

# ChiPPS E-Journal

***Children's Project on Palliative/Hospice Services***

*Released in collaboration with the National Hospice and Palliative Care Organization*

National Hospice and Palliative Care Organization  
1731 King Street, Alexandria, Virginia 22314  
[www.NHPCO.org/pediatrics](http://www.NHPCO.org/pediatrics)



**ChiPPS E-Journal**  
**Pediatric Palliative and Hospice Care**  
**Issue #36; August, 2014**

**Issue Topic: Children with Medical Complexities, Part One**

*Produced by the ChiPPS E-Journal Work Group*

Welcome to the thirty-sixth issue of the ChiPPS E-Journal (formerly, the ChiPPS electronic newsletter). This issue of our E-Journal offers a PDF collection of articles that explore selected issues that involve children with medical complexities. Because this is such an important subject and one with many dimensions, we have divided the discussion into two parts and will continue to explore these topics in Issue #37 of this E-Journal. Nevertheless, we appreciate that there may be many additional issues that touch upon such children, their families, and those who provide care to them. Our hope is that the topics addressed in this issue and in the one that to follow will be useful for and helpful to readers of this E-Journal. We welcome communications for anyone who has more to offer on these subjects.

This E-Journal 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-Journal Workgroup, co-chaired by Christy Torkildson and Maureen Horgan. Archived issues of this publication are available at [www.nhpco.org/pediatrics](http://www.nhpco.org/pediatrics).

Comments about the activities of ChiPPS, its E-Journal Workgroup, or this issue are welcomed. We also encourage readers to suggest topics, contributors, and specific ideas for future issues. Please contact Christy at [christytork@gmail.com](mailto:christytork@gmail.com) or Maureen at [horgan.maureen@gmail.com](mailto:horgan.maureen@gmail.com).

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## **Issue #36:**

### **Children with Medical Complexities, Part One**

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

#### ***Beyond the Door***

**p. 4**

#### **Scott Newport**

Recently, our "resident poet" interacted with a father who had previously found relief when his dying daughter received a new heart. This year, she needs another. When Scott talked to the father, he asked, "Do you think you have gone through that door we talked about earlier." The father was still crying when he said, "Yes." This poem tries to reflect what the author thinks may be the father's perspective.

#### ***After the Unexpected Happens***

**p. 5**

#### **Alison Kirkland**

William's mother describes some of the challenges associated with his diagnosis of Cerebral Palsy. Nothing is easy, but her conclusion is that, "You will experience no greater giving and receiving of love than from that of a child with special needs."

#### ***Caring in Uncertainty: Children and Families with Genetic Conditions***

**p. 7**

#### **Peggy MacKay, RN, MN, CPN**

This article reviews the chromosomal and clinical issues associated with some of the more common conditions that affect children and families who have genetic conditions. The author concludes that "palliative care feels a natural fit in the care of these children. Nurses in direct care can assist families in finding joy while processing loss of dreams, expectations, and sometimes a child."

#### ***The Partnership between Palliative Medicine and Children with Medical Complexity***

**p. 12**

#### **Margaret Hood, MD**

Writing from the perspective of a children's hospital, the author argues that applying a palliative medicine approach to children with medical complexities should be the standard of care. This includes tertiary centers, medical homes, and communities all working together to ease the journey for the child and family.

#### ***Complex Care Coordination***

**p. 15**

#### **Maria Kefalas, PhD, Bobbi Zimmaro, RN, MSN, CRNP, CHPN, HTP, & Jennifer Hwang, MD, MHS**

This article offers a case study of a child with late infantile metachromatic leukodystrophy. The case is examined from three perspectives—that of a palliative care team, the mother, and hospice nursing—during three crisis periods.

#### ***Pediatric Palliative Care and Pediatric Surgery: Common Issues***

**p. 19**

#### **Jennifer M. Hwang, MD, MHS, Thane A. Blinman, MD, & Chris Feudtner, MD, PhD, MPH**

Children receiving pediatric palliative care often require surgery. This article describes reasons why surgery might be required and advocates a strategy whereby pediatric palliative care practitioners can work to partner effectively with pediatric surgeons to provide the best care possible to these vulnerable children and their families by aligning goals of care with specific interventions.

#### ***Staff Bereavement in Palliative Pediatric Care***

**p. 22**

#### **Michael J. Brescia, MD, & Sherry R. Schachter, PhD, RN, FT**

In this article, the authors describe the case of a Down-Syndrome child who was abandoned to the care of the staff at Calvary Hospital in New York City. Despite his multiple complications and shortened life trajectory, we see here the staff's attachment to this child and their grief following his death.

#### ***Items of Interest***

**p. 25**

In each issue of our ChiPPS E-Journal, we offer additional items of interest.



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## "BEYOND THE DOOR"

Scott Newport

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Today was my last day  
standing so long  
at that door  
"Yea, the one I've seen  
for about a year or so now"

In my nights of sweat  
and low blood pressures  
I've peeked  
but never told my wife

My baby girl's been so long  
waiting for that heart  
another dad will  
one day lay and wait

The dreams of yesterday  
I now throw away  
and look for other ones  
like a brand new pair of steel toe boots

The cost of the transplant list  
is going higher  
the door shows me  
and I listen

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## AFTER THE UNEXPECTED HAPPENS

**Alison Kirkland**

William's mother

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It's been 5 years since our son, William, was born. I love thinking back to how excited Duncan and I were as we anxiously awaited his due date. I still remember decorating the nursery, meticulously packing our hospital bag, and shopping for enough baby clothes to last William his whole first year of life. Like most families expecting a new baby, we were in a state of pregnancy bliss. Our biggest worries were breastfeeding or formula feeding, cloth diapering or disposables and whether we would make our own baby food or buy jarred food. Never in our wildest dreams did we think that things could possibly be anything but perfect. Until the unperfect happened. William suffered a devastating hypoxic brain injury and was delivered via emergency cesarean. We were thrown into a world that we didn't know existed. In an instant, we became parents of a medically complex child.

When your baby is in the NICU, you get a crash course in medical terminology that physicians and nurses spend years studying. Seizures, brain damage, edema, platelet transfusions, MRIs, ultrasounds, lumbar punctures, TPN, PICC lines and feeding tubes. Within days your child has a Neurologist, Infectious Disease Specialist, Hematology/Oncologist, Neonatologist, Gastroenterologist, and an Ophthalmologist treating them. As a safety precaution, you are required to wear a gown, gloves and face mask when you enter his room. All you can do is sit and watch your precious, fragile baby, so tiny and beautiful, in an incubator with tubes and wires keeping him alive. The nurses assist you with handling hourly cares, as you anxiously await being allowed kangaroo care time.

