

**Legislative Issues**

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**Pediatric E-Journal**

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**NHPCO**

National Hospice and Palliative  
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# Pediatric e-Journal

## Pediatric Palliative and Hospice Care

### Issue #58; February 2020

#### Issue Topic: Legislative Issues

Welcome to the 58th issue of our Pediatric e-Journal. This issue offers a collection of articles that describe how legislative issues can and do affect pediatric palliative and hospice care. These articles include discussion of legislative goals and efforts to achieve new legislative initiatives, as well as examples of how legislation has influenced care in a sampling of states.

This e-Journal is produced by the Pediatric e-Journal Workgroup and is a program of the National Hospice and Palliative Care Organization. The Pediatric e-Journal Workgroup is co-chaired by Christy Torkildson and Ann Fitzsimons. Chuck Corr is our Senior Editor. Archived issues of this publication are available at [www.nhpc.org/pediatrics](http://www.nhpc.org/pediatrics).

Comments about the activities of NHPCO's Pediatric Advisory Council, its e-Journal Workgroup, or this issue are welcomed. We also encourage readers to suggest topics, contributors, and specific ideas for future issues. We are currently discussing topics such as ethical issues, the dying process, and self-care for future issues in 2020. If you have any thoughts about these or other topics, contributors, or future issues, please contact Christy at [Christina.Torkildson@bannerhealth.com](mailto:Christina.Torkildson@bannerhealth.com) or Ann at [ann@here4U.net](mailto:ann@here4U.net).

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## Issue #58: Legislative Issues

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

### *Do-Not-Resuscitate Orders, Michigan Schools, and One Boy’s Journey with His Family* p. 5 **Dawn Renee Krause**

This article discusses attempts to legitimize the status and implementation of Do-Not-Resuscitate (DNR) orders in all schools in the State of Michigan for children who are terminally ill with life-threatening disorders but are not actively dying. The author, Willy’s mother, explains the family’s agonizing decision to include a DNR order as part of his care plan and the devastation they felt when they discovered that his school would not honor that order. After Willy’s death and as part of his legacy, efforts were undertaken to amend the Michigan DNR Procedures Act, which does not currently address pediatric DNRs or the educational setting. These efforts passed the Michigan Senate unanimously in 2018 but must now start over in the Michigan House of Representatives.

### *Pediatric Palliative Care in California: The boy who never smiled* p. 10 **Lori Butterworth, MEd**

This article is organized around the story of a 13-year-old boy with osteosarcoma who never smiled during several weeks in a children’s hospital. He only smiled when he was driven home to be reunited with his migrant farmworker family and 12 siblings who lived in a “migrant camp made up of ramshackle houses in the middle of acres and acres of lush Central California strawberry fields.” About two years later, “As Saúl’s disease progressed, the pain and long drives to and from the hospital became unbearable and impossible to manage.” Unfortunately, Saúl did not qualify for hospice and “tragically, Saúl died somewhere between the emergency department and a makeshift room at a local hospital where no one knew him.”

The same year Saúl died, the Children’s Hospice & Palliative Care Coalition of California (CHPCC) was founded and undertook to pass legislation that would “waive” hospice regulations for child patients under the age of 21. Once passed, the waiver “enabled seriously-ill children and their families to receive in-home palliative care, while at the same time being allowed to continue pursuing curative treatment for the child’s life-limiting or life-threatening condition.” Subsequently, studies have “demonstrated dramatic improvements in the physical and emotional well-being of children and families participating in [the waiver], as well as significant cost savings to the State due to a reduction in the length and occurrences of hospitalizations.” However, as the article recounts, this is not the end of the story, other complications have arisen, and there remains more work to do.

*Massachusetts Department of Public Health, Division for Children and Youth with Special Needs, Pediatric Palliative Care Network* p. 16

**Jennifer Kenyon Bates, MEd**

“In 2004, the Hospice and Palliative Care Federation of Massachusetts led a group of stakeholders that included parents of medically fragile children, bereaved parents, and pediatric palliative care physicians to create legislation that would provide pediatric palliative care services to children with life-limiting conditions and their families.” That legislation was signed into law by Governor Romney in April 2006. It established the Massachusetts Pediatric Palliative Care Network, whose services, role, history, and admission criteria are described in this article.

*Greater Illinois Pediatric Palliative Care Coalition Legislation and Advocacy Efforts* p. 19

**Kristin James, LCPC and Ellen Byrne, MPP, CPHQ**

This article describes the work of the Greater Illinois Pediatric Palliative Care Coalition to inform legislators in Illinois about the limitations of Concurrent Care for Children and the advantages of home-based pediatric palliative care. The authors emphasize the importance of building awareness and relationships, as well as becoming informed about different approaches to state-funded programs. The result is a practical case example of ways to engage in legislation and advocacy in this field.

*Perinatal Palliative Care Developments Nationally and in Arkansas* p. 22

**Sara E. Peeples, MD, FAAP and Abigail M. Ramseyer, DO, FACOG**

In this article, the authors describe recent developments in perinatal palliative care both across the United States and in the state of Arkansas. In so doing, they point out that “Perinatal loss is unique in many ways, but still at its core involves the grief of a family over the death of a loved one. The concepts and domains of care that are applied in adult and pediatric palliative medicine also have their place in this special patient population.”

*Collaboration and Partnership is Key to Advocacy in Pennsylvania* p. 25

**Betsy Hawley, MA**

Using the Pennsylvania Pediatric Palliative Care Coalition as an example, this article argues that “Statewide Pediatric Palliative Care Coalitions (SPPCCs) play an important role in pushing forward both formal and informal palliative care advocacy efforts...No matter how they are started, SPPCCs are an opportunity for different stakeholders to come together in a neutral forum and create solutions.” The author maintains that, “The importance of developing and maintaining relationships in advocacy work cannot be overstated,” And she adds that, “In order to foster such collaborative efforts and better share information, an informal SPPCC group started to meet monthly via conference call to share ideas, ask questions of each other, and learn about topic areas that intersect group interests.” She invites interested parties to join in these calls.

*South Carolina Pediatric Palliative and Hospice Care Collaborative* p. 28

**Conrad Williams MD, FAAP, FAAHPM, HMDC**

*Pediatric Concurrent Care in Missouri*

p. 29

**Joan L. Rosenbaum, MD, FAAHPM**

*Partners for Children: A New Collaborative Program Model for Medically Complex Children in Michigan*

p. 30

**Natalia Simon, MBA, and Ken Pituch, MD**

These three articles describe challenges and responses that have been faced in three states in efforts to establish ways of improving pediatric palliative and hospice care: by creating a collaborative in South Carolina; by implementing concurrent care in Missouri; and by establishing a new program in Michigan to enhance and evaluate continuity between inpatient and outpatient care for children with complex medical conditions.

*NHPCO Legislative Priorities for 2020*

p. 32

**Lauren Drew, JD**

The National Hospice and Palliative Care Organization (NHPCO) is well known as advocating for and educating about hospice and palliative care in the United States. As such, NHPCO's legislative priorities are central to efforts to improve care in this field. This article describes three primary priorities for 2020: pass the Palliative Care and Hospice Education and Training Act; pass the Rural Access to Hospice Act; and continue working with congressional champions on program integrity legislation. The author notes how these legislative priorities can have a bearing on pediatric palliative and hospice care. She also invites interested persons to become involved in these efforts and points out what they can do.

*Pediatric Concurrent Care: Building Evidence, Informing Providers, and Serving Families*

p. 37

**Lisa C. Lindley, PhD, RN, FPCN, FAAN and Kristen A. Carlosh, M.A.**

This article describes a grant-funded research project at the University of Tennessee, Knoxville, College of Nursing entitled, "Effectiveness of Concurrent Care to Improve Pediatric and Family Outcomes at End of Life." The researchers "will provide evidence on the effectiveness of pediatric concurrent care to improve end-of-life care during hospice care" with the aim of comparing "the: (1) benefits (i.e., continuity of care; symptom management); (2) burdens (i.e., hospice care intensity, care fragmentation); and (3) cost of concurrent care versus standard hospice care for children and families."

## DO-NOT-RESUSCITATE ORDERS, MICHIGAN SCHOOLS, AND ONE BOY'S JOURNEY WITH HIS FAMILY

**Dawn Renee Krause**

Willy's Mother

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There is a growing number of students diagnosed with complex disorders who are considered terminally ill but not actively dying. Death for them could be years. As medical technologies advance, lifespans increase, and the question of how to manage their illness and life in general becomes an issue. Every child should have the opportunity to reach their full potential in whatever time they have, including the social life and peer experiences found in school. This academic piece is an integral part of the world and how children grow and develop and move away from childhood in stages.

Medically fragile children have access to individualized educational programs that meet their unique needs through Special Education. However, what happens when parents have a do-not-resuscitate (DNR) order for their child? Just like the other details in their individualized student plan, a parent wants to have assurance that a DNR will be honored in the event of a catastrophic incident at school.

In the state of Michigan, the policies with regards to DNR orders are inconsistent at best. For example, in one county it may be policy for teachers and school staff to carry out the DNR orders step-by-step, and in another county, school officials may not honor them at all. This creates ambiguity, confusion, and frustration for both parents and schools.

This is where we found ourselves as a family in 2014. Our son was terminally ill but not actively dying. Our family selected a school in our district that would give him the most appropriate education. However, this school had a policy to not honor DNR orders. Our son needed the education they offered. By law, this was guaranteed to him, but we were unable to appropriately include his DNR as part of his medical plan. The future was uncertain, and it was literally life or death.

William Douglas Pickett was born on March 12, 2004. After an uneventful first four months of life, he was diagnosed with lissencephaly on July 9, 2004 in the University of Michigan Emergency Department after a grand mal seizure. Lissencephaly is a rare, neuromigrational disorder in which the brain does not form correctly during gestation. Willy had no gyri (ridges) which are connected to motor skills. At diagnosis, doctors expected Willy to have a 2-year lifespan. They told us to take him home, be prepared to



*Willy Pickett, son of Dawn Renee Krauss*

deal with complex seizures and respiratory issues, and basically try to keep him comfortable until the end.

