutic play and humor in the hands of someone who has developed an intuitive knowledge of how to use it.

Dr. Bonky made split-second, instinctive decisions that were improvised, yet very deliberate. She knew that, in order to break through, she had to distract the child from her distress, and that the only way was
to match the energy and intensity of the child’s emotions. When that succeeded, she created a reason for
her to be in the room that had nothing to do with the child, but put the child in control by asking her
permission to be there. She knew that she could not interact with the child directly, so she worked
peripherally, unseen in the bathroom, then at the sink, and then with the bear. She wanted the child to
identify with her and trust her, so she acted vulnerable and afraid, as the child was. She modeled trust in
overcoming her fear of the bear, and showed the child that all of the adults present had fears to overcome
as well. She created a safe space for the child by involving and reassuring everyone. She reduced the
level of stress by providing the emotional release of humor. Finally, she gave the child an object of
security that had been acknowledged and loved by everyone in the room. In two or three minutes, she
accomplished as a clown what family and medical staff had been unable to do, and proved a valuable
asset and integral part of patient care.

Controlled studies are now being done that prove the effectiveness of therapeutic clowning in reducing
stress and anxiety for pre-operative patients. There are also studies showing how laughter boosts the
immune system, releases endorphins, and decreases pain. This above story, however, is anecdotal. I
share it in hopes that therapeutic clowning will be increasingly studied and incorporated as an integrative
therapy in health care settings, with the knowledge that sometimes its effects on a scared and sick child
are simply immeasurable.

Victoria Millard, a.k.a. Dr. La Foo
A YOUNG DOCTOR REFLECTS ON VOLUNTEERING IN PEDIATRIC HOSPICE CARE

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The death of a child is one of the most difficult experiences for a family to endure. There are many medical questions: Why did this happen? What could I, as a parent, have done to prevent this? What will happen to my other children? When parents are faced with these difficult questions, they turn to nurses, doctors, and other medical professionals for answers. In medical school, I received 4 years of training in answering a variety of questions related to the pathophysiology of disease. I learned how to break the human body down into a series of systems, and treat each organ as a separate entity. The notion that the human being was a whole rather than a series of parts was lost. And, regrettably, I received little training in how to approach and communicate with a family that is going through the death of a child. Medical schools have recently realized the need for more humanistic training in medical school, but many curricula are less than comprehensive. Many medical students graduate with only limited experience dealing with a dying patient. Luckily for me, I received this sort of training before I started medical school in 2008.

In 2005, I began volunteering at the Minneapolis Children’s Hospital Pediatric Hospice Program. In retrospect, I didn’t have any experience working with dying children. My mother had exposed me to the field of pediatric palliative care through her work as a neonatologist, but I had no idea what to expect. Having no formal medical training at this point, I was paired with hospice social workers and psychologists who taught me the value of listening to a family and attending to the ENTIRE patient. They showed that having no responsibility for the medical management of a child afforded me the opportunity to see how the process of dying can affect a family. I learned that no aspect of a family life is immune from the dying process. Even the most unshakable family structures can be weakened. And, fortunately for my future, I saw the amazing power of effective and compassionate communication.

One experience in particular sticks out from my time volunteering in hospice. I was paired with a family that had a daughter with a rare chromosomal abnormality and a poor prognosis. But my assignment wasn’t to work with the dying girl; it was to work with her sister. Often, lost in the care of a sick and dying child, is the health and mental wellbeing of their siblings. For obvious reasons, a parent’s attention and energy is often spent on the child with complex medical needs, while the siblings are unfortunately neglected. At this assignment, it was my responsibility to attend to the wants and desires of the healthy, 6-year-old sister. We played games, painted, and went for walks. The visits were solely for the sister. Looking back, I took several skills from this experience that I have been able to incorporate into my pediatric residency, but the most useful has been the ability to see how an illness can affect all facets of family life. Now when I go into a patient’s room to do a history and physical, I ask the parents how this illness is affecting the patient, but also the family as a whole. I make sure to ask about other family members, and see how they are dealing with their sibling’s sickness. In short, it has helped me view the patient as a whole.

My career in medicine is relatively young; I’ve recently started my pediatric residency at a major east coast program. My days are busy, and as any intern will tell you, there is little time to spend at the bedside when you have 6 notes to write and update 4 discharge summaries. But my experience in pediatric hospice reinforced the simple fact that parents of a sick child are scared, and they look to doctors and nurses for answers. It is our duty to attend to their questions with compassion and
understanding. And when these children go from sick to terminal, it is imperative that medical professionals have the appropriate training to tend to the family’s needs. It is unrealistic to expect new residents to have these types of skills innately without any type of formal training. Pediatric residents have rotations through the ICU and hematology/oncology services, services with high acuity and many sick kids. It is inevitable that sometime during our training, we will be required to talk to a family and tell them that their child is dying. Properly preparing the next generation of American physicians is a necessity. Thinking about a child’s death is uncomfortable. Kids are supposed to get bumps and cuts and scratches, but they aren’t supposed to get cancer and die. Unfortunately, the reality of life is that bad things happen, and as medical providers, we need to be prepared to deal with the consequences. I have been fortunate to experience pediatric hospice care and learn the skills necessary to work with a sick and dying child.

Volunteering with hospice has made me a more compassionate and complete physician, and I have benefited from the experience. But for everyone to benefit, there needs to be a concerted effort by both medical schools and residency programs to provide a structured curriculum that address the needs of the dying child and the child’s family and teaches medical students and residents the necessary skills. One would hope that our attendings and supervisors would provide this teaching, but with cutbacks in funding, hospital staffs are already struggling to simply keep up with patient care demands. More has to be done.

In closing, I think it is appropriate to thank the countless doctors, nurses, social workers, chaplains, and other hospital employees who dedicate their lives to walking parents and siblings through the death of their son, daughter, brother, or sister. They carry an unbelievable burden and provide a service that is desperately needed. My experience as a hospice volunteer provided me with the opportunity to learn how to interact with the whole family and provide support to a sibling. The skills that I learned will enhance my abilities to care for my pediatric patients, no matter what their conditions or illnesses. My hope is that the medical community will embrace this field and provide the necessary provider training that our patients deserve. Only time will tell if this wish will come to fruition.
LIFE AS I KNOW IT AS A PEDIATRIC PALLIATIVE/HOSPICE CARE RESPITE VOLUNTEER

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Through a non-profit I helped co-found after the death of my infant niece, I’d been trying to represent the “family voice” for supportive pediatric end-of-life care via advocacy, education, and research for more than ten years. And while I had my own personal story, and the privilege of having other families share theirs with me, I was yearning for more direct family contact and “hands-on” care of sick and dying children, where and when it made sense, given my lack of medical training. I subsequently left the non-profit and after some soul searching to find my place in all this, was reminded of a local Pediatric Palliative Care Program which cares for children of all ages with life-limiting illness, both in hospitals and, importantly, in the community. As programs like this usually are, they were happy to have someone who wanted to volunteer with their pediatric patients and it felt right to me, so I jumped in.

After undergoing all the standard types of activities one must go through to be cleared to volunteer in-home with palliative care/hospice patients, and especially with children, including an orientation, training, physical, TB Screen, background check, etc., I “passed” and waited for a child/family to help support. I didn’t have to wait long and when the request came, while I thought I was “ready,” I must admit I approached my first respite care visit with some trepidation and lots of questions and fears: “What made me think I was qualified to do this?”; “What if something happens to the child while the family is gone?”; “Will I be able to do anything to really help?”; and so many more. While I had provided hands-on care for my own loved ones under palliative/hospice care—my parents, niece, sister, in-laws—this was different. This was someone’s child and I knew how I would feel, as a parent, letting a complete stranger into my house to care for my seriously-ill/dying child. It was a daunting responsibility.