Once William was strong enough to be discharged from the NICU, we were elated and scared all at once. Finally our baby would be home with us where he belonged. That first year wore on us like we never imagined. We struggled to get into a rhythm at home while trying to manage our careers and juggle weekly appointments with specialists and therapists. You'd be shocked how quickly all of your sick and vacation days dwindle away when your child has 5 specialists and 5 therapists. When William wasn't sleeping, he was crying. Babysitters and daycare workers couldn't handle him. He struggled to gain weight as he battled against reflux and delayed gastric emptying. Seizures affected his mood and sleep cycles. Sensory processing disorder from his cortical visual impairment gave new meaning to the term colic. We bounced, we rocked, we swaddled, and we were officially exhausted. When William turned a year old, we received the dreaded Cerebral Palsy diagnosis. It was at this point that we realized that our journey in the world of special needs was just beginning. Doing what was best for William and our family, we made the decision for me to quit my job and become a stay at home Mom.

When you receive a diagnosis like Cerebral Palsy, you quickly enter the grieving process. While you are not mourning a loss of life, you mourn the loss of the "typical child" that you expected to have. Step one, *denial*. This really can't be happening; the doctors must be wrong. Step two, *anger*. Why us? Why our baby? Step three, *bargaining*. You question everything, trying to think of something that you can do to change the current circumstance. I hung out in step three for quite a while. Step four, *depression*. This one sneaks up on you so quickly, and if you are not careful, before you know it you are fully submerged. And finally the elusive step five, *acceptance*. Some of us look forward to finally being at this stage, while others are just never ready and continue bouncing around through the previous steps. It can be even more complicating when you and your spouse enter these stages at different times, especially when one enters into acceptance fairly easily and the other is still angry or in denial.

Everyone sees that you are doing your best, but you are overwhelmed by the stress and the anxiety of the ever growing medical expenses, household bills, surgeries, procedures, and providing round-the-clock care for your child. Before you know it, you have pushed away all thoughts of accomplishing anything in life that doesn't revolve around advocating for your child's medical, schooling, therapy, and emotional needs. You know that this isn't exactly healthy, but there just isn't enough time in the day to



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worry about anything else. Well-meaning family and friends remind you that caring for your own physical and emotional needs must remain a focus so that you can continue to properly care for your child. Their goodwill tells you that it can be as simple as taking a walk, reading a book or attending a local support group, but they do not fully understand just how thin you are really stretched.

The importance of taking time for yourself is critical. Imagine that you are on an airplane and as you are getting ready to taxi the runway, you hear the flight attendant explaining the emergency instructions. They say, "In the unlikely event of an emergency situation, please secure your own oxygen mask before assisting others." This statement rings true in so many aspects of our lives. As a parent of a medically complex child, you need to take care of yourself so that you are healthy enough both physically and emotionally to care for someone else. Most of the time this is easier said than done, but it's a good thing to remember.

The need for respite care is something that is frequently overlooked and not always available to everyone who needs it. Most state and private services are solely focused on what they specifically deem as medically necessary for the child. A lot of parents struggle to find a babysitter who can handle all of their child's medical needs, especially in an emergency situation. It's not as simple as calling on the teenage neighbor down the street so that you can enjoy a much needed date night with your spouse, let alone ever get a weekend away to regroup. You need a trained, trusted professional who can handle monitoring vital signs, bolusing a tube feed, spot a seizure, and have the ability to transfer a child who can't sit-up or walk on their own. Respite care can be just as rewarding for the child as it is for the parents. Children can develop new friendships with other kids their age who have similar needs and build long-term relationships with their care providers.

Despite the heartache and stress, parenting a child with medical complexities can be one of the most joyful and rewarding experiences of your life. William has a smile that lights up the room, his laughter is contagious, and his love is purely genuine. We have been able to show others that William is so much more than just his Cerebral Palsy diagnosis. His enjoyment of all things musical has opened our world up to enjoying different genres. He encourages us to welcome the simplicity of quiet time outside listening to nature, because we know that he doesn't handle busy parks and shopping malls. Parenting a child with special needs teaches you to appreciate the little things, knowing just how hard your child works to accomplish the smallest gains. You gather a new appreciation for just how fragile life really is, and mustn't be taken for granted. You will experience no greater giving and receiving of love than from that of a child with special needs.

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## CARING IN UNCERTAINTY: CHILDREN AND FAMILIES WITH GENETIC CONDITIONS

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Caring for children with genetic disorders and their families can feel like a complex puzzle. Often babies present with a single complaint, like feeding issues or a seizure. The process to uncover the true culprit can be protracted, painstaking, and filled with a gradual and persistent type of loss for families. Despite the mystery, there are shared challenges that nurses can anticipate and help parents to process. The nurse's first step is in helping to set expectations.

Even an amazing adventure can be stressful when one has a false expectation. Emily Perl Kingsley likens having a child with a disability to landing in Holland when a trip to Italy had been planned (1987). She expands on the metaphor by stating that there is much to recommend Holland, but it requires shift in attitude since Italy was expected.

As pediatric nurses we care for children with an array of conditions, some life-threatening and some not, but uniformly a crisis for the family. We adapt to meet their needs for control and information, and light the way for the road ahead. Children with genetic conditions often have a road ahead that not only is difficult to describe, but often unknown. Providing care for not only the patient but the family as a whole is a particularly daunting task for the nurse in the face of such uncertainty and ambiguity.

Chromosomal abnormalities are the most primitive health issue, affecting the very building blocks of life. Every cell and organ system can be affected. Given that reality, how can we care for, treat, and support these children and families? Several such disorders are listed here; the list is by no means exhaustive. Nurses can find bearing in their common challenges, the need for strategies rather than answers, and the imperative to redefine success when a cure is not possible.

A review of language can provide a framework for describing genetic conditions. A gene is the most basic physical and functional unit of heredity and is made up of DNA, which contains information needed to specify traits. The DNA is arranged in structures called Chromosomes, single long molecules only a portion of which correspond to a single gene. Normal human cells contain 46 chromosomes. Some diagnoses are excesses or partial or complete absences of chromosomes. Syndromes are a series of recognizable traits or abnormalities that tend to occur together associated with a specific disorder (Gened.nlm.nih.gov; Genome.gov; geneticalliance.org).

The genetic conditions nurses encounter vary by area of practice: those requiring life-saving surgical intervention would be seen in the acute care setting, while behavioral and intellectual disability might be the purview of the school nurse. Table A summarizes the chromosomal and clinical issues associated with some of the more common conditions.