The early years were the most difficult. As new parents, we were learning how to take care of this very sick baby while doing everything we could to keep him alive. Every time he was sick, we thought it was the end. Mott Children's Hospital at the University of Michigan became our second home. The stress of the entire situation placed an unimaginable hardship on our family, our other children, our jobs, our finances, and our marriage.

As time progressed, we started to pick up some confidence and hope. Willy had longer periods of improved health. He was enrolled in Early On, which offered early intervention, and the therapists and teachers started the blueprint for what would become his education. They opened up a new world for our family. A world where Special Education meant a life for Willy complete with his own goals and peers. The school had equipment that we could never have afforded at home. They had specialists who had studied how to educate and work with this very special population of students. Willy couldn't walk or talk, but they focused on what he could do, not what he couldn't do.

Sometimes their goals were lofty, which made us laugh. We joked that we really just wanted him to breathe and poop. Those goals weren't enough for his educators. He learned to hold his head up. He learned to make choices with his eyes. He enjoyed swimming in the therapy pool, which was not only fun, but therapeutic for his muscles. He received physical, occupational, music, and vision therapies. They went on outings in the town. They did crafts. They listened to stories. He worked hard during therapy sessions and would come home exhausted. He worked himself hard in school and it was a much healthier lifestyle than just lying around at home. After years of occupational therapy, he learned how to hold a toy on his own. He learned how to roll over.

Since lissencephaly is a regressive disorder, Willy's abilities peaked at a very young age and started to decline slowly every day thereafter. His disorder, along with seizures, pulmonary issues, and cerebral palsy, slowly destroyed his muscles. Any skills he had (swallowing, holding a toy, rolling over, holding his head up) slowly disappeared. Eventually Willy required a feeding tube so he could get enough nutrition. It is common for respiratory muscles to become badly damaged in children affected with these disorders, and they frequently succumb to respiratory distress as a result of pneumonia.

Regardless of regression, Willy's educators adapted his goals and met him where he was at. He continued to hit milestones and then regress. Everyone around him would celebrate the gains, and then grieve the losses. He continued to be a happy boy, enjoying music, the pool at his school, outings with his class, snuggling with his loved ones, and watching shows on his iPad.

Willy's lung function started to go downhill in 2009. We wound up in a cycle of hospitalizations that lasted over three years. Usually he'd start with a cold or snuffle and the next thing you know we were in the intensive care unit and he was fighting for his life. Until then, we had

maintained a very pro-active and aggressive approach to his care. Even though he had been given an approximate life expectancy of 2 and he was now 7, his life had been much better than we ever could have anticipated. When the hospice and palliative care teams would come visit our hospital rooms, we promptly sent them away. We knew Willy had a lot of life left to live.

In late fall of 2012, Willy had some increased breathing and swallowing issues due to the continued regression and obstructive sleep apnea. A pediatric otolaryngologist presented us with options that were not good and required some form of complicated surgery. The only viable option was a tracheostomy which, on one hand would have made life a little easier, and on another hand would have seriously increased the complication factor. We decided against all of the options and agreed to maintain our status quo. That night when we got home, I couldn't help but think that it was the "beginning of the end." There were no more procedures or life-saving surgeries that were good options. His regression had made it to that crucial juncture where medical technology and quality of life backed into each other.

In June of 2013 Willy was in the hospital for increased seizure activity. This wasn't something new. We were always looking for the right concoction of medications that would keep his seizures at bay but not drug him out. During this hospital stay, we were once again presented with the option to consider palliative care or hospice services. Not only had we tried almost everything we were willing to try, Willy had gone quite a bit downhill in the years preceding. It was time for us to consider palliative care or hospice services.

The passing into law of the Affordable Care Act (ACA) allowed for concurrent curative, life-prolonging, and hospice care in pediatric cases like these. By providing coverage for specialist care and hospice care simultaneously, the ACA makes it clear that some disorders are different in that although they are terminal, death is not necessarily imminent. These patients require the comfort measures that hospice provides and the ongoing care that comes from specialty clinic visits, care that is not available for most adult hospice patients.

Our goal for Willy was for him to have the best quality of life possible for that which remained, and we decided to go home from the hospital on hospice services. This meant that Willy would still be able to attend school. Hospice would support us with weekly nurse visitations, and our supplies were delivered, including oxygen in the home, morphine, and other comfort measure drugs. If Willy became ill, a call to hospice would provide a home visit from a nurse or doctor. If Willy needed antibiotics, we could get them. If Willy took a turn for the worse, we could either provide the comfort measures we had in the home or we could change our minds and head for the hospital for more aggressive treatment. We were also able to still see our physiatrist and our neurologist in clinic for the parts of his care not covered by hospice. If we could have designed a perfect set-up for our imperfect situation, this would be it.

We worked with a team of professionals to create a care plan for Willy which included a DNR. Knowing it was the right thing for our family did not make the decision to add the DNR into the care plan any less agonizing. We painstakingly listed all of the facts, and knew it was time. Every time Willy was sick, he came back to us a different boy. Less of his old self and more of a tired

and uncomfortable one. We knew that if his heart stopped beating and resuscitation was needed, we would not want that for him. We would want comfort measures. We would want him to be surrounded by people who love him, whether at home or at school, holding his hands and staying by his side. Once we made this decision we never looked back.

When we found out that Willy's school would not honor his DNR, we were crushed. We would have been devastated if something had happened at school and resuscitation was attempted. I am very sure this is a difficult concept to understand for parents and adults who do not live in a world where children are terminally ill. But we did live in that world and it was not acceptable that a school district could overrule our decision with regards to our DNR.

We decided to still send Willy to school even though we knew they would not honor his DNR because the pros outweighed the cons. Willy loved school, he deserved school, and it was his right. We began the process of a lawsuit against the district to force them to honor the DNR.

In late October 2015, Willy caught a cold. He went to school on Halloween. His cold turned into double lung pneumonia within days. We began treating him with a round of antibiotics, but his body did not respond to the drugs. At any point, we could have rescinded his DNR, called an ambulance, have him intubated, and waited. But we had already made that decision. We followed our DNR, made him comfortable, and waited to see if the medication started to work.

At 12:40 a.m. on November 5, 2015, Willy passed away lying next to me in bed. Our lawsuit with the school district ended when he passed.

We went through all the normal motions that came with losing a child. Even though we knew this day would come, we were devastated and not at all ready. The one thing that comforted me is that I knew we made the right decision for Willy. He died because his body was done. He died on his terms without artificial medical technologies prolonging the inevitable. I knew it would still be important to fight for DNR's in schools and I wanted to continue this as Willy's legacy.

After years of attempting the DNR fight through local courts, it was recommended to instead take legislative action. Luckily, Michigan already has a DNR Procedures Act, so we did not have to start from scratch. However, the Michigan DNR Procedures Act does not address pediatric DNRs or the educational setting.

With the help of the University of Michigan Pediatric Advocacy Clinic, The University of Michigan Hospice and Palliative Care team, and local educational leaders, work has been done to add language that explicitly says that parents can get DNRs on behalf of their minor children and explicitly mentions school as a context in which DNRs need to be respected.

After a year-long vetting process with different lobbyists and stakeholders, three bills were sent to the Michigan Senate Judiciary Committee in 2018 and subsequently all three bills passed the

Michigan Senate unanimously. However, the bills got stuck in Michigan’s lame duck session in late 2018 and the process started over.



*Michigan Advocacy Team*

At the time of this writing, the process has started over in the Michigan House of Representatives first this time. Representative Rebekah Warren (D-55) has gathered co-sponsorship support and the new bills are HB5417, 18, and 19. Next step is for the bills to be heard in a House Committee hearing before being sent to the House floor for a vote. There is more than a good chance they will pass since they passed the Senate unanimously in 2018.

For Willy and kids with these regressive disorders, the “end” can be years. In the meantime, they have to live. They deserve an education. They deserve a life of their own with an educational program designed for them. The fact that they have terminal disorders and may have a DNR should not infringe upon their right to an education. The school districts that serve our state must be consistent in their policies regarding pediatric DNRs. Their policies should not change across town or across another district’s border. Just as you’d write a medical care plan that included an EpiPen for a student with a deadly allergy, medical care plans for students with DNRs should also be included in the educational setting.

When a parent or guardian reaches the agonizing decision to write a DNR for their child, no one should be able to tell them that the DNR will not be honored. Especially in an educational setting where they have the right to have the same experiences as their peers right up until the day they pass. No child is less entitled to the right to a free, public, and appropriate education because of a diagnosis, prognosis, or a medical order.

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## PEDIATRIC PALLIATIVE CARE IN CALIFORNIA

### *The boy who never smiled*

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In describing the current landscape of Pediatric Palliative Care (PPC) in the state of California, it's important to begin with a child. Allow me, therefore, to introduce you to Saúl, the humble son of migrant farmworkers from the agricultural belt of California, who, in 1999, unknowingly ignited a statewide movement.

#### **The Boy Who Never Smiled**

It was late in the day when an oncology social worker from Lucile Packard Children's Hospital Stanford called asking if there was any possibility Jacob's Heart<sup>1</sup> could provide a ride home from the hospital for a 13-year-old boy with osteosarcoma. He had been hospitalized for several weeks recovering from surgery, intensive chemotherapy, and radiation, and was finally being discharged. With no options other than a public bus, I decided to pick him up myself. The social worker warned me, "This boy never smiles."

When I arrived at the hospital and met Saúl, I realized the social worker wasn't exaggerating; Not only was there no smile, there were no words, no eye contact. During the two-hour drive from Stanford to the farmworker camp where Saúl lived, I tried awkwardly to make conversation with his mother, who spoke a Spanish dialect that I barely understood. Saúl said nothing.