My first respite visit was for a teenage girl who couldn’t speak or get out of bed and who was severely developmentally delayed. In fact, it seemed almost impossible to be able to make any communication or contact with her, so my respite visit seemed like it was going to be more about making sure she stayed safe while her mom and younger sister went out for some “Mommy & Me” time, something they rarely got to given the teenage daughter’s condition. They were gone for a few hours and throughout my time with Mary (not her real name), I spoke to her, stroked her hair, and played music any teenager would want to listen to—Justin Bieber. While it seemed crazy at the time, Mary responded and smiled a beautiful smile as if to reassure me that this was “all good” and despite my doubts, she was enjoying the music and (hopefully) my ramblings and company. I had a few more visits with Mary and her family again to provide respite care for various outings (to attend religious services at their church, for a Dr. appt. for the Mom, etc.), and they all were much the same as the first although I expanded the musical selections to include other popular teen tunes. While Mary couldn’t sing or dance to any of them, inside her body was the soul of a teenage girl who wanted to soar and I can only hope she did during these respite visits with the music cranked up in her room and her smiling.

I was given another pediatric respite assignment and when I arrived at the house, no one answered. When I called my hospice contact, they informed me that the boy had been hospitalized over the weekend and probably wasn’t going to make it. This saddened me that the family had perhaps finally felt comfortable in reaching out for a respite volunteer, and that we were too late in providing some much needed breaks for this family from the burden of this child’s care.
My next respite call was for a beautiful 13-month-old girl whose pediatrician had referred the family to palliative care and hospice given the child’s condition, multiple surgeries, and potential future prognosis. While expecting the worst, I was pleasantly greeted by an angelic toddler named Grace (not her real name) who couldn’t walk or talk yet, due to developmental delays, but who was just a joy to be with. Her Mom was overburdened with Grace’s care and tube feedings and was in desperate need of some time to run errands without the baby and all her medical equipment. There were grandparents, but they weren’t comfortable being taught how to use the tube feeding equipment, nor were any close friends, so it was hard for Grace’s Mom to get the breaks from Grace’s often 24/7 care that she needed. My first visit was just a few hours but the Mom seemed so refreshed and accomplished after all she’d gotten done, that I felt it had benefitted Grace and Mom to have this respite visit.

Since then, I have provided respite care to watch Grace while Mom (or Mom & Dad) get out to do “regular, real life things” with their other child, a boy 6, that they have not been able to do before. They have had a bounce house birthday party for their son away-from-the-house while I watched Grace, the Mom has been able to finally take cupcakes to school for her son’s birthday for the first time (Grace can’t be around school children due to susceptibility to germs), she and her husband have had date lunches where they get some “them” time, and more. However, on my most recent visit, Grace’s Mom greeted me at the door and she did not look well. They had Grace on a new feeding regimen through a button tube into Grace’s stomach that she wasn’t tolerating and it showed on Mom. We talked for a while (actually, about 45 minutes) and then she showed me how to use the medical equipment to feed Grace with while she was gone. She then went to run a few errands. When it was time for me to leave, the Mom apologized for venting about all of Grace’s medical mishaps and trials/errors over the past few weeks. She said she felt this wasn’t a good use of my time being there and that she should have left to run errands earlier, but she also said she really needed someone to just listen to her as she didn’t think she had anybody to talk to who understood what it was like to care for a child with Grace’s medical needs. I explained to her that respite is whatever she needed it to be—and if her talking and me listening was what she needed while I held Grace—then that’s what we’d do. She seemed relieved and I promised to check my calendar and see if I could come provide this to this family more often.

While my journey towards being a volunteer in pediatric palliative/hospice care has taken some interesting twists/twists, the rewards have greatly outweighed any downsides (e.g., emotional burden, grief, more chaos in my already hectic schedule with 3 kids of my own, etc.) I may have experienced. I’ve grown more comfortable in the role and do not have much apprehension with each new house I approach, but instead, just focus on how I can help and make a difference. At some visits, it may mean I’m tube feeding an infant, at others, listening to a Mom rant about changes in her child’s care, and in yet others, I’m a DJ spinning tunes for a teenage girl while her family takes a needed away-from-home break. I have seen the difference that respite care can make to these children and their families. And despite all the team’s efforts, treatments, medical interventions and therapies, etc., sometimes there is nothing that can make the sick child and/or family feel better than the “human touch” and presence that a caring, compassionate person can bring to these situations.

To people considering volunteering to work with seriously ill and dying children in palliative care and hospice programs around the country in whatever capacity needed, I’d say “Just do it.” You can be trained and you will be supported by the pediatric palliative care/hospice team you’re volunteering for. Yes, there will be some fears (and maybe even tears), but the appreciation from the kids and their families is so heartfelt, that I can’t imagine not doing this. Our seriously-ill and dying children and their families need you to share of whatever time, talents, or treasures you have. I see firsthand how the burden of care on the families can crush them, resulting in a huge physical, emotional, and financial toll that impacts the seriously ill/dying child and the entire family. The need is great, the volunteers few, and the families of these sick/dying children are suffering. The time to volunteer is now.
SUNCOAST HOSPICE TEEN VOLUNTEER PROGRAM

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During the past seventeen years, the Suncoast Hospice Teen Volunteer Program has grown from 20 students to over 500 students in 2012. Teen volunteers range in age from 14 to 18 years of age and represent high schools and communities across Pinellas County, Florida. Suncoast Hospice has a rich history of uniting generations through non-traditional avenues to provide enrichment, education, and engagement for and between all age ranges. Suncoast Hospice’s Stepping Stones Program includes medical care and complementary therapies to relieve physical pain and symptoms, as well as emotional and spiritual counseling to help children and teens cope with the hardships of illness. The goal is to bring comfort to children and support to families so they can live life to the fullest with hope, courage, and strength. By partnering with Stepping Stones, teen volunteers support the youngest of patients and their family members through direct interaction. The most common teen volunteer activities offered to pediatric patients and their siblings include tutoring, companionship, and play time.

The Suncoast Hospice Teen Volunteer Program has had the opportunity to collaborate with Stepping Stones on some very special assignments: a teen volunteer helped an eight-year-old patient practice her cheerleading moves; a teen babysat a healthy three-year-old twin while the other three-year-old child received care from the hospice nurse; a teen provided respite for the mother and play time for a child who is not able to play with her twin sibling. Other teens bring their technical skills to the table by spending time and playing video games with young teen hospice patients.

Each teen volunteer assignment with a child is unique and designed to meet the needs of the pediatric patient and/or their family. As such, some volunteer assignments are one-time requests, while others allow for relationships to be built over time during regularly scheduled visits. The following excerpt highlights a special relationship between a teen volunteer and a pediatric patient who have spent time together for the past two years, as shared by the patient’s mother:

"The volunteer is a wonderful young lady who volunteers to come out and play with my sixteen-year-old special needs daughter. She has consistently come out every two weeks for a couple of years now. She is very responsible and if for any reason she can’t come, she always calls to let me know. She has made my daughter feel so special when she is here with her because [her daughter] doesn’t have many friends and Jackie gives her undivided attention… When I sit in the living room and listen to [her daughter] laugh and giggle when Jackie is with her it warms my heart and brings me to tears.”