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**Table A**

Condition	Abnormality	Challenges
Trisomy 21	Three 21 <sup>st</sup> Chromosomes	Cardiac anomalies, low tone, feeding issues, thyroid, cancers, diabetes
Trisomy 18	Three 18 <sup>th</sup> Chromosomes	70% miscarry; 1 in 20 live to 1 year; cardiac anomalies not considered lethal on their own
Trisomy 13	Three 13 <sup>th</sup> Chromosomes	Grim outcome, similar to Trisomy 18 though more rare
Cri du Chat	Deletion on short arm of 5 <sup>th</sup> Chromosome	Craniofacial anomalies, intellectual disability, hyperactivity, characteristic cry
Fragile X	Maternal, X-linked	Low tone, reflux, feeding issues, ADHD, autism, intellectual disability, aggression and self-injury, seizures
Angelman Syndrome	Deletion on short arm of 15 <sup>th</sup> Chromosome	Intellectual disability, smiling/laughing behavior, poor feeding, seizures, stiff lurching gait, hyperactivity, sleep disorders
Cornelia de Lange	Varies, chromosome 5, 11, X	Intellectual disability, anxiety, stimulation issues, elfin features, airway/feeding issues, poor fat deposition resulting in unstable blood glucose
Beckwith-Wiedemann Syndrome (BWS)	Multiple sites, often on short arm of chromosome 11	Prematurity due to polyhydramnios, macrosomia, macroglossia, abdominal wall defects, hypoglycemia, malignancy
Silver Russell	Similar sites to BWS	Opposite of BWS, undergrowth in utero and after birth
Turner Syndrome	Single X Chromosome	Small for gestational age, short stature, small jaw and high arched palate, cardiac anomalies, non-functioning ovaries.
Miscellaneous Deletions	1p, 5p, 7p, 10p	Poor feeding, floppy airway, poor tone, intellectual disability
CHARGE Syndrome	Flaw in DNA binding protein CHD7	Coanal atresia, tracheoesophageal fistula, external ear abnormalities, facial nerve palsy, immune issues, genital hypoplasia
Prader Willi Syndrome	Variations on the short arm of 15 <sup>th</sup> chromosome	Failure to thrive, dysmorphic facial features, low tone as infants, intellectual disability, obesity
DeGeorge	Microdeletion on Long arm of Chromosome #22	Cardiac anomalies, immunodeficiency, intellectual disability, hypocalcemia, cleft palate hypotonia
Wolf Hirschhorn	Deletion on short arm of 4 <sup>th</sup> chromosome	Cardiac anomalies, microcephaly, intellectual disability, hypertelorism Wide nasal bridge
Klinefelter		

Allen, T., 2012; Arron, K., Oliver, C., Moss, J., Berg, K., & Burbidge, 2011; Clayton-Smith, J., 2010; Collin, J., 2006; Hersh & Saul, 2011; Jyonouchi, S., McDonald-McGinn, D.M. , Bale, S., Zackai, E.H. , & Sullivan, K. E. , 2009; Lashley, 2007; Murray, G., 2012; Rooms, L., & Kooy, F., 2011; Skoto, B., Capone, G.T., & Kishnani, P.S., 2009; Spivey, P., & Bradshaw, W., 2009; Tuysuz, B., Nuray, K., Tugbe E., Filiz, G., Mehmet, V., Yildiz, P., Derya, E. & Nihan, E., 2014; Veerapandiyan, A., Gallentine, W., Schoch, K., & Shashi, V., 2011, Verrotti, et al, 2013.

For nurses caring for these babies and children there are challenges. Some are obvious: a cardiac anomaly or cleft begs repair. A genetic diagnosis may take months, but commonalities like poor muscle tone, feeding and weight gain issues, intellectual disability and seizures are shared features of several genetic conditions in children.

An infant might present to the pediatrician with low muscle tone and poor growth. Investigations may focus on one before the other, trying to determine if malnutrition caused the poor tone or if poor tone made it difficult for the infant to get nourishment. Is the feeding difficulty structural? Is feeding effort poorly



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coordinated? Is tone adequate to protect the airway? On the occasions when FTT is not simply the wrong choice of formula, a broader investigation ensues. Pediatric nurses are familiar with the premium parents place on feeding their infants and children. They at times resist NPO orders, and are as stressed about hunger as they are about pain. Feeding is close to the hearts of parents as a primary instinctive responsibility, and accepting the idea that typical feeding will not work for a baby can be devastating news, even before an explanation is given.

Intellectual disability is another clinical feature shared by several of these conditions. Intellectual disability may have replaced "mental retardation" or "developmental delay," long a euphemism for a child who had not, and likely never would, achieve developmental milestones. Evidence of this shift is noted in the name change for the journal formerly known as *Mental Retardation* to *Intellectual and Developmental Disabilities*. For nurses in the moment, focus narrows on whether the child is able to engage with, reward, and communicate needs to the parent.

Another clinical flag that may merit a genetics evaluation is a seizure in the absence of fever. More than 400 different chromosomal instabilities are accompanied by seizure disorder (Singh, et al., 2002) and can present in the newborn period or later. As with any other incidence of seizure, the goal is to extinguish seizures to prevent neurologic damage. This balance is tenuous as seizure medications are often sedating and can effect thought process and ability to learn and interact. When coupled with behavior issues linked to some genetic conditions, sedating medication can make the school setting arduous for all.

It is curious that there are few studies of parental coping in the face of genetic conditions. This small body of study cites loss of control, depression, and self-esteem issues as paramount. Parental stress is said to be highest in those with children with behavior problems. Factors known to effect coping in such situations are spirituality, partnerships with care team, how visible the condition is, how they received diagnostic information, presence of family support, and referrals to community resources (Lashley, 2007). It is not surprising that such a condition would be a crisis for a young nuclear family, and chronic conditions are often outside their realm of experience (Bartell & Kissane, 2005). Financial hardship can be a concern for families of children with chronic conditions (Birenbaum, 2010). Infants with genetic conditions can also be subject of ethical debate when issues of quantity of life and quality of life are unclear and family wishes may counter medical recommendations. (Farlow, 2009; Janvier, Okah, Farlow, & Lantos, 2011).

Adding to the already tumultuous adjustment genetic conditions require of a family is the recent finding that Assisted Reproductive Technology increases the odds of "imprinting disorders," such as Beckwith-Wiedemann and Angelman Syndromes (Odom & Segars, 2010). Couples that choose Assisted Reproductive Technology are left to wonder if those decisions contributed to the defect, adding another layer of distress. This association bears further study.

Congenital anomalies are the number 1 cause of death in infants, the number 2 cause of death in children 1-4 years of age, and number 4 in children 4 to 15 years (Bartell & Kissane, 2005). Yet palliative care for children is still a young specialty. Rallison, Hanger Limacher, & Clinton (2006, p. 99) defined palliative care as appropriate for "life-limiting illness, a life threatening illness, a life defined by illness, or a life given meaning by its length." With this perspective, palliative care feels a natural fit in the care of these children. Nurses in direct care can assist families in finding joy while processing loss of dreams, expectations, and sometimes a child.