But something extraordinary happened when we arrived at the migrant camp made up of ramshackle houses in the middle of acres and acres of lush Central California strawberry fields. Saúl began to smile.

As we pulled up to his family home, Saúl smiled and giggled as he was greeted with hugs and cheers from his 12 siblings, neighbors, and friends. He was *home*, and "the boy who never smiled," was laughing.

I snapped a photo for the social worker and kept a copy for myself. It wasn't that he never smiled...

About two years after that cheerful homecoming, Jacob's Heart had become intimately involved with Saúl and his family, providing rides to and from treatment, help with rent, counseling, and support to his siblings. As Saúl's disease progressed, the pain and long drives to

and from the hospital became unbearable and impossible to manage. As a neophyte in the fight for pediatric hospice, I tried to engage a local hospice to assist with Saúl's pain. Sadly, it was through this attempted referral that I learned why children like Saúl didn't "qualify" for hospice. Without options, we made an emergency 911 call. And tragically, Saúl died somewhere between the emergency department and a makeshift room at a local hospital where no one knew him.

Two weeks later, on September 11, 2001, I met Devon Dabbs, a documentary filmmaker and children's advocate. I poured my heart out to Devon; she was immediately sympathetic to Saúl's story, and we were connected by a purpose more profound than either of us could have imagined. Together, we committed to righting the injustices that hospice regulations, which were designed for adult patients, imposed on the families of children like Saúl. It would have been inhumane to ask Saúl's parents to give up treatment that might save their precious son's life in order to get his pain managed at home.

### **Removing the Roadblocks – The Path to the Waiver**

The Children's Hospice & Palliative Care Coalition of California (CHPCC) was founded in 2001, the same year Saúl died. CHPCC quickly grew to become a unification of children's hospitals, hospices, pediatricians, home health agencies, and families with the shared vision of a medical system that not only works to cure disease but also provides compassionate emotional support, and honors childhood.

The first step in forging a path to open access to home-based palliative care for children meant passing legislation that mandated a federal waiver, to "waive" hospice regulations for child patients under the age of 21. As a result, CHPCC, in collaboration with lawmakers and advocates across the state, drafted The Nick Snow Children's Hospice and Palliative Care Act of 2006 (Assembly Bill 1745).

The Nick Snow Act required the California Department of Health Care Services (DHCS) to submit a Home and Community-Based Services waiver, which enabled seriously-ill children and their families to receive in-home palliative care, while at the same time being allowed to continue pursuing curative treatment for the child's life-limiting or life-threatening condition.

The ensuing Partners for Children Pediatric Palliative Care Waiver (PFC) was a demonstration pilot program limited to designated counties and certain qualifying diagnostic criteria. In specified counties, the waiver allowed children with life-threatening conditions to receive curative treatment alongside home-based services including care coordination, pain and symptom management, expressive therapies, and family counseling. The waiver was an important step forward, but qualification criteria limited access for those who lived outside pilot California counties.

It is important to note that had the PFC waiver been available in 2001, Saúl would have met the three key qualification criteria: 1) He lived in Santa Cruz, a waiver-designated county; 2) His recurrent cancer was a PFC qualifying medical condition; and 3) He had full-scope Medi-Cal.

Perhaps, in a different time, the 911 call could have been avoided, and Saúl’s pain could have been managed at home without having to put his parents through the horror of not “qualifying” for hospice. The first child was enrolled in PFC in 2009, eight years after Saúl’s death.

In 2012, with two years of PFC underway, the UCLA Center for Health Policy Research published “Better Outcomes, Lower Costs: Palliative Care Program Reduces Stress, Costs of Care for Children with Life-Threatening Conditions,”<sup>2</sup> a study that demonstrated dramatic improvements in the physical and emotional well-being of children and families participating in PFC, as well as significant cost savings to the state due to a reduction in the length and occurrences of hospitalizations. The study’s key findings include: an 11% cost savings for a traditionally high-cost population, a 32% reduction in the average number of days spent in the hospital per month per member, and a 35% reduction in hospital stay costs.

A subsequent 2015 study,<sup>3</sup> “Impact of a Pediatric Palliative Care Program on the Caregiver Experience,” found a nearly 50% reduction in the average number of inpatient days per month, from 4.2 to 2.3; a significant drop in average hospital length of stay from 16.7 days to 6.5 days (more than a 60% reduction); a strong trend in reducing 30-day readmission rates, from 45% of admissions to 37%; and net savings—after deducting program costs—of \$3,331 per enrollee per month.<sup>4</sup> Impressive!

In spite of overwhelming evidence confirming the efficacy of the PFC program, providers were challenged by a complex billing structure, payment delays, and unreimbursed administrative costs (to name a few), which made it increasingly difficult to sustain their local programs. The final straw came in 2017 when the Federal Centers for Medicaid and Medicare (CMS) established a requirement that any agency responsible for care coordination and case management *could not* be the same agency delivering care. As a result, providers already struggling to manage an inefficient, bureaucratic system were presented with yet another roadblock; one that finally proved insurmountable. Despite advocacy efforts, Federal CMS declined to modify the new guidelines, and in 2018, California DHCS made the decision to not pursue renewal of the PFC waiver and, instead, work with stakeholders to find alternative mechanisms to deliver comparable PPC services to children and their families.

### **CHPCC becomes a Division of the Coalition for Compassionate Care of California**

The termination of the waiver was, on the one hand, disappointing news that rippled throughout the PPC community in California. But it also provided an opportunity to consider other options for a state-wide comprehensive service-delivery model for seriously ill children in California in partnership with the Coalition for Compassionate Care of California (CCCC).

A strategic alliance was formed, and CHPCC became a division of CCCC. The idea behind this unification was to combine two of California’s leading nonprofits dedicated to promoting access to high-quality, compassionate care for all who are seriously ill or nearing the end of life. The alliance leveraged Devon Dabbs’ expertise and leadership in advocacy and pediatric program development, while aligning the next phase of pediatric programming with CCCC’s palliative

care advocacy and location in Sacramento.

### **Current Options for Children after the Waiver**

The convergence of expertise with CHPCC and CCCC brings the pediatric palliative care movement in California to a critical juncture; we have a responsibility to creatively integrate available mechanisms to deliver home-based hospice and palliative care to children in the post-waiver era. Our current focus is on optimizing access to and utilization of existing programs, while advocating for adjustments and improvements where needed.

### **Concurrent Care for Children Requirement (Concurrent Care)**

Even before the waiver ended, some California hospice providers had already begun to move away from the PFC waiver. Instead, they chose to utilize the Concurrent Care for Children Requirement (Concurrent Care), Section 2302 of the Patient Protection and Affordable Care Act.

Enacted by Congress in 2010, Concurrent Care was designed “to remove the prohibition of receiving curative treatment upon the election of the hospice benefit by, or on behalf of, a Medicaid or Children’s Health Insurance Program (CHIP) eligible child.” A year later, in 2011, California adopted the Concurrent Care which made concurrent hospice and curative treatment available to children throughout the state regardless of their county of residence.

While this is a tremendous victory for the pediatric palliative care movement, the six-month life expectancy required for hospice eligibility still poses a barrier. This barrier is being chipped away by dedicated providers like Dr. David Sine in California’s Central Valley, whose award-winning team provides support and training to other hospice agencies navigating Concurrent Care with the best interest of children at the center of care. Like Dr. Sine says, “We find ways to get kids the care they need under Concurrent Care by fitting the program to meet the needs of the child, not the other way around.”

In short, if Concurrent Care had been available in 2001, it would have provided a way for Saúl to access hospice care while undergoing aggressive therapies to combat his disease, but his parents would still be confronted with pain of affirming that their son’s life would likely end in six months.

### **California Senate Bill 1004 (SB 1004)**

While the effective utilization of Concurrent Care has gained momentum in California, with the waiver gone, the application of mechanisms to deliver care to children upstream of the six-month barrier has been ongoing. On January 1, 2018, after significant involvement by pediatric palliative care advocates, California Senate Bill 1004 (SB 1004),<sup>5</sup> which required DHCS to establish standards for Medi-Cal Managed Care Plans to ensure delivery of palliative care services, went into effect for adult patients. SB 1004 was inspired by and based on the research (mentioned above) from the PFC waiver. The bill was designed as a cost-neutral benefit intended to extend palliative care to all Medi-Cal eligible patients at all stages of serious illness.

A year after its implementation for adults, on January 1, 2019, SB 1004 went into effect for children, with the intention of replacing the PFC program, which ended on December 31, 2018.

The implementation of SB 1004 in the pediatric population has not been without hurdles, and advocacy efforts are currently underway to ensure that children throughout the state have equitable access to home-based palliative care. CHPCC has worked closely with DHCS, hospice and home health agencies, palliative care providers, California Children's Services county programs, and Medi-Cal managed care plans to collectively address the concerns with both implementation of SB 1004 and the ongoing delivery of home-based palliative care. Three versions of Numbered Letter 16-1218,<sup>6</sup> the guidance for California Children's Services on SB 1004, have been released by DHCS this year, all with input from pediatric palliative care advocates. Additional guidance on SB 1004 in pediatrics is available through the All Plan Letter 18-020,<sup>7</sup> which provides direction for Medi-Cal Managed Care Plans, who are responsible for ensuring that the patients they cover have access to home-based palliative care.

Specifically, under SB 1004, there are seven palliative care services that Medi-Cal requires when determined to be medically necessary for eligible patients.

1. Advance Care Planning
2. Palliative Care Assessment and Consultation, including family training
3. Plan of Care
4. Palliative Care Team
5. Care Coordination
6. Pain and Symptom Management
7. Mental Health and Medical Social Services, including anticipatory grief bereavement counseling and family counseling

Notably absent from SB 1004 are expressive therapies, which were widely used under the PFC waiver, and respite care for families, which was administratively difficult but still utilized under PFC. However, there is great potential as creative utilization of Concurrent Care is expanding in California, and research and advocacy seeks to ensure that the benefit to children and their families previously shown in the PFC pilot studies is realized through the current suite of services offered under SB 1004.