By carefully matching teen volunteers with pediatric patients and family members, the possibility of creating special bonds is significant. This matching requires quite a bit of coordination on behalf of hospice staff and teen volunteers. Requests are made and coordinated through a series of steps: pediatric care team staff assesses for volunteer needs and requests a teen volunteer as appropriate; teen volunteer program staff recruit potential teen volunteer(s) for the assignment; pediatric care team staff makes field visit with teen volunteer(s) to introduce the teen volunteer(s) to the family and assist with first visit; pediatric care team staff, teen volunteer staff, and teen volunteer stay in close communication to assure patient and family needs are met. Whenever possible, the teen volunteer program selects more
than one teen volunteer for long-term assignments to provide back-up and support for consistency purposes.

In addition to direct patient and family interaction, teen volunteers also support the Stepping Stones program in a number of special activities: creating memorial slideshows for survivors of pediatric patients, providing childcare for pediatric family support groups, offering musical talents at pediatric memorial services, and providing technical assistance by videotaping special events and activities organized by the Stepping Stones program. One of the annual activities teen volunteers enjoy the most is providing assistance at Camp Erin, a Suncoast Hospice bereavement support camp for children. From assisting with special projects before camp to canoeing with children who are guests at camp, teen volunteers have special roles. Many teens also choose to participate in fundraising efforts to support the Stepping Stones program such as hosting bake sales at community events or gathering funds to purchase gifts for a family in need during the holidays.

For some teens, volunteering is a way for them to give back to a cause that is so near and dear to their own hearts – as survivors. After receiving hospice services in their own families, or attending Camp Erin as a child, some decide to volunteer for Suncoast Hospice. At Camp Erin in 2012, two teens returned to camp as volunteers – one seven years after participating in camp, the other five years after. It can be particularly inspiring, as described by Kathleen Quance, a Senior Counselor for the Stepping Stones Program to see them attend Camp Erin later in life as a camp volunteer, "It is cool to hear them say to camp participants, 'I was here’. They are modeling it is okay to be okay and to make good choices with your pain. It is a different level of healing for them, wanting to give others hope. You get to see them come full circle.”

The collaboration between Suncoast Hospice’s Teen Volunteer and Stepping Stones programs demonstrates the unique contributions teen volunteers can offer to pediatric patients and families. Whether it is time spent playing or time spent learning, there is a special bond that is built by providing teen volunteers with the opportunity to make a difference in the lives of someone so similar, yet different, than them. The experiences and stories shared by teen volunteers, clinical staff members, and patients and families paint a beautiful picture of the important connections made through youth-to-youth interaction.
THE VOLUNTEER PROGRAM IN A CHILDREN’S HOSPICE: 
THE CANUCK PLACE EXPERIENCE

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Introduction to Canuck Place Children’s Hospice

Canuck Place Children’s Hospice (CPCH) became reality in November 1995 when it opened as North America’s first free-standing children's hospice. Canuck Place Children’s Hospice offers four categories of services to children and their families living with life-threatening conditions: respite, pain and symptom management, transition, and end-of-life services. To this day, this program remains the model for children's hospices in North America, providing hospice care free of charge to children and their entire families. Canuck Place Children's Hospice is regarded as one of the leading pediatric palliative care systems in the world. This compassionate hospice work takes place in an environment with all the comforts of home, and provides support for the entire family.

An interdisciplinary and collaborative model of palliative care involves the work of many, including the child, family, caregivers, service providers, and volunteers. Volunteers are essential to the functioning of palliative care programs. They serve as an adjunct to the professional members of the hospice team to enhance the personalized care, meeting the needs of the patient, families, and the organization.

General Description of Canuck Place Children’s Hospice Volunteer Program

The volunteer program at Canuck Place upholds the mission of the hospice: to be a caring, innovative, and community-based service that fully embraces the life of each child and family. The hospice has a large pool of active volunteers with diverse talents, skills, and abilities that supplement the work of the professional staff. Volunteers provide a variety of services ranging from housekeeping and cooking to gardening, house maintenance, and social and emotional support. At CPCH, the money saved by using volunteers is put toward clinical care and other front-line services that directly benefit the children and families. Volunteers contributed over 23,000 hours of service in 2011 to supporting the work of Canuck Place Children’s Hospice.

Volunteer Recruitment and Screening

Volunteer selection and screening are the groundwork for ensuring that new additions fit well with the existing hospice team. There is a great deal of community interest in volunteering at CPCH; therefore, we do not actively recruit new workers. The main methods of recruiting volunteers are through word of mouth, community awareness of the organization, and the hospice website. The website provides a list of volunteer openings, along with an outline of potential volunteer roles and expectations. Response is high, averaging between 30-80 prospective volunteers each month. Applications are filed and when a vacancy arises in a relevant area, the prospective volunteer is contacted for an interview.

The Manager of Volunteer and Support Services is directly responsible for the hiring, training, and support of volunteers. Potential volunteers are chosen to complete a one-hour face to face interview. Following training, candidates must provide two personal reference letters that specifically outline their suitability as a CPCH volunteer. A criminal record check is conducted (including a vulnerable sector...
check) and all volunteers, regardless of role, must sign a confidentiality agreement. This respects the privacy of the children, family, and staff members at CPCH. After successfully completing the training course, the candidate receives an invitation to become a volunteer, with the expectation to commit to a minimum one-year time frame.

Volunteer Roles

Canuck Place currently has 354 volunteers and of these 245 volunteers work directly with the children and families. Some of the volunteer roles are below:

**Family Support Volunteer:** Family Support Volunteers work alongside the professional care team to enhance the quality of life of the child with a progressive, life-threatening illness, and his/her family. This volunteer is that missing friend or neighbor who can lend a hand when time and energy are depleted. The Family Volunteers are with the children during activities, in the school room, working with arts and crafts, or on outings in the community and generally are there to support the child and family with whatever activities they are doing. Family Volunteers must be at least 20 years of age, complete a 30-hour training program, and commit for a minimum length of one-year post training.

**Bereavement Support Volunteer:** The Bereavement Support volunteer supports the Bereavement Coordinator by attending bi-weekly support groups with parents and siblings. This volunteer must have completed the 30-hour Family Volunteer training, and been in that role a minimum of one year before being considered for this position. Bereavement Support Volunteers must be comfortable discussing topics related to death and dying with children and parents, individually and in a group setting, and have a basic understanding of children’s developmental levels as they relate to grief.

**Peer Volunteer:** Peer Volunteers support the Family Volunteers and the professional care team. Peer Volunteers are between 16-19 years of age. The Peer Volunteer is a friend to children by playing, creating arts and crafts, playing computer games, and generally interacting with the child on a companion to companion basis. Peer Volunteers must complete a 5-hour Canuck Place Children’s Hospice training program.

**Office Reception Volunteer:** Office Reception Volunteers assist the full-time receptionist with reception and switchboard duties for Canuck Place Children’s Hospice during the evenings and weekends. The Office Reception Volunteer is a pleasant, articulate first contact for the guests, visitors, and callers to Canuck Place Children's Hospice. The Office Reception Volunteer must be at least 20 years of age. Reception Volunteers also work at our Development/Fundraising/Finance Office in a similar capacity.

**Kitchen Volunteer:** Kitchen Volunteers provide support to the kitchen staff by assisting with baking, some preparation of meals, and cleaning in the kitchen and dining room areas. The Kitchen Volunteer plays a huge part in helping to keep this as a warm and welcoming place that provides the families with the comforts of home. Kitchen Volunteers must be at least 16 years of age. It is required that all Kitchen Volunteers have Food Safe Level I Certification and a current Hepatitis A Vaccination.