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## THE PARTNERSHIP BETWEEN PALLIATIVE MEDICINE AND CHILDREN WITH MEDICAL COMPLEXITY

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Nancy is an 11 year old with a mitochondrial disorder who has experienced intestinal failure for the past year, and is now TPN dependent through an indwelling Broviac. She has had two line infections in the past year. Her mother notices that she is shivering and takes her temperature @ 105 degrees Fahrenheit. She calls the consulting nurse who instructs her to present to the Children's Hospital ED.

Mom and daughter arrive at triage. Imagine this scenario:

The triage nurse looks at them and asks the question: "Is your daughter still full code?"

Not only does the mother almost start crying, my heart aches as well.

The way in which goals of care were addressed is disrespectful, disparaging and yet still "in line" with our current practice of medicine.

So as tertiary or quaternary institutions, what do we owe children with medical complexities and their families and their communities?

What models of care provide the optimum service?

First, we must identify or have triggers for inclusion for children with medical complexity (CMC). In the past, they have been identified by "you know them when you see them." As the Patient Protection and Affordable Care Act is implemented, health care systems increasingly need strategies to allocate resources. The recently released public domain Patient Medical Complexity Algorithm (PMCA) uses claims data to identify children with chronic complex disease(s). Both institutions and patients and families would benefit by a methodology to identify these children in our systems and thus allocate adequate resources.

Currently transitions between separate venues of care are often fragmented and poorly coordinated. Reports and analyses from the Children's Hospital Association document common gaps in care faced by children with complex medical conditions in Medicaid, who often cross state lines to access specialized care. Medicaid's state-by-state variability creates a fragmented and unnecessarily burdensome system lacking in care coordination, quality measures, and cost containment. Approximately two-thirds of the 3 million children with medical complexity are covered by Medicaid, and represent nearly 40 percent of Medicaid costs for kids.

Children with chronic complex disease are most likely to benefit from care coordination and other resources. The idea of an interdisciplinary team is an excellent model to deliver care coordination, with involvement of specialty, community physicians, and resources.

In the future, there are some exciting opportunities for improving care of CMC. On June 21, 2014, Representatives Joe Barton (R-TX) and Kathy Castor (D-FL) announced they and distinguished colleagues had introduced the Advancing Care for Exceptional Kids Act of 2014 (H.R. 4930). "ACE Kids Act of 2014" would help coordinate care to ensure optimal outcomes for children with medical complexity in Medicaid, while helping to contain costs. (1)

In a different arena, on July 21, 2014 the Center for Medicare & Medicaid Innovation (CMMI) announced the final recipients of round two of its Health Care Innovation Awards. Among the awards, Children's



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Hospital Association, in partnership with 10 children's hospitals, is the recipient of a \$23 million grant to test "Coordinating All Resources Effectively (CARE)" for children with medical complexity. The effort aims to inform sustainable change in health care delivery through new payment models supporting improved care and reduced costs for children with medical complexity. (2)

What the parents and community physicians tell us, is that the most important way to engage with them is through ACCESS to the tertiary/quaternary institutions. A perfect scenario would enable a patient/family, whenever they enter the system—via phone call, emergency department, inpatient admission, to experience the approach as seamless. They don't have to tell the story 500 times; they can be asked sensitive questions in a kind and caring way and be encouraged to participate in any discussion.

Continuum of care from inpatient to outpatient to specialty care to home-based care depends on honest and mindful dialogue and documentation between all members of the patient's health care team, including the patient and family.

Applying the principles of palliative medicine to children with medical complexities is a necessary and urgent paradigm shift for those of us who serve children and their families.

So, what are some of the tools that we have to facilitate information exchange and communication?

- 1) Complex care listserv—this is a public listserv where participants can ask questions of others across the country who care for children with medical complexity.

To join, please contact Rishi Agrawal: [ragrawal@luriechildrens.org](mailto:ragrawal@luriechildrens.org).

- 2) Documenting outpatient non face-to-face work by the team.

Complex chronic care coordination codes were added to CPT in 2013 and revised extensively in 2014. Significant revisions include expanded description of the typical service, patient selection methods, definition of a care plan and required abilities of practices that report complex chronic care coordination. While Medicaid and private insurers do not reimburse for these codes, using them to document the interdisciplinary work is important for the future.

- 3) Seamless provision of care is enhanced by accessible and shared documentation.

This is a challenge as care is often provided across multiple sites and providers. For example, electronic system -wide documentation of patient's/family's wishes through physician discussion/orders, featured below, may help us communicate with patients in a caring and non-threatening manner. As another platform, Washington State has implemented a state wide system entitled Emergency Department Information Exchange. Discussion is in process regarding use of this system for posting emergency department treatment plans for CMC.

So, let's re-imagine the scenario:

The triage nurse greets Nancy and her mother by name, stating that the consulting nurse had called ahead. The triage nurse has Nancy's electronic record on screen and asks: "I noticed that you had a discussion with Dr. Smith in April 2014 regarding your wishes on how Nancy is to be treated. Have there been any changes since then?"

Essentially the same question was asked in two ways, resulting in drastically different perceptions on the part of the patient and family.

In conclusion, applying a palliative medicine approach to children with medical complexities should be the standard of care. This includes tertiary centers, medical homes, and communities all working together to



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ease the journey for the child and family.

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## COMPLEX CARE COORDINATION

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### Introduction

Medically complex and fragile children with progressive diseases present unique and complex challenges for their medical management that require coordination, flexibility, and consistent communication. In this article, the authors present a case study that makes clear the necessity of good communication and care coordination in order to assist children and families through changing goals of care. By describing this child's case from three perspectives—the palliative care team's, the mother's, and the hospice nurse's—we seek to show how these groups worked together to manage a difficult and changing situation over time.

### Palliative Care Team's Perspective: Establishing the Relationship

Cal was born healthy to experienced parents who noted mild developmental delays but were thrilled as she continued to make developmental progress during her first two years of life. When she was 2½ years old, she lost the ability to walk without assistance and was admitted to the hospital. After multiple tests, they received the life-altering news that she had late infantile metachromatic leukodystrophy.

Metachromatic leukodystrophy is a lipid storage disease in which the body does not have enough of the enzyme arylsulfatase A. Without this enzyme, the brain is unable to build normal myelin sheaths, the "insulation" that surrounds many neurons in the brain. Children with this disease often present with developmental delay and/or loss of motor milestones and then develop weakness, spasticity, blindness, seizures, and inability to swallow. Most children with the infantile form die from their disease by age 5. Over the next six months, Cal developed a myriad of distressing symptoms—irritability, insomnia, and constipation. She continued to eat by mouth but feeding her was a labor of love that took multiple hours each day. Her family developed a special bond with her home health aide who spent hours holding and feeding Cal. She was most comfortable, day and night, while being held and was very distressed when placed in any specialty equipment designed to safely position her body, including her car seat. This meant that travel, even to and from medical appointments, was a source of stress for both Cal and her family.