### **Back to the Future**

As noted earlier, studies have shown that to improve the quality of life for a child combating life-threatening illness while at the same time using public dollars efficiently, a compassionate system of care that attends to the physical, emotional, spiritual, and psychosocial needs of a child must be implemented early on in the disease trajectory, not only in the final six months. So, in the post-waiver era in California, we are charged with the responsibility to ensure that the supportive services currently available to seriously ill children and their families are well understood and implemented to the highest extent of their availability.

Looking back over the past two decades, much has been accomplished since the day Saúl died in unnecessary confusion and suffering. There can be a tendency to rest in the pride of a job

well done. However, humility is the order of the day as we have yet to completely embrace the needs of seriously ill children in the arena of public policy with the same ardor and tenderness with which we embrace children in other areas of life. Those too little or too sick to speak for themselves require an extra measure of love and concern from lawmakers and healthcare systems. Saúl deserved a better end to his story, as do all children whose time on this earth is brief.

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1. Jacob’s Heart Children’s Cancer Support Services provides psychosocial, emotional, and financial support to seriously ill children and their families in Central California.
  2. Gans, D., Kominski, G., Roby, D., Diamant, A., Chen, X., Lin, W., & Hohe, N. (2012). Better Outcomes, Lower Costs: Palliative Care Program Reduces Stress, Costs of Care for Children with Life-Threatening Conditions.
  3. Summary and History of CHPCC and the Coalition for Compassionate Care of California (2018).
  4. Gans, Daphna, et al., Impact of a Pediatric Palliative Care Program on the Caregiver Experience. *Journal of Hospice & Palliative Nursing*, vol. 17, no. 6, 2015, pp. 559–565.
  5. [http://leginfo.legislature.ca.gov/faces/billNavClient.xhtml?bill\\_id=201320140SB1004](http://leginfo.legislature.ca.gov/faces/billNavClient.xhtml?bill_id=201320140SB1004)
  6. <https://www.dhcs.ca.gov/services/ccs/Documents/CCS-NL-12-1119.pdf>
  7. <https://www.dhcs.ca.gov/formsandpubs/Documents/MMCDAPLsandPolicyLetters/APL2018/APL18-020.pdf>

**MASSACHUSETTS DEPARTMENT OF PUBLIC HEALTH**  
**Division for Children and Youth with Special Health Needs**  
**Pediatric Palliative Care Network**

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In 2004, the Hospice and Palliative Care Federation of Massachusetts led a group of stakeholders that included parents of medically fragile children, bereaved parents, and pediatric palliative care physicians to create legislation that would provide pediatric palliative care services to children with life-limiting conditions and their families. It took three years, but in April 2006, Governor Mitt Romney signed into law *“An Act Providing Access to Affordable, Quality, and Accountable Care.”* The *Pediatric Palliative Care Program* was established within Chapter 111 of the General Laws. The program is administered by the Massachusetts Department of Public Health (MDPH) within its Division for Children and Youth with Special Health Needs (DCYSHN).

The Massachusetts Pediatric Palliative Care Network (PPCN) is a home-based program designed to complement existing services to meet the needs of eligible children with a wide range of life-limiting illnesses and their families or guardians, even when cure remains a possibility. The PPCN program supports the child and family with services designed to achieve an improved quality of life by meeting the physical, emotional, and spiritual needs experienced during the course of illness, death, and bereavement. The PPCN program supports the child and family to accomplish these goals in accordance with their values, needs, and preferences by providing access to a full range of consultative and direct care palliative services. The services complement those rendered by the child’s primary care provider who retains professional responsibility for the child’s plan of care. Examples of these services include but are not limited to skilled pain and symptom management, case management, music therapy, child life specialists, spiritual care, advance care planning, referrals to other community services, short-term respite care, and bereavement care for the family.

The Admission Criteria for the program requires the child and family to be residents of Massachusetts, ranging in age from prenatal to the 19<sup>th</sup> birthday, with a signed order from a physician confirming a life-limiting diagnosis. The program is open to all who qualify and there is no charge for services. Anyone can make a referral to the PPCN: physicians, clinics, school nurses, families, and more.

The PPCN was first funded in FY07, contracting with ten licensed hospices to provide pediatric palliative care services across the state. The first family was admitted to the PPCN in February 2007. For FY20, we have eight licensed hospices providing services, with each program having a

significant geographic service area. The largest program has 148 children and families and the smallest in a rural county has six.

Our state Hospice and Palliative Care Federation continues to champion our program and spearhead the advocacy efforts with the state legislature.

Today, we have 535 children on service with 132 families waiting. Four years ago, we were forced to start a waiting list for services. Even with significant funding increases, referrals to the program outpace our ability to take on new children.

With eight providers covering the entire state, it means geographic service areas are extremely large, with many families being more than an hour drive from program headquarters.

Alternative therapies play an important role in the quality of life of the family. All programs are required to offer music. Two additional alternative therapy offerings determined by the individual programs are also required. Examples are aromatherapy, pediatric massage, Reiki, pet therapy, and expressive arts.

The Pediatric Palliative Care Network is in the Division for Children and Youth with Special Health Needs (DCYSHN) within the Bureau of Family Health and Nutrition, within the Massachusetts Department of Public Health. There are several other programs within DCYSHN that also provide services to families with medically fragile children, which has been advantageous in facilitating the coordination of services in the community.

The eight PPCN teams work closely with medical centers and their in-house pediatric palliative care services throughout the Commonwealth in a reciprocal referral relationship. Often a PPCN team will determine that a family may benefit from a pediatric palliative care consult and a referral will be made. When a child on the PPCN has an inpatient stay, every effort is made to have a smooth hand-off back to the home setting. These partnerships result in more effective case management and a better experience for the family.

Many families report the services they value most are support for their other siblings by a child life specialist or a music therapist, as well as social events that give them the opportunity to get to meet other families in the program. Both of these activities address a common theme of isolation reported by families.

In 2013, the PPCN expanded services to include prenatal cases. The pediatric palliative care providers work with genetic clinics and NICUs that identify families who are told their unborn child has a diagnosis that is incompatible with life. The goal of care in these cases is to support the family in their decision to continue the pregnancy and to help other children in the family understand and process the situation. This is usually a combination of Child Life services and music therapy. PPCN music therapists will record the infant's heartbeat in utero and set it to music chosen by the family.

In the spring of 2020, the Pediatric Palliative Care Network will begin its thirteenth year. The original funding was \$800,000 and as of this fiscal year, it is now \$4,800,000. With the ongoing and steadfast support of the Hospice and Palliative Care Federation of Massachusetts, we hope to continue to grow and increase services to children and their families in the future.

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## GREATER ILLINOIS PEDIATRIC PALLIATIVE CARE COALITION LEGISLATIVE AND ADVOCACY EFFORTS

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### Key Points:

- Get to know your legislators! Individual visits to legislators' district offices
- Plan Advocacy Days with visits to legislators' offices at the state capitol
- Create partnership with Illinois Association of Medicaid Health Plans and MCOs
- Communication with Medicaid Medical Director
- Attendance at state's Hospice & Palliative Care Advisory Panel
- Meetings with IL Department of Health & Family Services (HFS), Division of Medical Programs (Medicaid)

We began 2019 with an ambitious goal to work with policymakers, healthcare providers, and families in developing a care delivery model for home-based pediatric palliative care (HBPPC) under Medicaid. While Illinois had successfully passed the Pediatric Palliative Care Act in 2010, the program was never funded as Illinois suffered under the absence of a state budget for several years and the PPC Act expired. With a recent change in government leadership, the Greater Illinois Pediatric Palliative Care Coalition (GIPPCC) began a quest to inform state legislators about the limitations of Concurrent Care for Children and new opportunities for children to benefit from HBPPC, highlighting the small, targeted number of children who require a unique service approach as compared to adult models of hospice care. Armed with increasing evidence that HBPPC can be an effective way to improve medical outcomes and quality of life while reducing costs for children with serious illness by shifting costly inpatient care to more coordinated and less expensive outpatient care, GIPPCC began our Legislative Campaign.

“Home-based pediatric palliative services have been shown in multiple studies to keep children out of the hospital, improve the medical management of symptoms, decrease family stress, and

result in better childhood quality of life.” (e.g., Journal of Pain & Symptom Management, September 2016)

While it may seem daunting, much of the work is in building awareness and relationships. We were fortunate to have a team of physicians, hospice providers, policy professionals, and parents who were willing to speak with lawmakers and advocate for PPC through a series of face-to-face meetings.

Alongside our legislative outreach work, we dedicated efforts to become more informed of different approaches to state-funded programs. We are grateful to our colleagues in California, Massachusetts, Colorado, and Vermont who graciously shared their experience with waivers and state plan amendments, and to the Coalition to Advance Palliative Care (CAPC) which provided on-going supports and problem solving. While we used the 2010 PPC law as a foundation, we also wanted a new bill to incorporate lessons learned, strengths, and challenges from other state models, in hopes of developing an innovative approach to HBPPC program development, implementation, and administration. Rather than pursue a waiver program and pilot as originally stated in the PPC Act 2010, both the Director of Medicaid and the Medical Director of Medicaid recommended a state plan amendment (SPA) and full state-wide program.

One of the biggest challenges we experienced was the lack of information and/or consistency in language across different state programs. Each state seemed to have their own approach to eligibility, mandatory services, payment, and provider requirements. Additionally, there was a dearth of information about the delivery and cost of HBPPC currently occurring in Illinois as well as in other states. We were frequently asked how many children may be impacted and what the cost of HBPPC care would be. Again, limited data collection, lack of consistency, and experience across organizations caring for seriously ill children made this difficult to answer. And then how to account for the fact that most hospice agencies report using philanthropic funding to supplement their pediatric programs.