**Garden Volunteer:** Canuck Place is set in beautiful gardens lovingly maintained by a dedicated team of volunteers. The gardens are a place of joy and tranquility for the children and families at the hospice. Garden crew members must be at least 16 years of age and be able to manage some light to moderate physical labor. This Garden Crew works all year round in all types of weather!

**Indoor/Outdoor Maintenance Volunteer:** Maintenance Volunteers work with our Facilities team on a variety of projects to help preserve the beauty of our Hospice facility. These volunteers will assist with paint touch ups, furniture repairs, facility inquiries, and other various duties. Maintenance Volunteers must have experience in this type of work.
**Housekeeping Volunteer:** Housekeeping Volunteers work with our Housekeeping department on a variety of light housekeeping duties to help preserve the beauty of our Hospice facility.

**Volunteer Driver:** Volunteer Drivers provide support to the Recreation Therapy Program and enable children and families to be transported to outings and to activities. They drive the Canuck Place bus, a 26-foot bus with capacity for a combination of 8 wheelchairs or 18 passengers. Regular outings are scheduled for Monday and Friday afternoons and Tuesday evenings. Volunteers are welcome to join in the fun! Volunteer Drivers must possess a Class 4 Unrestricted License to be considered for an interview.

**Volunteer Training**

After interviewing, selected individuals are invited to take part in a training program for their preferred role. Training provides another opportunity for both the Volunteer Manager and volunteer candidate to assess if the hospice and role are a good fit. Training is also a community building exercise, giving volunteers the opportunity to meet volunteers and staff members in a relaxed environment.

Family Volunteers have a unique 30-hour group training opportunity. The volunteers are given background on the mission, vision, and values of the hospice. The basic procedures and policies of the volunteer program are outlined, and professional staff members present on their work and how volunteers support them. Once training is complete, volunteers do a “buddy” shift with experienced volunteers, and are contacted and monitored in the first few months by a volunteer mentor. The Family and Peer Volunteers have direct contact with the children and their families, and thus require more intensive training. These volunteers are also educated about a variety of subjects, including:

- CPCH school program
- CPCH recreation program
- Communications skills
- Medical aspects of life-limiting illness
- Spiritual aspects of death and dying
- Expressive therapies
- Bereavement

**Volunteer Retention**

Sustaining a volunteer workforce requires an understanding of what drives individuals to volunteer in a hospice. With over 350 volunteers at present, CPCH has built a successful program that can serve as a model in pediatric volunteer services. It is interesting to note that CPCH has found the motivation to volunteer in palliative care is based on a desire to help those in need, and that younger volunteers identified factors such as personal growth and desire to work in the medical profession later in life.

CPCH also has a Policy with regard to Volunteer Attendance. The policy includes this information: "A volunteer who is inactive for more than 6 months will be notified that they will be removed from the Canuck Place active database of volunteers unless circumstances are approved by the Manager, Volunteer and Support Services." This process helps us to identify the real and accurate number of volunteers and to better serve the children and families on the Canuck Place Program.

Although CPCH has an expectation that all new volunteers commit to at least one year of service at 4 hours per week, the reality is that volunteers typically stay for much longer. We currently have many active volunteers who have been with us from the beginning in 1995! Our turnover is variable – in 2011 we had 69 volunteers leave the organization and 81 enter the organization – in 2010 52 volunteer leaving and 100 joining us. The majority of volunteers who leave are students. An exit interview is conducted with all volunteers with over 100 hours of service, and a small Canuck Place framed picture is given to them.
Volunteer Recognition

Volunteers are recognized in many different ways at CPCH. In policy, the milestone hours for recognition are 250 hours, 500 hours, 750 hours, and 1000 hours. At different times kids cards, branded T-shirts, and gold pins are awarded. These milestones are measured quarterly, and communication is sent to staff, fellow volunteers, and posted on our website. Annually, we hold an off-site Appreciation Event. Over the years, we have partnered with our Community Partners at venues such as: the local Baseball Diamond, Horse Racing, Hockey Practice, Bowling Alley, and Theatre Sports to name a few.

Continuing Education is offered on an on-going basis for volunteers and is viewed as part of the recognition/appreciation program. This builds community at the same time as providing further learning.

CPCH sees volunteer recognition and management as the responsibility of all staff. For “in the moment” thanks, staff are encouraged to give volunteers a $10 Starbucks card, as a token to their appreciation for their work. These cards can be signed out at Reception and given at any time.

Volunteers are also mentors, coaches, and trainers. All practical training is done by volunteers; all follow up check-in calls for new volunteers are done by the Volunteer Leadership Team.

Communications: It is also important to help volunteers see the bigger picture of Canuck Place Children's Hospice. Volunteers are only exposed to a small portion of the activities during their shift. A weekly e-newsletter is sent to all volunteers to keep them informed on all areas within the hospice, such as administration, development (events), and marketing and communications. A secure "volunteer room" on our website has also been created. Volunteer Substitute lists are here, and a blog for volunteers to share stories and experiences.

Current Initiatives

As with any organization, it is important to ensure volunteer stability, satisfaction, and opportunities for growth.

Community Partnership Ambassadors: The purpose of the Community Partnerships Ambassador volunteer is to represent CPCH in the Community. They act as a liaison and representative between CPCH and its Community Partners and attend special events/fundraisers/corporate service days as requested. Volunteers attend a one-day public speaking training program. These volunteers were interviewed and selected very carefully based on their knowledge and their confidence/articulation.

Extension of Services: “One Province, One Program” - To meet the growing need, Canuck Place is currently building a second facility - a 10-bed, 5 family suites, 30,000 square foot hospice in Abbotsford, BC, which will essentially double the capacity of Canuck Place. Operations will be phased in over a three-to five-year period, beginning with a consultation team, outpatient clinic, and support groups, then three to four beds open 24-hours per day, working incrementally to a fully operational 10-bed children’s hospice as funding is secured on an ongoing basis. Volunteers will be phased in as needed in all roles. Currently we have 20 office administration/special events volunteers at our second site.

Conclusion

Canuck Place Children’s Hospice aims to fully embrace the life of each child and family. This is in part accomplished by a committed group of volunteers that generously dedicate their time. The initial recruiting process is important in finding the right role for the volunteer and the right volunteer for the organization. Substantial training further equips volunteers with the knowledge to carry out their role with competence and confidence, and helps retain these volunteers within the hospice. The talents of
volunteers at CPCH are diverse, and CPCH aims to recognize and thank volunteers for their continuous contributions.

The volunteer program at Canuck Place Children's Hospice is focused on welcoming the children and their families into the comfortable, loving atmosphere that they deserve, and we could not provide this level of support without this dedicated team of volunteers.
VOLUNTEER TRAINING: ONE PROGRAM'S EXPERIENCE

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As the first program director of the first free-standing facility to provide Pediatric Palliative Care encompassing end-of-life care, respite, and transitional care (pain and symptom management as well as goal directed care to bridge between hospital and home) in the United States I faced many challenges including the following: The challenge of bringing to life the principles of palliative and hospice care in a country that feared death, most especially the death of a child, while bringing to reality the vision of cofounders Barbara Beach, MD, and Kathy Hull, PsyD, MA; The challenge to educate not only patients and families but also to educate our community of health care providers and staff to this new option in the care of the medically fragile child; and The challenge of providing care that was never available before in the United States, "selling" the necessity of this care, and making it a reality.