Not long after her third birthday, the distress of travel to medical visits and therapy appointments combined with Cal's worsening symptoms demanded a new perspective. The Pediatric Advanced Care Team (PACT), which is the palliative care team at The Children's Hospital of Philadelphia (CHOP) was consulted and suggested that hospice care could be a way to support Cal and her family in the



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environment she was most comfortable. Because of Section 2302 of the Affordable Care Act, the “Concurrent Care for Children” requirement, Cal was eligible to continue to receive private duty nursing while hospice services were layered in to provide additional expertise.

Since that initial consultation, the care of Cal and her family has required an ongoing dialogue and careful coordination between her hospice agency, her private duty nursing agency, the palliative care team, her pediatrician, and her medical subspecialists. Many office visits and hospitalizations have been avoided thanks to the trained eyes of hospice and her private duty nurses, as well as the ability to titrate medications for symptom control at home. Occasionally, admissions to either the hospital or inpatient hospice unit for symptoms that could not be adequately managed in the home setting have been necessary, as described in the next section. These admissions have always been a proactive, collaborative decision between her family, hospice, and the palliative care team.

### **Mother’s Perspective: Crises and Coordination**

#### **First crisis**

It was a Wednesday when the hospice nurse called me on my cell—I was at the DMV renewing my license—to let me know that my daughter’s fever had spiked. The low grade fever was now 102. The PACT team from CHOP was alerted and consulted, and it was decided we would monitor the condition with extra home nursing care over the next few days. With Tylenol and Advil the fever stabilized and Cal had no congestion. But by Saturday morning, the hospice nurse heard crackling in the chest and Cal was taken to CHOP ED for evaluation. In order to maximize care coordination and ensure our goals of care were communicated, PACT agreed to meet us in the ED and guided the residents and medical team in evaluating our daughter. We were concerned the ED staff might intubate and, though we had a DNR order, it would be difficult to prevent a new team from not addressing a crisis by following standard medical protocols. PACT and Abington Hospice had worked very hard to keep our daughter at home and we had pushed off a feeding tube and managed her care at home for over a year before this admission for pneumonia.

The ED evaluated our daughter and ordered x-rays which didn’t reveal pneumonia. Nevertheless, everyone agreed that the nurse practitioner’s concerns should not be dismissed, so our daughter was put on a regimen of antibiotics and fluids. Because of the advocacy of the PACT team with our hospice home care team, we had kept our daughter out of the hospital and had caught her pneumonia before a standard evaluation might have. She was admitted for three days and responded well to the treatment and was released. During this admission, given our daughter’s ongoing struggles eating, it was decided we would try an NG tube to see if that helped her eating. Because a blizzard was about to hit the East Coast and we wanted to go home, CHOP released our daughter to us the day before the storm hit.

#### **Second crisis**

We were home for a day with the new NG tube and then we lost power and heat. With a medically fragile child on a new feeding tube, we struggled to spend the night at a friend’s house, and the home care nurses (who drove out in blizzard conditions to check on our daughter) feared that our daughter was not tolerating the NG tube and that there might be aspiration. Since no one felt we needed the acute care of a hospital, we were admitted to the hospice unit to monitor the feeding tube and the recovery from pneumonia.

During that time, the PACT and hospice teams problem-solved a range of issues to determine the best way to get our daughter eating. We slowed down the feeds, attempted using the gravity feed and the pump, and worked on positioning to make sure aspiration was under control. On our third day of continuous feeds when our daughter had pulled out her NG tube yet again, we decided to use a protein shake recommended by the hospice director. Much to everyone’s surprise our daughter started taking food by mouth and the new protein shakes bought us two more months without a feeding tube.



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### **Third crisis**

It was not until April, three months later, when our daughter would return to CHOP, almost two years after diagnosis, for a G-tube. By that time, PACT and hospice were joined by ICS (Integrated Care Service, a medical service at CHOP that provides an inpatient medical home to medically fragile children), GI, IR (Interventional Radiology), and Neurology who all consulted on the best options for our daughter's nutritional needs. She had swallowing and aspiration studies performed through radiology. The ICS attending recommended a G-tube alone—without a fundoplication or GJ tube. Although our daughter's condition was degenerative, ICS wanted to give her a chance to have the least invasive procedure with the goal of improving her quality of life. While some subspecialists felt a more invasive procedure might make more sense, the ICS, Neurology, and PACT teams were able to advocate for the G-tube alone. Our daughter went to IR and not surgery for the procedure to minimize the risks of the anesthesia to such a medically complex case.

During this time in the hospital, Neurology also had the chance to observe tremors and muscle spasms that had caused our daughter increasing discomfort but could be treated with baclofen. Because of this new drug, we found we had a much reduced need for valium or valium rescues and moving our daughter to her chair or bed did not cause nearly so much discomfort.

Because our daughter was already an inpatient in the days leading up to the procedure, her team could monitor her case closely and ensure that all factors were considered. While our daughter's condition is fatal and degenerative, the concerns for her comfort and home-based care remained paramount to our team. And, with explanation from the IR team, it was decided to suspend the DNR order so that the doctors could do the feeding tube procedure with all safety procedures in place.

The close contact with the teams continued as GI, IR, Neurology, and PACT monitored our daughter's response to the tube insertion and tolerance of the feeds. We also kept in contact with our hospice team to ease her transition home. Much to everyone's relief, the G-tube was effective; there was no need to return to GI to consider another procedure like a GJ tube

We were pleased to get home and have the new feeding tube. After one incident with a bowel obstruction, which was cleared up with an enema after a short readmission, our daughter is back home, six pounds heavier, and doing well. Her home-based hospice team monitors two days a week and she returns to CHOP every six months for evaluations from Neurology and Pulmonary with input from ICS and PACT when needed.

### **Hospice Nursing's Perspective: Flexibility and Adjustment**

When we first opened Cal's case for home hospice, we worked collaboratively with PACT to determine goals of care and treatment plans in order to facilitate Cal's care at home with her family. Through the first six months, we established a trusting relationship with all of the parties involved including all of the family members to the best of our ability. We dealt most with mom and dad and peripherally with Cal's older siblings. In the beginning, we recognized that this was a very educated family unit with predetermined points of view about the prognosis and potential decision making moments. A clear deciding point was to put off as long as possible the introduction of a feeding tube and perhaps avoid it altogether. There were many moments that a feeding tube was an option. The hospice team along with PACT addressed the issues while respecting the goals of care, and Cal's care was adjusted each time to avoid the feeding tube. It wasn't until the development of aspiration pneumonia and inability to maintain a reasonable nutritional state that we needed to consider a feeding tube.