A second challenge involved conversations with our own team members and advocates for pediatric palliative care about balancing access and high quality. How do we ensure high quality care without setting the standard so high that very few hospices would be able to meet the requirements? And optimal services are likely to increase cost and decrease participation by providers, especially in rural areas. On the other hand, if these same standards are not set high enough, we lose the integrity of NPC clinical practice guidelines and PPC standards; children will not receive the high-quality care they need and deserve. Over many conversations with all stakeholders, we worked towards a consensus around the descriptions of eligible children, essential services such as child life and expressive therapies, and what provider expertise is necessary and how that expertise is defined by certification and/or training. We remain focused on our goal to work together to assure the state’s most medically fragile children have the quality care they deserve.

## STAKEHOLDER DISCUSSIONS AROUND DEFINING CRITERIA IN THE REGULATIONS:

- Qualified Child
- Authorized Provider
- Reimbursable Services
- Administration & Oversight

As advised, one critical piece of any legislative initiative is having champions in each of the chambers of legislation and across both parties to be sponsors of the bill. We successfully identified and worked with our chief sponsors, who, along with their staffs, agreed to help us and submit a bill for consideration by the General Assembly of Illinois. But the speed and intensity of our efforts quickly picked up following a meeting on a Monday at 5:00 pm with the Chair of the State Senate Human Services Committee who requested a bill be presented to her committee that Wednesday morning at 8:00 am. With the foundation of the 2010 law, a cell phone and laptop, we drove to Springfield, dictating suggestions for legislative language as we drove! We later laughed about a *USA Today* article “Who’s Writing Your Laws?”.

Then with much trepidation and a fast-beating heart, we testified before both the Senate and House committees. Senate Bill 1105 unanimously passed through the State Senate and was approved by the Appropriations, Human Services committee in the State House. Unfortunately, no money was provided in the Medicaid budget for this program, so the bill was tabled until HFS could further evaluate the program and budget for reasonable funding.

We are thankful for the legislators and their tireless efforts to secure support from HFS and Illinois’s Medicaid managed care organizations to develop a state plan amendment for HBPPC. We are eager to work with HFS in exploring a care delivery model that reflects the resources within Illinois and helps control the cost of care while improving the quality of care for our most seriously ill children and their families. The Director of Medicaid has voiced his support for a state plan amendment and the intent to include funding for HBPPC in the Medicaid budget proposal that will be sent to the Governor in February. Stay tuned for the final outcome of our efforts!

We hope to work with other state champions and coalitions to support their advocacy efforts and to develop an information bank to share information. And do not hesitate to outreach if we can be of help in your efforts.

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## PERINATAL PALLIATIVE CARE DEVELOPMENTS NATIONALLY AND IN ARKANSAS

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Every year in the United States, more children die in infancy (the first 12 months of life) than in all other pediatric age groups combined. Two thirds of these deaths occur in the neonatal period (the first 28 days of life), and two leading causes of infant mortality are complications of prematurity and congenital malformations/chromosomal abnormalities. According to the American Academy of Pediatrics, nearly 1/3 of all in-hospital pediatric deaths in the United States occur in neonatal intensive care units.

With advances in medical technology and obstetric care, it is now possible to diagnose many conditions prenatally, including some that may be life-limiting. Options for in utero intervention have also expanded, but that is not always possible or desired by the family. While some perinatal losses are unexpected, many neonatal deaths are preceded by decisions to limit, withhold, or withdraw certain treatments or interventions. Similar to a serious diagnosis later in life, these families often struggle with medical decisions, anticipatory grief, anxiety over the unknown, and the loss of their hopes and dreams for the future. As the field of hospice and palliative medicine has continued to grow and expand over the years since its inception, its reach has gradually extended to the perinatal period, in efforts to meet the needs of families simultaneously preparing for the birth and death of their child.

Perinatal Palliative Care is evidence-based. It recognizes the value and meaning of a child's life (even if that life is limited to the pregnancy). It provides the family with some options and opportunities for mementos and memory-making that may not be available with pregnancy termination. The ongoing interdisciplinary support promotes healing of the entire family and can help reduce the emotional stress and psychological trauma associated with perinatal loss.

Other benefits of early and integrated perinatal palliative care include better parental understanding of the disease trajectory, potential outcomes, and available care options; better clinician understanding of the family's goals, values, and perspectives; and the opportunity for shared decision making (Carter. Arch Dis Child Fetal Neonatal Ed 2017). Additionally, advanced care Birth Planning is associated with increased parent and family satisfaction, giving a better sense of control, and less fear, anxiety and emotional distress at the time of delivery; this leads to a healthier grieving process and better bonding for families affected by pregnancies with life-limiting fetal diagnoses. (Cole et al. A Proposed Model for Perinatal Palliative Care. Journal of Obstetric, Gynecologic, and Neonatal Nursing. 2017: 1-8.) Perinatal hospice referrals can provide continuity of care over time and across locations, compassionate medical care for the dying neonate, holistic care of the entire family, and ongoing bereavement support after death.

In 2007, the American Academy of Pediatrics (AAP) published a policy statement on Non-Initiation or Withdrawal of Intensive Care for High-Risk Newborns. The Academy has also published other statements and clinical reports regarding palliative care for children. In recent years, the American College of Obstetricians and Gynecologists (ACOG) has also begun to incorporate recommendations regarding palliative care into their policy statements and guidelines, most recently in Committee Opinion #786 Perinatal Palliative Care that was published in 2019. The committee opinion supports perinatal palliative care as an option on a care spectrum for pregnancies complicated by life-limiting fetal diagnoses and states that this option should be discussed with patients. "The College stresses informed consent, good communication between health care providers, the availability of support services, and multidisciplinary care as important aspects of care for life-limiting fetal diagnoses."

Other nursing and professional organizations have authored statements and guidelines supporting this concept and practice, and there is ongoing research regarding outcomes and best practices for perinatal palliative care. Additional language specific to the care of neonates was emphasized in the most recent National Consensus Project Clinical Practice Guidelines for Quality Palliative Care Guidelines in 2018, and the American Academy of Hospice and Palliative Medicine (AAHPM) Essentials series includes a section on the "special case" of perinatal palliative care, and recommendations for birth plan content.

In addition to this progress on the national front, there have also been some recent developments in the state of Arkansas to support perinatal palliative care referrals. The Hospice & Palliative Care Association of Arkansas works at the state level to advocate for and educate on hospice and palliative care. In 2019, an Arkansas law was created to guarantee that a woman who has received a diagnosis of a lethal fetal anomaly is presented with information on the option of perinatal palliative care.

According to the Arkansas Department of Health, there were nearly 1,500 reported perinatal losses in the year 2018: 280 infant deaths, 243 fetal deaths, and 928 miscarriages. Though not all of these would have been appropriate for perinatal palliative care referrals, the numbers illustrate how common perinatal loss is in our community.

Through the work of many dedicated individuals, organizations, and bereaved parents, options for pediatric and now perinatal hospice referrals have expanded to nearly every corner of our state. There are published guidelines for healthcare providers available online, an active fetal anomalies interdisciplinary management program through the University of Arkansas for Medical Sciences (UAMS) and Arkansas Children’s Hospital, multiple organizations and foundations started by bereaved families to assist other families along their grief journeys, and the recent formation of the Central Arkansas Perinatal Loss Coalition to combine the efforts of multiple hospitals and organizations in supporting families and healthcare providers.

In addition to direct patient and family care, education and staff support are other crucial aspects of perinatal palliative care. The UAMS Love Lives perinatal bereavement program holds an annual workshop on perinatal loss and bereavement that includes specific presentations on perinatal palliative care and has recently developed a second workshop for staff using some of the Initiative for Pediatric Palliative Care curriculum. The curriculum for the neonatal-perinatal fellows at UAMS and Arkansas Children’s Hospital includes specific lectures, simulation, and other training in perinatal palliative care. Other local hospitals have provided dedicated training and staff education through Resolve Through Sharing. And the topic of perinatal palliative and hospice care has been presented at two recent statewide conferences for hospice and palliative care providers.

Perinatal loss is unique in many ways, but still at its core involves the grief of a family over the death of a loved one. The concepts and domains of care that are applied in adult and pediatric palliative medicine also have their place in this special patient population. As awareness of the issues surrounding perinatal loss continues to increase, and more information and resources are available to both healthcare providers and caregivers, we will continue to see improvements in the care available to these families, both in Arkansas and throughout the country.

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## COLLABORATION AND PARTNERSHIP IS KEY TO ADVOCACY IN PENNSYLVANIA

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Statewide Pediatric Palliative Care Coalitions (SPPCC) play an important role in pushing forward both formal and informal palliative care advocacy efforts. Across the country, SPPCCs come in all different shapes and sizes, but they all serve as a united front to ensure better care for families and children in their respective states. Oftentimes, an SPPCC will form when a local issue in coverage or payment arises. Or there is simply an understanding of the need for more networking and education across a state. No matter how they are started, SPPCCs are an opportunity for different stakeholders to come together in a neutral forum and create solutions.

In Pennsylvania, the Pediatric Palliative Care Coalition (PPCC) has existed in a variety of forms for almost 15 years. What started as a small committee in a church grew to a statewide organization with national impact. Throughout that time, the main emphasis has been on collaboration and partnership. Through a sustained mission to provide information, education, and advocacy, PPCC statewide activities have established a network of advocates ready to speak to issues concerning pediatric palliative and hospice care as they arise. By developing and maintaining relationships with state legislators, PPCC is poised to react quickly to opportunities for input and action.

For a small grassroots organization with minimal resources, it is an excellent strategy to partner with others to advance your goals. By collaborating with like organizations across the state, PPCC is able to keep members in front of legislators and state officials on a variety of issues. By networking with other SPPCCs across the country, PPCC has been able to advance new ideas in Pennsylvania that have been successful in other states.