In many ways, the initial challenge was easy. Developing the program and services, writing the principles, the policies and procedures, and creating the framework in which to deliver the care within the regulatory restrictions of state, federal, and professional governing bodies was not difficult because the vision was clear. The mission and values were clear—providing services to children and families who may not survive childhood under the umbrella of the pediatric palliative care framework. This meant that not only were we going to provide professional "medical" care encompassing nursing, medicine, social services, child life, and pastoral care, but also the supportive care in an all-embracing "home away from home" environment. To accomplish these goals we needed help; as a new organization, a not-for-profit organization, whose mission was to provide services with no direct means of reimbursement—we needed help. Following the tradition and model of hospice we knew we wanted, needed, to incorporate not only professional healthcare providers but also volunteers in our programs and services. Volunteer help had made the possibility of George Mark Children’s House (GMCH) a reality. Volunteers would continue to help to provide services to children and families, while also helping with the operations and the ever-present need to raise funds for the success of our program.

This provided another challenge, how to train not only the healthcare providers but also volunteers who would work with dying children and their families in this brand new environment. In order to meet the needs of all our staff (staff are both volunteers and paid employees), our leadership team met to review resources available and to determine our objectives for the training. As an advisor for the End-of-Life Nursing Education Curriculum – Pediatric Palliative Care (ELNEC-PPC), it was an easy decision to use this curriculum as the basis for all training at GMCH. As the curriculum was initially developed to be integrated in nursing education, we knew we had to make some changes but found the core curriculum and the associated additional tools and references a wealth of information that could be easily used with our interdisciplinary participants!

For the initial opening all staff were required to participate in a two-week, full-time training. Not only was this a unique experience but it was also an incredible tool in team building. We followed our training with a 3-day simulation, encompassing all shifts and roles; our patients were our children, grandchildren, and friends; family members were volunteers and staff who were "off shift"! The first week was primarily the ELNEC-PPC core curriculum reinforced with interactive exercises. During the second week all participants were separated into groups based on roles for the morning and brought back together for debriefing and interactive role-playing. We incorporated role playing of different potential scenarios that any member of the staff—volunteer and paid—may be faced with, from the overexcited siblings/visitors to the child dying with difficult pain and symptom management issues and a large distressed family in residence.
During the two-week training we required daily evaluations and a comprehensive evaluation following completion of the training. The week following the training we compiled all the data from the evaluations to ensure we addressed any areas of need during the 3-day simulation where we simulated full operation from providing tours, admitting children and families, caring for children and families, pets moving in with children and families, providing meals, housekeeping, child life, 24/7. This reinforced the training done during the initial two weeks of training. This included training to work with children and families, working in the kitchen, helping in the office/administration area, helping in the garden, housekeeping, engineering, and nursing. As a "home away from home" each and every person working at the House would be involved with and part of the care of the child and family respective to scopes of practice and regulations.

Of course, when opening a new facility, designing the ideal training is easy. How to do this once we were open to ensure each member of the team would be as comfortable and ready to work with children and families was the new challenge once our doors opened. Being able to hold to the same standards and basic requirements was of the upmost importance, but how to do it while providing services and have the same impact seemed daunting. Again we went back to our framework, our vision, mission, and values. We took the ELNEC-PPC curriculum, the evaluations of our initial training, the policies and procedures, and the regulations governing all aspects of our organization. We reviewed each job description and determined what education was essential, what education would be helpful, and what education would be nice but not necessary to start. We wanted to provide the same for all our staff, i.e., a mentor who understood and shared the same experiences that could provide friendship and support to each staff member. Just a reminder—staff at GMCH refers to both volunteers and paid staff.

The staff that opened GMCH were a mixture of adult trained and pediatric trained professionals. Almost all of our first House volunteers had helped with fundraising and special events to get the House open, but none had actually worked with sick children; however, they were committed to the mission of GMCH. As we progressed we had many volunteers come from the adult hospice world who were familiar with end-of-life care, but not with pediatric care. All primary professional roles were experienced pediatric professionals: Program Director, Medical Director, Psychologist, Social Worker, Child Life Specialist, Nursing, and physician staff (we had our own 24/7 physicians on call). Our aides came from both adult and pediatric backgrounds and our first chaplain was also a licensed Marriage and Family Therapist. Although all the professional staff were trained and experienced in pediatric care only one was actually experienced in pediatric palliative and end-of-life care. As time progressed we had potential staff come from acute care, home care, and hospice with adult or pediatric training. With a staff this diverse comprehensive training, set expectations, and creating a common foundation was critical. The training plan incorporated the following topics under each category: essential, helpful, and nice. Essential included:

- What was palliative and hospice care
- The history, mission, vision, and values of GMCH
- What was the difference between adult and pediatric palliative and end-of-life care
- Growth and development inclusive of normal, sick children, siblings, parents/family members, and ourselves
- The children we care for or may care for—review of pediatric conditions vs. adult conditions that may limit a child’s life and the trajectories these conditions may follow. Pathophysiology was included for clinical staff. Review of challenges with pediatric care from perinatal, neonatal, toddlers, young and middle school age, adolescence, and young adults.
- Cultural Competence -- GMCH is in the San Francisco/ San Jose/ Oakland Bay Area, one of the most diverse areas in the United States with a population over 9 million people. In the first 6 months of service to children and families we were introduced to 19 different cultural/ethnic backgrounds in our children and families.
Children’s Project on Palliative/Hospice Services

- Pain and symptom management—both "clinical/pharmacologic" for healthcare professionals and non-pharmacologic for all staff.
- Child Life—the work of children, play, school, activities appropriate by developmental levels and physical abilities.
- Ethical and legal considerations inclusive of boundaries, regulations governing the House, scopes of practice, policies, procedures, and issues that may be presented when caring for a child who may not survive childhood and their families.
- Death—our own mortality, our experiences or lack of experience with death; the feelings this might bring out, and how to recognize possible feelings and how to care for self.
- Care at the time of death—for the dying child, as well as the family and friends and each other.
- Loss, grief, and bereavement—for all who are touched by the loss of a child including family, friends, and staff.
- Resources available—including psycho-social support, pastoral support, and educational resources and support.

Essential training had to be accomplished before the staff member could start working. Consequently, this training was offered twice a month with day and evening sessions. Each session was 4 full days followed by "on the job" training with the direct supervisor—typically for at least two to six+ shifts dependent on role.

During the first year of operation it was clear that a teen "peer" program would be of benefit for our children—both patients and siblings. Although our adult volunteers were and are wonderful, they were adults. Intellectually, we knew kids would prefer to play with and be with other kids. Our experience demonstrated that our kids (patients and siblings) yearned to be "normal"—to be kids, to play with kids, to have friends, and to forget about being sick or having a sibling that was sick. Although we could not make the illness go away, we could provide for "friends" in keeping with our focus of a "home away from home."

Training for the teen volunteer program was established following the same principles as our initial trainings; however, we also expanded the interview process for participants. Potential participants were interviewed by both our social worker and our child life specialist, in addition to our volunteer manager and program director. Training covered the primary topics as the adult training, but a stronger emphasis was placed on appropriate play and activities, communication, boundaries, role-playing, seeking assistance, policies, and procedures. Teens were able to volunteer to work with children or to help in other ways such as in the dining room, special events/fundraising, or in the office. All teens were paired with adult mentors and none were allowed to work unless a senior adult volunteer was also working. A specific job description for teen volunteers was created and our child life specialist was their liaison.

In order to facilitate the experience for all volunteers with children and families that were in the House, during their shift our child life volunteer created a notebook with a short summary of the child and family, likes/dislikes, recommended activities, and an outline of the child’s/children’s routines. Additionally, we created a journal in which all volunteers briefly documented what had occurred during their shift. All volunteers were required to sign-in and read the summary on each child and family, signing the log that they had read the notebook. At the end of their shift they had to log out and document in the journal.