The collaboration has been successful because all of the key players keep communicating with each other. PACT and hospice have a regular biweekly conference call to assess the current plan. We address any updates to the goals of care needed, anticipate future potential crisis points, and make sure each member has the necessary tools and skills to identify key contact moments. This way the hospice nurses visiting Cal and her family know what to do and who to call when appropriate. When the first crisis



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occurred, the hospice nurse knew to call the mother and then have a discussion with PACT and the mother to determine that an ER visit was necessary. The mother advocating for her daughter brought all of the team to be part of the ER evaluation so that the goals would be followed.

At the second crisis point, the electricity failure was an unanticipated crisis to which the team responded in a coordinated fashion with a decisive plan of action. We utilized the hospice unit to deal with both the energy failure and the feeding tube problems. During Cal's stay in the unit we continued to evaluate and address creative solutions for her feeding intolerance. This process occurred over a week and allowed Cal to recover completely from her pneumonia and resume sippy cup feedings with a protein drink instead of a feeding tube. The feeding time was a sacred moment with family and caregivers, and feeding in a more natural way helped to achieve this sacred time. It was important for all of the stakeholders to be with Cal during this time. It was obvious that Cal's condition was deteriorating but the more we could achieve normalcy, the better the adjustment of the family to the process.

By the time of the third crisis, it was evident that new goals were needed for Cal's comfort and the family's well-being. Placing a G tube was a hard decision for the family but important for the care and comfort of Cal. PACT, specialists, and hospice continued to collaborate at each of the decision points. More importantly, we remained flexible with the change in Cal's status and perhaps the refocusing of the perspectives of the parents and family. This is a necessary process to ensure the patient and family's ability to cope and to maximize the comfort of their child. We now have different goals than what we had at the beginning of care when a feeding tube was not a part of the plan.

In conclusion, caring for Cal and other medically fragile children with life limiting illnesses requires ongoing, deliberate coordination between the family, hospice and medical teams. While established goals of care can help guide all stakeholders, ongoing flexibility is needed to adapt as the situation evolves. Readjustment of the goals of care is part of the larger journey.

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## PEDIATRIC PALLIATIVE CARE AND PEDIATRIC SURGERY: COMMON ISSUES

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Pediatric surgery and pediatric palliative care (PPC) often serve overlapping populations of medically fragile children who benefit when providers communicate well. The focus of PPC is to help children with severe chronic and life-limiting illnesses live comfortably and well. For many of these children, their underlying medical conditions may warrant surgical intervention either at diagnosis or over the course of their life span. This may range from a one-time routine surgery to a lifetime of complex surgical interventions. Some of these children, such as a child born with complex congenital heart disease who requires a staged palliative repair or an infant who develops necrotizing enterocolitis with subsequent extensive bowel resection and short gut syndrome and who ultimately receives a small bowel transplant, may have long-term ongoing relationships with one or more pediatric surgeons. As PPC practitioners work to partner effectively with pediatric surgeons to provide the best care possible to these vulnerable children and their families, several issues commonly arise: whether or not to do surgery, whether surgery is consistent with the goals of care, and what to do regarding DNAR orders when undergoing surgery.

### Reasons for Surgery

Children receiving palliative care with previously existing limitations of interventions may benefit from undergoing surgery for a variety of reasons. A child might have a life-limiting condition that can be palliated with surgery. For example, a child with abdominal cancer might benefit from a venting gastrostomy tube. Without this surgery, the same child could require chronic use of a nasogastric sump. If a venting gastrostomy is better tolerated or allows greater freedom of movement, this surgical procedure could greatly enhance a child's quality of life and a family's ability to care for their child at home. Another child might have a new problem unrelated to their underlying primary diagnosis which is optimally treated by a surgical procedure. For example, the family of a child with appendicitis might consent to a surgical procedure because the risks of not treating the acute problem (pain, chronic sequelae, death) outweighs the risk of intervention for that particular child at that particular moment in time. Thus, for a child with profound neurologic impairment who develops appendicitis, an appendectomy could be the best way to manage that child's symptoms. Finally, a child might develop an indication for surgery related to the natural progression of their primary condition—such as the need for a gastrostomy tube in a child with a neurodegenerative disease.

### Goals of Care and Specific Interventions

For some children in these types of situations, earlier conversations with their families about the goals of medical care have led to discussions about limiting specific interventions (such as intubation or CPR). Families make these decisions when the risk of pain and suffering from the intervention far outweigh the possibility of restoring a child to health. When a family decides to limit an intervention, it is typically after careful consideration of the risks of that *specific* intervention in the broader context of a child's illness. Unfortunately, the medical teams may falsely generalize and misinterpret these limitations, applying them to broader medical decision making. We cannot assume that the parents of a child with a DNAR order (placed, for example, because of his underlying profound neurologic impairment and recurrent episodes of respiratory failure requiring care in the PICU) would refuse surgical intervention for a treatable condition such as appendicitis. We also cannot assume that the standard surgical consent, often obtained by the least experienced member of the surgical team during hours when they are less likely to be supported by more experienced colleagues, is adequate for weighing the complex decision making required in such cases. A decision about a surgical intervention must involve an open conversation between the parents and the medical team—including the attending surgeon, anesthesiologist, and



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palliative care team—to understand the goals and risks of the proposed surgical intervention given the underlying diagnosis, the surgical issue at hand, and the unique circumstances which led the parents to place limitations of interventions in the first place.

### **DNAR in the OR**

Members of the medical team will often raise questions about the status of a DNAR order for a child who will undergo a surgical procedure. If teams are already uncomfortable discussing limitations of interventions, they are typically even more uncomfortable and inexperienced discussing when and if those limitations should be temporarily modified. Suspending a DNAR order during the surgical procedure and immediate perioperative period is a common practice which, under many circumstances, may be the simplest choice which respects the spirit in which the original decision was made. If a DNAR order was placed to protect a child from resuscitation in the case of inevitable progression of their disease, temporary suspending the DNAR order during the operative and immediate perioperative procedure may make sense. Interventions which temporarily support a child's respiratory status or blood pressure during or immediately after a surgical procedure are undertaken to manage *temporary* effects from anesthesia or surgery—effects which are expected to be time limited and reversible. These kinds of interventions stand in stark contrast to a sisyphian struggle against a chronic or degenerative disease.

Importantly, surgeons should consider the duration of time that DNAR orders should be suspended after the surgery in order to accommodate expected post-operative healing processes, and discuss this with patients or parents prior to embarking on the surgery. For instance, following tonsillectomy and adenoidectomy, during the several days in which patients with compromised neurologic function may need extra support to manage oral secretions, would intubation to protect against aspiration be permitted? This type of decision should be addressed ahead of time and not await a crisis.