Likewise, by joining together with national organizations, PPCC has been a “boots on the ground” resource for advocacy. For instance, NHPCO has an incredible advocacy team with much wider resources and connections than is possible for a small nonprofit. By participating in their advocacy day on the Hill, PPCC has been able to solidify relationships with Pennsylvania legislators in DC. Not only is PPCC able to help advance the larger efforts important to both PPCC constituents and NHPCO, but there is an automatic avenue for further relationships back in Pennsylvania home districts.

Similarly, on a statewide level, by partnering with the Family Paid Leave Coalition in Pennsylvania, PPCC has been able to raise awareness of pediatric palliative and hospice care

needs while advocating for the important issue of paid leave for family caregivers. Recently, PPCC was asked to testify in front of a state Senate committee about the importance of paid family leave. This was an excellent opportunity to tell personal stories about the issues facing families of medically complex children.

On a local level, SPPCCs are also able to touch audiences that are outside the scope of the healthcare organization. PPCC utilizes their speaker's bureau for programs on palliative and hospice care in churches, Rotary clubs, educational institutions, and other organizations all across Pennsylvania. This creates opportunity for greater dialog and conversation about important issues that are often not discussed.

The importance of developing and maintaining relationships in advocacy work cannot be overstated. What can seem like an overwhelming and daunting process can be made so much easier through collaboration and combined resources. While the pediatric voice is often the "small voice in the room" of adult healthcare concerns, it is so important to ensure that the pediatric voice *is* heard. In the world of palliative care, the pediatric providers have much to offer to the adult providers. Developing partnerships and entering into collaborations help to ensure that pediatric palliative and hospice care issues are addressed alongside the adult concerns.

Collaborative endeavors have also been the catalyst for promoting larger initiatives in partnership with other SPPCCs. In an effort to reach a wider audience with educational programming, PPCC joined forces in 2017 with the Greater Illinois Pediatric Palliative Care Coalition (GIPPCC) and Children's Hospice and Palliative Care Coalition (CHPCC) in CA to present an annual webinar series. In 2018, 2019, and now in 2020, the joint team has presented a monthly webinar series to provide low cost, easy access education to pediatric palliative care providers across the country. This year, Jacob's Heart Cancer Services, Stanford Medicine, and CSU Shiley Palliative Care Institute have joined the team with the result of providing excellent CME and CEU accreditation. Key to this team are the many PPC clinicians who provide world class interdisciplinary presentations each month. It truly takes a village and a lot of coordination, but these collaborative efforts initiated by SPPCCs are the perfect spark for this important work to happen.



*Hospice Advocates Outside Senate Hearing, February 2018*

An additional example of the benefit of statewide organizations combining forces for a larger impact is the *Following the Death of a Child* program funded through a grant from the Funeral Service Foundation. Realizing that the project had the potential for national impact, PPCC, GIPPCC, and CHPCC joined together to submit a proposal to the Funeral Service Foundation to work with funeral professionals on supporting families following the death of a child. The result has been a national task force of funeral professionals, pediatric palliative and hospice

clinicians, and bereaved parents that have taken a deep dive into how best care for families after their child has died. The intent is to produce educational materials for funeral professionals, as well as to create mechanisms for better communication between hospitals, hospices, funeral professionals, and families.

In order to foster such collaborative efforts and better share information, an informal SPPCC group started to meet monthly via conference call to share ideas, ask questions of each other, and learn about topic areas that intersect group interests. This has been a wonderful forum for learning about advocacy efforts in other states as well as to cross promote educational opportunities and statewide initiatives. If you are involved in a statewide group, however loosely defined, you are most welcome to join. Simply contact Betsy Hawley: [betsy@ppcc-pa.org](mailto:betsy@ppcc-pa.org) to be put on the contact list.

Collaborations and partnerships can be difficult, but the rewards are great. With overflowing workloads and too few hours in the day, finding ways to work together and avoid duplicative efforts is key. If your state doesn't have an SPPCC, take that first step and bring a small group of stakeholders together. If you do have an SPPCC in your state, reach out to a neighboring state and begin looking at regional priorities. And by all means, jump on the national conference call! We're all in this together!

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## SOUTH CAROLINA PEDIATRIC PALLIATIVE AND HOSPICE CARE COLLABORATIVE

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Recognizing the need to work together to advance the care of the children in South Carolina with serious illnesses, the South Carolina Pediatric Palliative and Hospice Care Collaborative (SCPPHCC) was formed in April of 2016. Inaugural and current membership includes the three hospital-based pediatric palliative care programs and the sole community-based hospice and palliative care program for children in South Carolina. This organization provides services across the entire state. The South Carolina Children's Hospital Collaborative serves as the parent organization for SCPPHCC. There is no cost to membership and approximately three meetings have been held per year since initiation. Meetings are held in the central part of the state, allowing for same day travel.

The group has primarily focused on advocacy issues related to the care of children with serious illnesses and their families. For example, we continue to work on passing legislation to remove the age limit on Do Not Resuscitate (DNR) orders for children receiving hospice services in the community. Unfortunately, there have been situations in which a child dying of a life-limiting illness at home has undergone attempted resuscitation despite parent wishes.

At the request of the collaborative, one of our member physicians served on the South Carolina Palliative Care and Quality of Study Committee. This committee was focused on making recommendations to enhance access to palliative care in South Carolina. The involvement of the SCPPHCC ensured that children were considered equally in the recommendations.

The collaborative is hopeful to make progress in efforts beyond advocacy. There is a significant need to improve palliative care education for all audiences in South Carolina. We also are starting to work on statewide quality and outcomes efforts to ensure that a consistent level of high-quality services are delivered throughout the entire state. These efforts are focused initially on describing the population currently and historically served by the member programs and then working collaboratively to complete quality projects.

The challenges we face include not having a position dedicated solely to the work of the collaborative. All members serve voluntarily. The director of the state children's hospital collaborative has been especially skilled in helping with the legislative and advocacy priorities; however, education and quality work have thus far lacked true champions with the time available to commit to moving projects and initiatives forward.

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## PEDIATRIC CONCURRENT CARE IN MISSOURI

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Concurrent care for children receiving hospice in Missouri became effective on April 1, 2010 when Section 2302 of the Affordable Care Act (aka Health Care Reform) entitled "Concurrent Care for Children" removed the prohibition of receiving curative treatment upon the election of the hospice benefit. Since that time, MO HealthNet hospice services for children (ages 0-20) may be concurrent with the care related to curative treatment of the condition for which a diagnosis of a terminal illness has been made. The Affordable Care Act does not change the criteria for receiving hospice services or the hospice provider responsibility. The hospice provider continues to be responsible for all services related to the palliation and support services for the terminally ill.

Claims for curative treatment services for children enrolled in hospice are submitted for reimbursement by the provider of the service in the same manner as claims for individuals not enrolled in hospice. The hospice provider must continue to submit the Hospice Election Statement, Physician Certification of Terminal Illness, and Notification of Termination of Hospice Benefit. Although claims for curative services are reviewed on an individual basis, MO HealthNet has been tremendously responsive to requests for concurrent care in children on hospice with complex, life-limiting diseases.

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## PARTNERS FOR CHILDREN: A NEW COLLABORATIVE PROGRAM MODEL FOR MEDICALLY COMPLEX CHILDREN IN MICHIGAN

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Currently, there are hundreds of Michigan children with complex conditions who receive care from multiple health care specialists. These experts include neurologists, rehabilitation specialists, gastroenterologists, lung specialists, pediatric surgeons, urologists, mental health providers, and more. Many of these children also have limited mobility, take more than nine medications daily, and depend on technology and equipment such as feeding tubes or respiratory devices to help them survive and integrate into their families and communities. For the majority of parents of children with such complex illnesses, life revolves around frequent trips to specialty clinics, pediatrician offices, or emergency departments that often result in hospital stays.

Partners for Children (PFC) is a program designed with these children and families in mind. It is run through Michigan Medicine with the support from the Michigan Health Endowment Fund and Hospice of Michigan. Michigan Medicaid provides funding for the program evaluation. The evaluation activities focus on the qualitative analysis (surveys), as well as quantitative analyses (claims and utilization data). In 2020, The State of Michigan's Children Special Health Care Services contributed to enhancing the program by funding a clinical care coordinator position (RN). The RN will help with phone triage, documentation, and other non-billable services, and will assist in ensuring continuity of care on both the inpatient and outpatient sides. Since August 2018, PFC enrolled 113 children within 75 a mile radius from C. S. Mott Children's Hospital, with 17 discharges, and 11 patients on the waitlist.

We are encouraged by the preliminary results showing a decrease in ER and inpatient care days from the pre-PFC to the PFC period. However, additional work is necessary to assess data completeness, validate results, and update the analysis accounting for all children enrolled in the program. We anticipate these results later in the year. In the meantime, legislators in the state of Michigan are also interested in seeing the results. Together we will be exploring various

design and staffing models, as well as sustainability efforts moving forward. These efforts will include partnerships with other Michigan hospitals, as the ultimate goal for the program is to provide this layer of support to all children in Michigan who would qualify for the benefit of having a similar community-based service.

For more information on this program in Michigan, email [PEDS-PartnersForChildren@med.umich.edu](mailto:PEDS-PartnersForChildren@med.umich.edu).

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## NHPCO LEGISLATIVE PRIORITIES FOR 2020

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If recent politics has taught us anything, it's that prognostication is a difficult game. As Congress proceeds through a presidential impeachment, and the political world prepares for elections in the fall, substantive health care legislation will be competing with a lot of other priorities. Some legislators will be looking to rack up bipartisan wins to tout during their campaigns, while others may face a primary challenger and be less inclined to work across the aisle. By mid-year, the entire House will be focused on the 2020 election. That said, the hospice and palliative care community is well-positioned to leverage this difficult environment and work strategically to get important policies adopted.