At the start of each shift, after signing in, all volunteers reported to the nurse in charge to get report and to receive their specific assignment for their shift. The nurse in charge was responsible to oversee any volunteers working with children and families. If a volunteer was working in another area of the House, then the paid staff member was ultimately responsible for the volunteers working in their area such as helping in the kitchen or the front office.

Many of our teen volunteers started their volunteer service to fulfill a service requirement for high school; others came because of a possible interest in a healthcare profession. One of our first teen volunteers...
just filed her dissertation, earning her PhD in Child Psychology with an emphasis on Pediatric Palliative Care. As a teen volunteer she was also awarded the NHPCO Volunteers and Foundation of Hospice Teen Service Award in 2007. Another produced a documentary on the work of George Mark Children’s House, winning an award and scholarship to the university of her choice. Several have completed special projects benefiting the House and families we serve.

Our volunteers have shared more than just their time with our children and families; they have shared their hearts and are often our loudest advocates. Our hydrotherapy program, which has been highlighted for the benefits it has provided in pain and symptom management, is the product of a volunteer. Volunteers maintain the organic gardens. The level of care and caring provided to the children and families of GMCH could not be achieved without the work and help of our volunteers. The importance of their membership in the interdisciplinary team cannot be emphasized enough.
PEDIATRIC HOSPICE/PALLIATIVE CARE TRAINING AGENDA

Maureen Horgan, LICSW, ACHP-SW
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Date
Time 2 ½ - 3 hour training

1. Introductions (10 min) – Overview of Palliative Care/Hospice Volunteer experience & Hopes and Fears about pediatric volunteering

2. Overview of Pediatric Program (15 min)
   - Show Program Fundraising video
     a. Program History
     b. Team Composition
     c. Palliative Care and Hospice Levels of Care

3. Differences in Pediatric Hospice Care and Adult Hospice Care (10 min)
   - Show picture of pediatric patient and adult patient – conversation about images leads to education on differences.

4. Choosing Thomas Video (10-15 min)
   - http://www.youtube.com/watch?v=ToNWquoXqJI

5. Developmental Considerations when Working with Families with an Ill Child (20 min)

6. Lion in the House – Video (15 min) Part II, Part IV –

7. Break (10 min)

8. Love and Sorrow Video (20 min)

9. Break (10 min)

10. Stepping Stones Team and Volunteer Panel: Sharing Experiences (30 min)
    - a. What do you like best about your role
    - b. What part is hardest about the work
    - c. Tips for new pediatric volunteers

11. Active Listening as a Tool for Effective Communication (20 min)

12. Assuring Solid Volunteer – Participant Relational Boundary Overview and Role Plays (15 min)

13. Volunteer Procedure(s) Review (5 min)

14. Thank You – Closing Ritual (5 min)

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MAINTAINING OUR INNER LIGHT IN PEDIATRIC PALLIATIVE CARE

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As a Family Therapist working in pediatric palliative care I am often asked why I chose this field and how I can stay in a job where I daily encounter children and families struggling with life-and-death issues. While that is a complicated question to answer, my primary response is personal and begins when I witnessed my paternal grandfather, my family’s dearly loved patriarch, dying slowly from pancreatic cancer. For me, it was a lived experience in how consuming, devastating, and lonely the illness and death of a loved one can be. Although difficult to endure, that experience has actually become the foundational experience that I return to when I am in the midst of helping others navigate life-threatening illnesses. I have found that the death of my grandfather and additional grief, losses, and health experiences I’ve encountered are now my most powerful generators of passion, empathy, and resilience—they are my touchstones that I revisit when I need to regain my perspective and compassion in order to continue the hard work that is required in pediatric palliative care. However, these touchstone experiences can also easily become the primary obstacles in my way of providing quality care to patients when I disconnect, distance, or protect myself or, on the other hand, when I connect too much, get too close, and refrain from protecting myself from the thoughts and feelings that can emerge in this work.

To be able to stay passionate, empathic, and resilient is the most challenging aspect of being involved in PPC. To maintain our resiliency in this work it is crucial that we understand our own experiences of suffering, illness, and the healthcare system and realize the impact those experiences may be having on us as we try to help others. In order to build our capacity for the significant burden of the work we do, we need to pay attention to what happens when we’re suffering, afraid, angry, or feel out of control—what happens in our body and mind—so we are consciously aware of our internal state and can monitor how we’re doing. While it’s not fair to assume we won’t ever be afraid, angry, overwhelmed, or disconnected when faced with a situation that is challenging, what we can do is recognize and explore those experiences that impact our ability to be appropriately present and engaged in hopes that we can respond more effectively the next time. While a commonly espoused way of dealing with the stress inherent in PPC is to “check out” or “keep your distance,” actually the most effective way for us to sustain engagement in our work is to connect, get closer, and be vulnerable in terms of how these experiences are personally affecting us and find the help we need to buoy us during these difficult times. As volunteer supervisors it’s important to be asking our volunteers about their internal experiences and how they are making sense and coping with the present pain and suffering they are experiencing. As volunteers, we need to be aware of ourselves and tell our supervisors when we find we feel stifled, overwhelmed, numb, scared, out of control, or angry as we interact with a patient, family member, or healthcare team member. Another way to think about this internal work we need to do is in the form of considering we have an internal light as Elizabeth Kübler-Ross suggests.

“People are like stained-glass windows. They sparkle and shine when the sun is out, but when the darkness sets in, their true beauty is revealed only if there is a light from within.”
— Elisabeth Kübler-Ross

This quote provides a way to think about our resiliency in our role as part of pediatric palliative care. For me, one of the ways I know that my inner light is too dim is when I find myself tempted to respond with an abundance of anger or blame in response to patients, caregivers, colleagues, or people in my personal
life when things aren’t going as planned. Feelings of anger and blame now trigger me to stop, take inventory of what’s going on in my life, and try to figure out what I can do to provide the balance I need to help brighten my inner light. I also usually find that I am in need of more rest, more water, more times of enjoying life and laughing, and more connected conversations with others who understand this work. These things are the keepers of my internal light.

What about you? How do we ensure our inner light stays bright and we can remain resilient in the light of the suffering and injustice at hand? When the darkness sets in, what helps keep your light from within bright? When your internal light begins to dim, what do you need to do to take care of yourself?
LEARN HEALING TOUCH AND HOLISTIC HEALTH GAMES:
LIFE-CHANGING, THERAPEUTIC, FUN, FREE

Samuel Schoonover
TLC Holistic Health Foundation
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Everyone wants to experience meaningful personal connections, nurturing, and deep emotional bonds with others. The non-profit organization, the TLC Holistic Health Foundation, designed fun games that teach you and your loved ones, whether healthy or ill, therapeutic touch techniques. Our mission is to teach you how to give and receive the TLC Holistic Health Games© (TLC HHGames) with your family and loved ones for lasting mutual benefit.

We have uniquely combined therapeutic touch and upbeat holistic health techniques to help children and adults with cancer and other illnesses, and those who provide care for them, to satisfy physical, emotional, and spiritual needs. Both the Giver and the Receiver simultaneously benefit from feelings of nurturing and energizing. In addition to teaching therapeutic touch we teach Guided Imagery along with a technique of hypnotherapy called “anchoring” which is a simple kinesthetic way to bring back all the happy feelings and memories of doing the games by simply putting your hand on your heart.