In other situations, honoring a DNAR order during and immediately after surgery may be entirely consistent with the goals of care. In such cases, insistence that the DNAR order be set aside may cause tension between the family and the medical team. To open up the discussion, one can start with the important reality that limitations of interventions do not represent all-or-nothing, black-and-white decisions. If a child with advanced cancer is undergoing a palliative surgery to improve symptoms, she will need to be intubated in order to perform the procedure. If there is concern that this patient is at increased risk of failing extubation, that needs to be part of the discussion and should be juxtaposed against the risks and benefits of the surgery. Moreover, this should be discussed with the family as part of a larger conversation about the goals of care rather than in a narrow discussion exclusively about surgical and anesthesia consent. Accepting the risk of intubation as a prerequisite for surgery intended solely to relieve symptoms is, however, qualitatively different than accepting the risk of CPR in the same patient if she develops an arrhythmia in the operating room. Intubation is 100% necessary for the surgery to happen, an obligatory intervention in order to have the opportunity to gain the potential benefit from the surgery. Cardiac arrhythmia leading to cardiac arrest is quite rare in pediatric surgery, and may be a sign of a body more weakened by a life-limiting disease than was previously recognized. In the case of a child with advanced cancer and previously agreed-upon limitations of interventions, CPR (especially prolonged CPR) is certainly not in her best interest and will not restore her to health.

Therefore, in cases where the limitations of interventions have not been fully suspended, careful dialogue is necessary to ensure that the surgeon and anesthesiologist will have a clear understanding of what actions would be undertaken, to what degree and for how long, and what actions will not be undertaken, in order to sensibly honor the goals of care. Given that these decisions require dialogue and discernment of what is best, and that different individuals may differ in these judgments, in cases where irreconcilable differences arise, discussion with colleagues may find other clinicians who can collaborate with the patient and family to operate within an agreed-upon set of intervention parameters.

### **Conclusion**

Children receiving PPC may need surgical interventions to help treat their underlying diagnosis, palliate their



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symptoms, or treat a problem completely unrelated to their primary diagnosis. Families make decisions about limitations of interventions in the context of their child's underlying condition, but these do not automatically generalize to decisions about surgical intervention. Palliative care teams can help families and surgical teams navigate the conversations that are necessary to weigh the particular risks and benefits for each child. These conversations should not be left to the least experienced members of the team since even experienced physicians often struggle to do this well. Many times families and medical teams are mutually agreeable to temporarily suspending limitations of interventions during surgery and the immediate post-op period, and this choice can still honor the spirit of the original decision. If limitations of interventions do remain in place during an operative procedure, the attending surgeon and anesthesiologist need to have a clear plan for intervention. Finally, many families may have long term relationships with their pediatric surgeons. Supporting excellent communication in this relationship is part of the larger work of pediatric palliative care.

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## STAFF BEREAVEMENT IN PALLIATIVE PEDIATRIC CARE

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**Michael J. Brescia:** My earliest memory of Anthony was on an overheated August day in the early 1950s with the ceiling fans whirring. I passed a statue of St. Martin and encountered Sister Celeste carrying a small child who looked to be approximately 6 months old. As soon as I looked at him, he smiled but did not move his legs or arms. I asked Sister Celeste, "Who is this?" She told me, "A gift from God."

It was common for children to be left on the door steps, hallways or in the lobby of Calvary Hospital. We named him Anthony and he soon became a favorite of all the staff, frequently being passed from one staff member to the other.

As Anthony grew within the institution, he became one of the most socialized Down's syndrome children that I had ever seen. Both legs were afflicted with some disorder which made them hyperextend, or spread out further than they should. He had a café au lait mark on his abdomen. His large head was surrounded by blond curls, and he had large red cheeks with a tiny nose, characteristic of Down's syndrome.

We had decided early on that exhaustive diagnostic testing was not going to invade the few years Anthony had with us. He had numerous symptoms consistent with Down's Syndrome including frequent (and often life-threatening) upper respiratory infections, a heart defect (septal), and a loud heart murmur, which we decided we would not treat with long diagnostic studies and invasive surgeries, since there were increased risks and Anthony was deliriously happy in the arms and care of our staff.

As the months and years passed, Anthony was also diagnosed with seizures, hearing and speech problems, hypothyroidism, and eventually with leukemia. Throughout his life he was plagued with intestinal problems, often accompanied by small bowel obstructions. His care was frequently complicated because of severe diarrhea resulting from all the antibiotics he was often on. The use of these antibiotics would cause thrush infections requiring local mouth care and the inside of his mouth was often painted with purple stain, gentian violet. Upper respiratory infections and pneumonia became a recurrent threat to his survival.

I was scheduled to leave Calvary for an academic appointment in organ transplantation and kidney dialysis because of the fame I had achieved with the invention of the fistula; I never did leave. When asked, I have always said that I didn't leave Calvary because of the insistence of our Cardinal and other religious leaders, but in reality, it was really Anthony who kept me at Calvary. I found myself overwhelmed with this baby, and was unable to leave him on the weekends. In spite of my own large family, on Friday evenings I would take Anthony home for the weekend. My excuse was that he would have the opportunity to play with other small children, namely my three eldest.

Each Saturday, a birthday cake was made and presented to Anthony, with which he would smear much of the contents on his face. Bath time resulted in at least half of the water on the floor. By age four, Anthony's legs did not move as they should and they appeared to be underdeveloped.



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Because of his socialization with the nuns, Anthony was friendly and loving and slept between my wife and me. I remember falling asleep with my lips pressed against his cheeks, from which he never moved. I told myself and my children that Anthony was on loan to us from heaven and would return earlier than we could ever want.

Despite the multiplicity of physical ailments, Anthony had a happy life until the last three months, when it became obvious that all the conditions were now interfacing and we were entering a final phase. When his symptoms became unmanageable and progressively worse a pall settled over the entire staff, recognizing that by treating Anthony we really were attempting to treat ourselves and our own misery in the coming unthinkable ending.

**Sherry R. Schachter:** The case that Dr. Brescia describes highlights the significant grief that clinicians frequently experience before and after the death of a beloved patient –especially one that they have cared for over time. Issues of countertransference often accompany our work and heavily influence our interventions when working with dying patients. How can this not be so?

As challenging as Anthony's medical care was, the hospital staff was drawn towards him perhaps because he had been abandoned by his parents and family. The culture of Calvary Hospital allowed for, and in fact, encouraged, the close bonds that were formed between Anthony and most of the staff. While we recognize that most hospices and hospitals, even those focusing on palliative care may not encourage these close bonds, the uniqueness of Calvary supports these actions. We are guided by our core values of compassion, respect for the dignity of every patient, and non-abandonment of patients and families. Founded in 1899 The House of Calvary (our original name) only focused on palliative care specifically for indigent women dying of cancer (men were not admitted into the hospital until 1947). Infants and children, especially those who were abandoned by their parents and literally left on our doorsteps, were an early significant part of our history.

Managing Anthony's complex medical care required many disciplines, and the bereavement follow-up after his death provided services for all of those disciplines. Bereavement support actually began before Anthony's death as we recognized the staff's growing involvement. While our general staff did not have the liberty of taking Anthony home (as did Dr. Brescia), it soon became apparent that if they could have, they would have.