Legislative priorities for 2020 remain similar to those for the second half of 2019:

- Pass the Palliative Care and Hospice Education and Training Act
- Pass the Rural Access to Hospice Act
- Continue working with congressional champions on program integrity legislation

Let's look at where each of these priorities left off at the end of 2019.

### **The Palliative Care and Hospice Education and Training Act (H.R. 647/S. 2080)**

The Palliative Care and Hospice Education and Training Act (PCHETA) passed the House in October 2019 and the House version was moved to the Senate for consideration. There is also a Senate version of the bill that was introduced in July, but it differs slightly from the House version. The Senate is most likely to move the Senate version, which means once PCHETA passes the Senate, there will have to be some reconciliation in the language between the House and Senate version before it is sent to the President for his signature.

Specifically in relationship to pediatric palliative care, PCHETA focuses on increasing workforce training in hospice and palliative care with the goal of expanding access. Toward that end, the bill that passed the House includes:

- **Establishing Palliative Care and Hospice Education Centers** which would provide in-depth and improved training for physicians, nurses, social workers, chaplains, pharmacists, and other allied specialties in palliative care. These education centers would also offer **fellowship programs** to provide training for faculty members in

various medical institutions to enhance knowledge and care skills for patients facing life-limiting illnesses.

- **Expanding Palliative Care Research** by directing the National Institutes of Health to allocate existing funds for research to advance clinical practice and care delivery for patients with advanced and life-limiting illness.
- **Providing Academic Awards and Career Incentive Awards** to promote career development of board certified/eligible physicians in palliative medicine and offer grants and contracts for eligible healthcare professionals who agree to teach or practice in the field of palliative care for several years.
- **Establishing a National Awareness Campaign** which will inform the public and healthcare professionals about this important field of practice and ensure it is equipped to serve the increasing need of patients.

PCHETA currently has 37 cosponsors in the Senate. It had briefly been scheduled for a mark-up in the Senate HELP committee in December but was pulled from the markup due to some technical assistance received from the Department of Health and Human Services. Unfortunately, there was not enough time to address HHS's concerns before the markup, so PCHETA was pulled. Congressional supporters are still working through the technical assistance and we hope to see PCHETA scheduled for markup again soon.

We would appreciate all hospice and palliative care advocates [contacting their Senators through our Legislative Action Center, and asking them to please pass PCHETA.](#)

### **The Rural Access to Hospice Act**

The Rural Access to Hospice Act (HR. 2594/S.1190) has 38 cosponsors in the House and 16 cosponsors in the Senate. NHPCO spent much of 2019 working to get the Rural Access to Hospice Act included in larger bill packages, including a possible program integrity package. RAH is a small bill, much smaller than PCHETA, and it is expected that it will have to be coupled with something else to help it move through the legislative process. NHPCO has been working with the House Ways and Means Committee Rural Taskforce and submitted RAH for their consideration as a priority policy initiative for 2020.

Whereas PCHETA is a larger bill that touches many different areas of government and includes several different provisions, RAH does one very specific thing: it adds “hospice attending physician services” to the list of services that Federally Qualified Health Centers and Rural Health Clinics are reimbursed for performing. Currently, these hospice attending physician services are not included in the bundled payments that FQHCs and RHCs receive, which can leave some patients with the choice of keeping their FQHC/RHC provider, or transitioning to hospice care. Unfortunately, under current law, they cannot do both, even though any other patient who does not have an FQHC/RHC provider would be able to keep that provider, who would then assist with their transition and coordinate with the hospice team. By including “hospice attending physician services” in the list of services that FQHCs and RHCs can provide,

we can ensure that patients served by these safety-net providers have the same choice and access to care as other patients.

We believe that the Rural Access to Hospice Act is an important step to improving coordinated care, especially for vulnerable communities in rural and underserved areas. It is important that FQHCs and RHCs have strong relationship with their local hospice and palliative care programs, and that there are no barriers to referring their patients and assisting with transitions to different care settings.

NHPCO will continue to find a vehicle for RAH to move with and continue to work on explaining this technical issue to Members of Congress. It is possible that RAH could be attached to a program integrity package that is currently in the works. We would appreciate all hospice and palliative care advocates [contacting their Members of Congress through our Legislative Action Center, and asking them to please pass RAH.](#)

### **Hospice Program Integrity Package**

In July 2019, two reports issued by the Office of the Inspector General identified vulnerabilities in the Medicare hospice benefit. Congress and regulators in the Administration took notice. Fortunately, the vulnerabilities are limited in scope and focus on a small number of hospice providers. NHPCO staff worked closely with provider members on our Legislative Affairs, Quality, and Regulatory Committees to create a Program Integrity Initiative that we presented to Congress in the fall. Since then, NHPCO worked closely with Senators Rob Portman (OH) and Ben Cardin (MD), who introduced the Hospice Care Improvement Act (S.2807) on November 7, 2019. This bill incorporates many of NHPCO's suggested Program Integrity Initiatives. NHPCO continues to work with partners on the House side to ensure that any House bill contains many of these initiatives.

NHPCO's Program Integrity Initiatives includes provisions to establish additional enforcement remedies and establish additional intermediate remedies for poor hospice performance, to strengthen the survey process and its oversight, to provide more information to beneficiaries and their caregivers, to enhance patient access and understanding of the hospice benefit, and to educate hospice providers about common deficiencies and those that post particular risks to beneficiaries. To learn more about NHPCO's Program Integrity Initiatives, [click here.](#)

NHPCO is also working to ensure that the Rural Access to Hospice Act can move along with any Hospice Program Integrity Packages, since we believe that a good quality program should be available to all Americans, regardless of their zip code or status of their primary care provider.

### **A Win from 2019: The ACE Kids Act**

On April 18, 2019, the Advancing Care for Exceptional (ACE) Kids Act was signed into law as part of a larger package of Medicaid bills. According to the Children's Hospital Association, "The ACE Kids Act is designed to improve care for children with medically complex conditions in

Medicaid. This new law addresses existing challenges—identified by families and physicians—facing children with medically complex conditions by expanding access to patient-centered, pediatric focused coordinated care models tailored for these children across multiple providers and services, and by easing access to out-of-state care.”

Specifically, the ACE Kids Act includes a provision that incentivizes states to create voluntary “Health Homes” for children with medically complex conditions. It also has increased data collection and reporting requirements for participating states, including requirements for states to develop methodologies for tracking reductions in inpatient days and reductions in total cost of care resulting from improved care coordination and management, proposals for the use of health information technology in providing health homes services, and methodologies for tracking prompt and timely access to medically necessary care from out-of-state providers.

### **Looking Ahead: What to Expect in 2020**

NHPCO will be taking advocates to Capitol Hill to advocate on behalf of these issues during our Management and Leadership Conference in March. Advocacy training is Monday, March 23, and meetings with Congress are Tuesday, March 24. If you are interested in attending, you can [learn more and register here](#).

Because of the upcoming Presidential (and all of the House and 1/3 of Senate) Elections in November, most of Congress’s work will probably take place in the first half of the year. We are hoping that some of our legislation could be included in a possible May Medicare Extenders package, but with how contentious healthcare has been as a policy issue, it is unclear if there is enough bipartisan support to create a viable package that can actually move to the President’s desk. It will be important for hospice and palliative care advocates to pay attention to what is moving on Capitol Hill, and to be in contact with their Members of Congress frequently.

### **So, What Can I Do?**

Building relationships between hospice and palliative care advocates and their Members of Congress is key to advancing our agenda. It is one thing for Members of Congress to hear from lobbyists, but they really need to be hearing from their constituents. The hospice and palliative care providers in their district provide a much better explanation for how policies would affect the citizens at home and can help personalize what can be weedy and technical bill language.

A great way to kick off your advocacy is to join us at the Leadership and Advocacy Conference, but understanding that it is not possible for everyone to travel to Washington, DC, here are a few things you can do from home:

1. [Sign up for the Hospice Action Network Updates](#).
  - a. We send monthly emails, and other alerts when necessary, to keep you informed about what is going on in Washington, DC.
2. [Complete our Action Alerts on our Legislative Action Center](#)

- a. We update these as bills move through the process, and the suggested wording is editable. If you sent an email a few months ago, it is perfectly fine (and encouraged!) to send another one. Members of Congress need reminders, too.
- 3. [Check our Advocacy Toolkit for other ways to get involved!](#)
  - a. In it, you'll find links to webinars and resources to help you be a better advocate.

If you have any questions, you can email the Hospice Action Network team at [info@nhpcohan.org](mailto:info@nhpcohan.org), or the author at [ldrew@nhpco.org](mailto:ldrew@nhpco.org). If you have other federal legislative issues you'd like us to explore, we are happy to bring them before the Legislative Affairs Committee for their review and approval. Additionally, keep your eyes open for the Legislative Survey, which will come out at the end of 2020, and help us set the legislative agenda for the new Congress starting in 2021. We do this legislative survey of NHPCO members at the start of each new Congress to ensure that everyone has a say in our legislative priorities for the next two years.

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## PEDIATRIC CONCURRENT CARE: BUILDING EVIDENCE, INFORMING PROVIDERS, AND SERVING FAMILIES

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and

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Those who care for children and their families at end of life know the social and cultural response to pediatric death and grief is complicated. Each year more than 30,000 families in the United States face the “terrible choice” of continuing life-prolonging, curative therapies for their seriously-ill children and adolescents or utilizing standard hospice care.<sup>1</sup> With the enactment of the Patient Protection and Affordable Care Act (ACA, Section 2302), Medicaid/CHIP programs have enabled pediatric patients and their families to opt for a relatively new choice, concurrent care—the continuation of life-prolonging therapies while enrolled in hospice care—to improve quality outcomes in care at the end of life. While this federal regulation has been in place since 2010, there is a low level of evidence regarding its effectiveness to improve children- and family-centered outcomes, which is one reason the uptake rate of implementing concurrent care has been slow. Though all state Medicaid plans are required to pay for both life-prolonging therapies and hospice services for children under the age of 21, as of 2017, 22% of states do not offer concurrent care, and less than 30% of children and adolescents in hospice care received concurrent care.<sup>2-4</sup> Unfortunately, much of this may be due to the fact that there just is not enough scientific information available to assist clinicians, families, and state administrators achieve full implementation.