If your loved one chooses, they can verbally interact throughout the games asking to receive their favorite healing color, magic wishes to come instantly true, and receive massage strokes where they need them the most. We bring in humor, verbal words of mutual appreciation, and gratitude to create lasting win-win qualities for both the receivers AND the givers.

Cancer statistics raise awareness of the acute need for these games to aid healing and recuperation. Each year there are 353,000 new cases of cancer in children age newborn to 19; 1.6 million new cases of cancer in adults; 11.7 million cancer survivors. In addition, caregivers for all these patients need the game to rejuvenate themselves to nurture the patients, as well as those processing bereavement.

Factor in the 141 million people in the U.S. with other chronic illnesses, plus the needs of their caregivers, and the need for the game multiplies rapidly. When these totals combine with the steady trend of a decline in people spending family time together, it becomes clear how much all people, whether ill or healthy, benefit from giving, receiving, and exchanging the TLC HH Games. Our games mutually promote immediate self-nurturing and healing for both the receivers and givers. Our experience shows that young children and even teens enjoy this so much, they begin to initiate exchanging the games with their parents, siblings, and friends.

The Giver becomes the hero/heroine of their family or social circle by learning how to appropriately teach all ages how to exchange the TLC HHGames. The TLC Holistic Health Foundation describes in our teaching booklet many of the positive benefits of practicing our games once parents commit to massaging their children for a few minutes every day. Our TLC Holistic Health Games© are simple to learn by following easy, short, illustrated instructions in our 28-page booklet. It is free to view, download, or print from our website at www.tlchhf.org and then click on "TLC Games." These show instructions for giving the “Back Rub Game,” “Hand and Arm Rub Game,” “Smiling Heart Guided Imagery Game,” Anchoring Techniques, and the “TLC Nurturing Holds” game (all with clothes on).
We encourage the Giver to ask permission of the Receiver if they would like the Back Rub Game applied directly on their skin using massage oil or lotion. One popular metaphor is planting magic seeds in the garden of the receiver’s back, hand, or arm using traditional massage strokes. If the receiver is too young or unable to verbalize their preferences, then the Giver can trust that their own intuition is just right.

First, the Receiver picks his or her own special hero/heroine nickname to use during the game like “Mike the Mighty” or “Awesome Alice.” Using this name, the Giver uses guided imagery to send the Receiver his or her favorite color to warm, knead, and smooth the soil.

The Giver uses circular massages to “dig the holes” at the acupressure points for the seeds. Both the Receiver and the Giver ask for their own personal magic seeds to plant. Using appropriate light-to-heavy strokes, the Giver “brings” thunder and lightning, followed by rain and double rainbows. The Giver infuses love to the seeds with heart-shape strokes, happy face strokes, and an “I love you” stroke. At the end both the Giver and Receiver plant mutual admiration and appreciation and then choose what they are specifically grateful for.

To ensure that the games are safe, the Giver reviews the S.A.F.E. acronym with the Receiver:

“S”...Say what you want and do not want throughout the game/stroke.

“A”...Ask them: Want the ___ Game/stroke now? (Answer: “Yes.” or “not now.”)

“F”...Feedback: Say: “Lighter, more pressure, not there, go here.”

“E”...Each time you can exchange immediately, or later.

Here is an abbreviated version of our Smiling Heart Guided Imagery. Our booklet has more details along with various potential variations. First, you the Giver (right now) place one hand on your heart and your other hand on your belly or a part of your body that needs healing or attention. Imagine as you inhale breathing your favorite or healing color into your chest. Figuratively make your heart bigger as your inhale your color into your heart, which is about as big as your fist. Continue breathing slowly as you see and “feel” your heart filled with this color along with imagining your heart itself is smiling. See the smiling heart on our cover.

Now match this smile by also placing a big constant smile on your face. Now on your slow exhale send your loving color out your enlarged Smiling Heart to fill your chest, down your arms, and out your hands. See and feel the color go back into your heart and your belly or the part of your body that needs the most attention.

Now if possible and/or appropriate read these same instruction to your loved one (Receiver) to do this on themselves. This serves as practice for them to give it to themselves in the future any time, any place for self healing. Ask them what THEIR favorite color is and repeat the guided imagery above as you place the one hand in the middle of their back opposite their heart and your other hand gently either behind their neck, on their lower back, or a place they direct you to where THEY want extra attention or healing. Instruct your receiver to take (with you) slow deep breaths and continue the Smiling Heart Guided Imagery for as short or long of a time as you like.

Anchoring is a powerful technique from hypnotherapy in the TLC Games that works to kinetically trigger, duplicate, and bring back the positive experiences felt above by just putting your hand on your heart. The concept originates from Ivan Pavlov’s famous studies of stimulus-response in dogs. He put a steak in front of hungry dogs and as soon as they started salivating, he rang a bell. After several trials, he discovered they would salivate when he rang the bell without any meat. He concluded that the dogs
learned to associate the sound of the bell with satisfying their hunger. The stimulus of the bell was the anchor for that conditioned response.

Any time a consistent stimulus creates an intense feeling state, the state links to the nervous system; forming an anchor which is the conditioned response that triggers people into the specific state through the five senses. For example, the sight, sound, taste, smell, and feel of buttered popcorn trigger the prior pleasant experiences of a movie theater. The process is anchoring. Feeling your own hand on your heart or putting your hand on your loved one’s back opposite their heart will kinestically anchor the joyful happy memories of doing the games in the past through the sense of touch.

To anchor the memories even more the Receiver is asked to continue to have their hand on their heart. The Giver continues to have one hand on the middle of the back of the Receiver. In the first step, the Giver asks their Receiver what state of mind or what feeling they would like to remember. It can be anything you want, for example joy, happiness, relaxation, fun, love, peace, acceptance, laughter, trust, or healing.

The second step is for the Giver to place the Receiver in their desired state by asking a series of focused questions: Remember a time when you felt ______ (fill in here what feeling they said above). Can you remember a specific time? As you go back to that time, can you step into your body and see what you saw through your own eyes, hear what you heard, and feel the feelings that you felt then when you were totally ______?

The third step is for the Giver to say to the Receiver, “As you begin to fully experience the desired state of ______, use your physical anchor of having your hand on your heart for at least 15 seconds or more, until you are at the peak of the experience. Then, let go of the anchor. The Receiver helps to set the anchor by touching them on their back opposite their heart. The Giver asks the Receiver to nod their head when they are fully in their desired state.

For the Receiver to set off and activate Anchor any time any place, put your hand on your heart throughout their daily life to learn to successfully trigger themselves into “resourceful state” whenever they want to. The Giver can help duplicate and bring back the happy memories of doing the games by simply gently placing their hand on the Receiver's back. Using this anchoring technique can shift emotional states to new Resourceful States creating options for new ways to feel, act, and respond.

Here are several “win-win” mutual benefits for the Giver and Receiver of the TLC Holistic Health Games©:

The TLC Holistic Health Foundation promotes the philosophy of "the win-win of quality one-on-one time to significantly improve their overall quality of life and create memories that last a life time."

- Deeper connection and bonding between Givers and Receivers.
- Receiver gets “I am special; I am loved” messages, leads to greater self-worth.
- Giver gets recognition for providing self-worth and warm feelings of expressing their love.
- Receivers and Givers experience an immediate increase in Oxytocin, the “cuddle hormone,” or the “love hormone,” which is released immediately while exchanging massage. This euphoria increases the ability to bond with others, maintain healthy interpersonal relationships, and build trust.
- Sloan-Kettering Cancer Center research showed that giving just 20 minutes of massage cuts symptoms and side effects in half.