As Anthony was dying, the staff was given the opportunity to hold and care for him. He was approximately six months old when he first came to us and spent six years at Calvary. The nuns took turns holding Anthony as they sat in their rocking chairs. After Anthony died, others bathed, cleaned, and dressed him. They reminisced and told stories about his young life and the impact he made on their lives. The hospital dietitian laughed through her tears as she recounted his favorite food: spaghetti and ketchup (not the traditional tomato sauce).

Anthony had given so much of himself to others that Dr. Brescia and the Hospital administration made the decision to donate his organs and tissues so that other children might live. By doing so, we validated and echoed the staff's concerns that we give meaning to his short life.

Immediately after Anthony's death, support groups were offered on each of our three shifts. These groups provided opportunities for the staff to reminisce and validate their feelings. Not all staff members attended these groups and some preferred other outlets for their grief. They planned a tree planting on our property and what was initially thought would be a small ceremony, actually turned into a large gathering of staff witnessing the planting and the placement of a plaque in Anthony's memory. Today, we now recognize the differences in the way we grieve and that these "instrumental staff grievers" were more cognitive and perhaps required a more active and behavioral approach for their grief.

I believe that this brief synopsis of Anthony's life and his effect on the professional and paraprofessional staff caring for him depict the need for support and bereavement follow-up. Long after our patients die we are reminded of the lessons they taught us. If we can look back on the care we gave them, recognizing



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our limitations but also acknowledging the importance of our presence and actions, our lives can become richer and more meaningful.

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## ITEMS OF INTEREST

In each issue of our ChiPPS E-Journal, we offer additional items of interest.

- 1. NHPCO's PEDIATRIC PALLIATIVE CARE TRAINING AND INTENSIVE.** Held in conjunction with NHPCO's 15<sup>th</sup> Clinical Team Conference in Nashville, TN, the two-day Pediatric Palliative Care Training will be held October 25-26, 2014. This two-day preconference seminar will provide pediatric palliative care training for new and developing pediatric palliative and hospice care professionals. The Pediatric Intensive held during the Clinical Team Conference, Oct. 27-29, is an intermediate level session track designed to develop professionals and organizations to provide care to infants and children facing life-threatening conditions and their families. Visit the [CTC webpage](#) for more information and registration details.
- 2. A TWO-DAY PEDIATRIC PALLIATIVE CARE SEMINAR.** The seminar will be held September 9-10, 2014, in Montreal in conjunction with the 20th International Congress on Palliative Care. Seminar sessions will cover a wide range of topics, from difficult clinical issues, to parental grief, to access to services. Keynote speakers: Ann Goldman, London; Betty Davies, University of Victoria, BC; Patricia Lück, Gauteng Centre of Excellence for Palliative Care, Johannesburg; Rose Steele, School of Nursing, York University, Toronto; Charles Corr, Tampa Bay, FL. Additional information is available at <http://www.palliativecare.ca/>.
- 3. PEDIATRIC PAIN MEDICINE COURSE.** Boston Children's Hospital is holding an expanded course on pediatric pain medicine this fall in Boston on October 17 and 18, 2014, "[Pediatric Pain Management: The Art and the Science](#)." The program will provide up-to-date information on the theory and practice of pediatric pain management for all clinicians caring for children. The format is unique as most of the presentations will link a basic scientist with a practitioner to provide a more comprehensive understanding of pain treatment.
- 4. THE 19TH BIENNIAL INTERNATIONAL PERINATAL BEREAVEMENT CONFERENCE.** Presented by the Perinatal Loss and Infant Death Alliance, November 6-9, 2014, in San Antonio, the conference aims to provide networking and educational opportunities for those who support bereaved families. More information is available at [www.perinatalbereavementconference.org](http://www.perinatalbereavementconference.org).
- 5. LIVES WORTH LIVING WEBSITE AND BOOK.** A new book entitled, [Lives Worth Living](#), is available online. Although published in the UK, this is a resource for families of children with life-limiting conditions with stories and lessons that are universal. The [Lives Worth Living](#) website also offers a connection to their Facebook page which affords these families the opportunity to connect with others like them facing similar journeys with their children with life-limiting conditions.
- 6. MEDICINES MANAGEMENT TOOLKIT.** The UK charity, Together for Short Lives, has just made available the second edition of its 143-page document, "[Medicines Management Toolkit](#)," available to download free of charge. It is intended for professionals and is framed in its UK context.
- 7. THE COURAGEOUS PARENTS NETWORK.** This website and digital video library was created BY parents FOR parents and professionals caring for a child who has a life-limiting illness. The mission of [Courageous Parents Network](#) is to lessen the fear and isolation that parents experience as they begin to adjust to their child's prognosis, as they manage the complicated psychosocial and emotional issues during their child's life, and then as they contemplate their child's transition to end of life.
- 8. NEW MOMENTS OF LIFE VIDEO ON CAMP ALOHA.** A new video, "[Grief through a Child's Eyes](#)" has been added to the website of the national, awareness campaign [Moments of Life: Made Possible by Hospice](#). Take a journey with courageous young people who participated in Hospice of Savannah's annual Camp Aloha.



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**9. SUBJECTS AND CONTRIBUTORS FOR FUTURE ISSUES OF THIS E-JOURNAL.** In the many of our past issues, we have addressed a wide range of subjects. For upcoming issues, we are thinking about addressing issues related to: continuing discussion of children with medical complexities; advance planning tools; a starter kit or "how to" tools for new programs in pediatric palliative/hospice care; respite care; and another look at concurrent care. If you know of good topics and/or contributors (including yourself) for these and/or other future issues of this e-journal, please do not be shy! Step right up and contact any of the following: Christy Torkildson at [christytork@gmail.com](mailto:christytork@gmail.com); Maureen Horgan at [horgan.maureen@gmail.com](mailto:horgan.maureen@gmail.com); or Chuck Corr at [ccorr32@tampabay.rr.com](mailto:ccorr32@tampabay.rr.com). We will work with you! In the meantime, you can [visit archived issues](#) of this e-journal.

**10. READER'S CORNER.** Our occasional 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/hospice care, but that may not be known to all readers of this newsletter. Contributions can be sent to Christy Torkildson at [christytork@gmail.com](mailto:christytork@gmail.com).

**11. CALENDAR OF EVENTS.** As a reminder, there is a calendar of pediatric educational opportunities on the ChiPPS section of the website at [www.nhpco.org/pediatrics](http://www.nhpco.org/pediatrics). Please e-mail [pediatrics@nhpco.org](mailto:pediatrics@nhpco.org) 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 E-Journal 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 [pediatrics@nhpco.org](mailto:pediatrics@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 NHPCO/ChiPPS Web page at [www.nhpco.org/pediatrics](http://www.nhpco.org/pediatrics) for further materials and resources of interest.

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