However, that is changing. Our research team at the University of Tennessee, Knoxville, College of Nursing was recently awarded an NIH-NINR grant for a funded research project entitled, “Effectiveness of Concurrent Care to Improve Pediatric and Family Outcomes at End of Life.” This project is designed to address concerns about the quality of health care specifically for the vulnerable populations of children and adolescents during pediatric end of life. Our team is a multidisciplinary team of researchers from nursing (Drs. Lisa Lindley, Pamela Hinds, and Jessica Keim-Malpass), medicine (Dr. Jennifer Mack), and health economics (Dr. Melanie Cozad). This team represents one of the first initiatives to examine the influence of concurrent care on pediatric and family outcomes. The team will provide evidence on the effectiveness of pediatric concurrent care to improve end-of-life care during hospice care, utilizing rigorous analyses of nationally-represented Medicaid data from 2011 to 2013. The study aims are to compare the: (1) benefits (i.e., continuity of care; symptom management); (2) burdens (i.e., hospice care intensity, care fragmentation); and (3) cost of concurrent care versus standard hospice care for children and families.

Our team is examining the potential benefits of concurrent care. We know that maintaining a relationship with the treating physician and curative team matters to families. Prior to concurrent care, it was common for children and families to discontinue hospice care to seek more aggressive care in the acute care setting, utilize the emergency department service for acute symptom episodes, or delay entry into hospice care as they hoped for a cure.<sup>5</sup> For this study, we are investigating whether continuity of care with concurrent care might be improved through continued communication and bonds with the curative team. We also know that symptom management is the hallmark of standard hospice care for children, and yet, evidence suggests that children still suffer with end-of-life symptoms in hospice. For example, a common pediatric symptom is constipation from opioid medications, disease progression, and/or end-of-life physical changes.<sup>6</sup> We hypothesized that the combined clinical expertise of the treating team and the hospice team may more effectively manage symptoms.

The research team is also interested in the potential burdens of concurrent care for the children and families. On the downside, care intensity, care fragmentation, and costs of care may be aspects of concurrent care that adversely affect children and their families. We are unsure whether concurrent care will increase hospice care intensity. Prior ChiPPs publications and other researchers have suggested that receiving concurrent care therapies may require intensive hospice care because of procedural pain and treatment medication-induced symptoms, along with acute symptom crises (e.g., uncontrolled pain, seizures, change in level of consciousness) of continued treatments at end of life.<sup>7</sup> Additionally, children receiving concurrent care have another layer of health care providers added to their teams of specialists, subspecialists, and pediatricians. It is unclear whether the addition of the hospice team contributes to an increased risk of care fragmentation.<sup>8</sup> And finally, there is the cost of care. Obviously, with all these other services, in addition to standard hospice, it is unclear whether concurrent care will affect cost of care.<sup>9</sup> Overall, this line of investigation is expected to ultimately improve the care and outcomes for children and their families at end of life.

We have a comprehensive plan to not only examine these issues, but also work with the data that come from the Centers for Medicare and Medicaid Services. Our project will include developing advanced procedures to protect the Medicaid data, assisting with the findings from that data, and creating a centralized, publicly available repository for as much information as possible. For example, our team has assembled information and documents from each state regarding legislation that pertains to pediatric concurrent hospice care. We have also created a [website](#) where that information can be accessed by anyone, as well as a library of research from other palliative care studies and the clinical evidence we have accumulated as it becomes available. Our website will also provide updated news about awards and funding opportunities. We are constantly looking for ways to communicate the importance of these families' experiences and of this work with the greater community outside of pediatric concurrent hospice care. Ultimately, we expect this research to move the subject from the isolation of those experiencing and working with it to a place of inclusion, through awareness, respect, and validation.

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## ITEMS OF INTEREST

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

### 1. **NHPCO Palliative Care Online Resources:**

NHPCO has a variety of pediatric hospice and palliative care resources available at [www.nhpc.org/pediatrics](http://www.nhpc.org/pediatrics). Also, more palliative care resources are available at [www.nhpc.org/palliativecare](http://www.nhpc.org/palliativecare), including:

- Community–Based Palliative Care
- Legal and Regulatory Resources
- Webinars and Courses
- Plus, more for NHPCO members

### **Palliative Care Programs and Professionals**

Founded in 1978, National Hospice and Palliative Care Organization (NHPCO) is the world's largest and most innovative national membership organization devoted exclusively to promoting access to hospice and palliative care and to maintaining quality care for persons facing the end of life and their families. **Join NHPCO Today!**

[Individual Palliative Care Membership](#)

[Palliative Care Group Application](#) - Save by registering your entire team

### 2. **Pediatric Hospice and Palliative Care Resources:**

- **CaringInfo**, a program of the National Hospice and Palliative Care Organization, provides free resources to help people make decisions about end-of-life care and services before a crisis. [www.caringinfo.org](http://www.caringinfo.org)

- *When Your Child is in Pain*
- *Talking with Your Child About His or Her Illness*
- *Talking to Your Child's Doctor: When Your Child Has a Serious Illness*
- *When a Child Dies: A Guide for Family and Friends*
- *Helping Children Cope with the Loss of a Loved One*

- **NHPCO's Palliative Care Resource Series** includes pediatric palliative resources such as:

- *Communication Between Parents and Health Care Professionals Enhances Satisfaction Among Parents of the Children with Severe Spinal Muscular Atrophy*
- *Consideration for Complex Pediatric Palliative Care Discharges*
- *'Who You Gonna Call?' Men with Duchenne Muscular Dystrophy Discuss End-of-life Planning*
- *Songs of the Dying: The Case for Music Therapy in Pediatric Palliative and Hospice Care*

- *Nonpharmacological Pain Management for Children*
- *Sibling Grief*
- *Pediatric Pain Management Strategies*
- *Communicating with a Child Experiencing the Death of a Loved One: Developmental Considerations*

### 3. Trends in Pediatric Palliative Care Research

Every month, PedPalAScNET collects new pediatric palliative care research. For past lists visit [their blog](#), [browse in their library](#), or join the [Zotero group](#).

[View the New Citation List in their Library](#)

### 4. Pediatric Hospice and Palliative Care Training:

- **[Upcoming 2020 Webinars](#) provided by the Pediatric Care Coalition:**
  - **February 18, 2020** – Can Compassion Fatigue? – with Lori Butterworth, Jacob’s Heart Children’s Cancer Support Services and Kelly Johnson, Lucille Packard Children’s Hospital
  - **March 12, 2020** – Spirituality in Children & Families Facing Serious Illness – with Betty Farrell & Gay Walker, End-of-Life Nursing Consortium
  - **April 21, 2020** – Together in the Sandbox: Palliative Care and Complex Care Partnerships in the Medical Neighborhood – with Sarah Frieber, Akron Children’s Hospital
  - **May 21, 2020** – Guiding Families to Mindfulness Supports Decision Making for Adults and Children – with David Steinhorn, Children’s National Medical Center and Jana Din, Tao Center for Healing
  - **June 16, 2020** – Ethical Questions in Pediatric Palliative Care – with Sabrina Derrington, Ann & Robert H Lurie Children’s Hospital
  - **July 21, 2020** – Beyond Fairytale Endings: Using Storybooks and Other Therapeutic Tools to Explain the Death of a Child – with Lori Weiner, National Cancer Institute and Meaghann Shaw Weaver, Omaha Children’s Hospital
  - **August 20, 2020** – Pediatric Concurrent Care – with Lisa Lindley, University of Tennessee
  - **September 22, 2020** – Explaining Pain: Pain Education and Mind-Body Tools for Pediatric Chronic Pain – with Rachel Zoffness, American Association of Pain Psychology
  - **October 22, 2020** – Through the Eyes of a Grieving Child – with Viki Jay, NAGC – National Alliance for Grieving Children
  - **November 17, 2020** – Partnering with Funeral Professionals to Support Families Following the Death of a Child – with Kristin James, Greater Illinois Pediatric Palliative Care Coalition and Kelly Manion, Funeral Service Foundation

- The [2020 NHPCO Leadership and Advocacy Conference](#) is where hospice and palliative care leaders gather to exchange ideas, strategies, and solutions. This year we will focus on strengthening your organization and connecting with other leaders in the field.

The conference will offer peer-to-peer educational sessions that will address these specific topic areas:

- Advocacy
  - Clinical and Operations Management
  - Emerging Markets and Partnership Opportunities
  - Engagement and Marketing
  - Finance
  - Fund Development
  - Leadership
  - Palliative Care
  - Quality
  - Regulatory
  - Staff Development
- [Submit Your Proposal Now!](#)  
2020 Interdisciplinary Conference  
October 10 – 11, 2020: Preconference  
October 12 – 14, 2020: Main Conference  
Submission Deadline: February 24, 2020

Be a part of the premier conference for members of the hospice and palliative care interdisciplinary team. Your ideas could impact and inspire other providers in leading their own teams to success.

IDC20 will offer peer-to-peer educational sessions addressing these specific topic areas:

- Community-Based Palliative Care
  - Interdisciplinary Team Leadership
  - Medical Care
  - Pediatrics
  - Quality
  - Regulatory
  - Supportive Care
5. **Subjects and Contributors for Future Issues of This E-Journal.** We are currently discussing topics such as ethical issues, the dying process, and self-care for future issues in 2020. If you have any thoughts about these or other topics, contributors, or future

issues, please contact Christy at [Christina.Torkildson@bannerhealth.com](mailto:Christina.Torkildson@bannerhealth.com) or Ann at [ann@here4U.net](mailto:ann@here4U.net).

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