- The Touch Research Institutes University of Miami School of Medicine found that when parents gave ill children massage, it lessened physical pain, managed pediatric pain, and reduced the need for pain medication. Massage also lessened anxiety, loneliness, isolation, depression, touch-deprivation, and more.

- Studies proved that massage promoted faster weight gain for premature babies and strengthened immune systems of kids with cancer.

- Research reports massage benefits people with abuse, asthma, autism, ADHD, mild to moderate Juvenile Rheumatoid arthritis, behavior problems, burns, Cerebral Palsy, Cystic Fibrosis, depression, Diabetes, Down Syndrome, HIV/AIDS, pain, psychiatric problems, sleep disorders, and those in hospice care.

- Researchers discovered Givers and Receivers had cherished memories of the heart connection from their massage experience a decade earlier.

- Massage promotes pleasant times of laughter; leading to boosted immunity, lowered stress hormones, decreased pain and anxiety, increased relaxation and hope, zest and joy for life, better bonding, and improved relationships.

- Guided imagery during massage elevates moods and decreases stress, fatigue, and depression, especially when the anchoring techniques are used.

- Teaching and learning the TLC games promote feelings of usefulness. Children as young as four have found a new purpose in helping family and friends benefit by exchanging the game.

The TLC Holistic Health Foundation is setting up a program, "My Extended Family Tree," that will track worldwide how individuals personally begin a legacy by "Paying It Forward" via email, etc., similar to the book and movie whereby everyone turns on three new people to the TLC Games. And then asking them continue this so on and so forth.

We are the first and only non-profit organization in the country who focuses giving our FREE services to: (1) teaching parents/caregivers how to give therapeutic touch to their child with a life-limiting/chronic illness, Special Needs, in Hospice care or with present or past issues of bereavement; (2) empowering children by teaching them how to exchange the TLC Games and other exercises on themselves and others; (3) training existing volunteers and staff of organizations to share the TLC HHGames with their clients/patients; and (4) instructing our own volunteers to become Certified TLC HHGames Teachers and provide the services free of charge.

To date we have:

- Served more than 70 children at a children's hospice, the George Mark Children's House in San Leandro, CA.

- Taught the Back Rub Game to more than 480 kids and parents at Camp Arroyo in Livermore, CA, for various life-limiting/chronic illnesses.
• Plan to expand the above services and return again to service the Family House in San Francisco identical to a Ronald McDonald House.

• Plan to repeat our successful pilot study of certifying college university students to receive academic credit by serving as TLC HHGames teachers.

Please contact the director, Samuel Schoonover, by email at tlchhf@gmail.com or call 831-334-0333 to share your ideas, networking, potential connections, or to plan bringing the TLC Games to serve your organization. Be sure to view our TLC HHGames Booklet you can download and print for FREE on our website at www.tlchhf.org.

Thank you for your help by sending this article directly to your contacts or forwarding their contact information to us for new connections to serve or inform: (a) any person/family in need; (b) hospices, hospitals, clinics; (c) directors of service agencies; (d) Ronald McDonald Houses; or (e) anyone else interested in donating time or funds.

Please subscribe to our mailing email list for:

• Updates on upcoming DVD on teaching the TLC HHGames

• To participate in a research study which includes a grant to design an application on our TLC HHGames in the form of interactive game that will go on iPhones, etc.

• Updates on an upcoming Internet Class whereby professionals and families can become Family TLC Games Teachers

• Provide your testimonials of the games to help us receive more funding.

Thank you for being open to receiving, giving, and exchanging our TLC Holistic Health Games with all of your family, friends, and those in need.

Note: The TLC Holistic Health Foundation invites you to download a free 28-page booklet, TLC Games©, (PDF) available on the TLC Holistic Health website.
Items of Interest
In each issue of our ChiPPS e-newsletter, we offer additional items of interest.

1. PEDIATRIC PALLIATIVE CARE TRAINING SERIES. An expanding list of modules on pediatric palliative care is available on E-Online (NHPCO’s online education portal). Created with our ChiPPS committee members, we encourage you to take advantage of the existing modules which offer immediate CE/CME credit. The list of available modules:

- Module 1: Pediatric Palliative Care Principles and Standards
- Module 2: Pediatric Palliative Care Delivery Models
- Module 3: Ethics, Decision-Making, Advance Care Planning
- Module 4: Pediatric Palliative Care - Childhood Development in Health and Illness
- Module 5: The Spectrum of Complex, Chronic and Fatal Conditions in Pediatric Palliative Care
- Module 6: Pediatric Palliative Care-Assessment and Management of Pain

2. PEDIATRIC INTENSIVE AT CTC A SUCCESS. NHPCO’s 13th annual Clinical Team Conference and Pediatric Intensive, held the first week of November in Orlando, was a resounding success. Attendance at the special two-day preconference seminar on pediatric palliative care was booked to capacity. Many of those participants stayed for the subsequent conference and took advantage of the pediatric palliative care session track that was offered. Audio recordings of the concurrent sessions from the CTC are available for purchase from DPS – our audio recording vendor.

NHPCO extends its deep appreciation to the members of the ChiPPS work group and from the hospice and palliative care community who helped develop these pediatric offers and served as faculty. Next year’s pediatric intensive will be September 26-28, 2013 at the Sheraton/Westin Hotels at Crown Center in Kansas City, MO. We hope to see you there!

3. 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, self care, ill and dying teens, perinatal loss, neonatal loss, spirituality, memory building and legacy making in pediatric palliative and hospice care, ethical issues related to pediatric palliative and hospice care, help and healing in relationship to bereavement perspectives, stress and moral distress (identifying stressors and supporting staff), using social media and electronic communications to network by families and practitioners, the role of pediatric palliative and hospice care in creating systems to support children, families, and the community, and children are not little adults (i.e., respecting differences in providing pediatric palliative/hospice care). (Please note that you can visit archived issues of this newsletter at www.nhpco.org/pediatrics.) For future issues, we are thinking about addressing subjects such as pre-natal pediatric palliative/hospice care.

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 christytork@gmail.com; Maureen Horgan at Horgan.Maureen@gmail.com; or Chuck Corr at ccorr32@tampabay.rr.com. We will work with you!

4. READER’S CORNER. Our Reader’s Corner column provides brief summaries and bibliographical information about journal articles and other publications that are important and likely to be of widespread interest to individuals who are involved or interested in pediatric palliative care, but that may not be known to all readers of this newsletter. Contributions to the Reader’s Corner 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 christytork@gmail.com.

5. Calendar of Events. As a reminder, there is a calendar of educational opportunities linked on the ChiPPS section of the NHPCO website, www.nhpco.org/pediatrics. Please e-mail Christy Torkildson at christytork@gmail.com to have your pediatric palliative care educational offering listed.

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

Thank you for taking time to read this issue and for any feedback that you can offer us. Providing pediatric palliative and hospice care to children, adolescents, and their family members has made great strides in recent years, even though it is certainly not always easy and still faces many challenges and obstacles. We wish you all the best in your good work.

If you are not on our mailing list and received this newsletter from a friend or some other source, please send an email message to CHIPPS2@NHPCO.org requesting to be added to our mailing list. If you are a member of NHPCO, you can go to the Communications Preferences tab in your individual member record online and “opt-in” for communications from ChiPPS. Member Services will be happy to help you adjust your communications preferences; contact them at 800-646-6460. Visit the ChiPPS Web page at www.nhpco.org/pediatrics for further materials and resources of interest.