



E-NEWS

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and Maureen Horgan, LICSW***

Pediatric Hospice and Palliative Care in the United States: The Current State of the Art

Welcome to the nineteenth issue of the ChiPPS electronic newsletter. This issue of our e-newsletter offers a PDF collection of articles that are meant to depict the current state of hospice and pediatric palliative care in the United States. We realize, of course, that we cannot hope to offer more than a sampler of articles on this topic in a single issue of our newsletter. We invited a wide range of contributors to write about a broad spectrum of topics under the general heading of this issue. Not everyone was able to accept our invitations within the timeframe required by our quarterly publication schedule. Still, we believe that the articles you will find in this issue are broadly representative of activities and programs currently active in the United States in pediatric hospice and palliative care.

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

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

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



Issue #19 – Pediatric Hospice and Palliative Care in the United States: The Current State of the Art

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

Models of Pediatric Hospice and Palliative Care in the United States

p. 4

Christy Torkildson, RN, PHN, MSN

Christy provides an overview of the many different models of pediatric hospice and palliative care programs that are currently active in the United States.

The Impact of the Robert Wood Johnson Foundation Program Promoting Excellence in End of Life Care on the Status of Pediatric Palliative Care in the United States

p. 9

Suzanne S. Toce, MD

Suzanne describes the development of the "Footprints" program at Cardinal Glennon Children's Medical Center in St. Louis, initiated in the late 1990s with the support of the Robert Wood Johnson Foundation, focusing on anticipatory guidance, advance care planning, and care coordination for children and their families, along with the positive effects of the interdisciplinary research and education efforts generated by the program.

National Hospice and Palliative Care Organization, ChiPPS National Update, 2010

p. 12

Gwynn B. Sullivan, RN, MSN, and Kathy Brandt, MS

Gwynn and Kathy offer a concise description of NHPCO's diverse efforts in support of pediatric hospice and palliative care.

Center to Advance Palliative Care

p. 14

This article offers a brief overview of training and technical assistance currently being offered by CAPC in support of pediatric palliative care programs in hospitals and other healthcare settings.

AAP (Provisional) Section on Hospice and Palliative Medicine (PSOHPM)

p. 15

Marcia Levetown, MD

Marcia relates efforts within the American Academy of Pediatrics on behalf of pediatric hospice and palliative medicine, including activities to date and plans for the future.

Reports from the States and Local Programs

The reports that follow illustrate some of the many ways in which efforts within specific states and localities have worked to improve care of children with life-threatening and life-limiting conditions and their families.

Pennsylvania Update, 2010

p.16

Katey Lawson, RN, Bereaved mother

Illinois Update, 2010

p.17

Kimberly Downing, RN, JD

The District of Columbia Pediatric Palliative Care Collaboration (DCPPCC)

p. 18

Susan Rogers, MS, BSN, RN, CHPN

State of Ohio Update, 2010

p. 19

Sarah Friebert, MD, FAAP, FAAHPM



<i>Florida's Evolution of Pediatric Palliative Care</i> Terry Eason, BS, RN CHPN, and Kelly Cronin Komatz, MD, MPH, FAAP	<i>p. 20</i>
<i>Partners for Children, California Update, 2010</i> Devon Dabbs, BBA	<i>p. 23</i>
<i>The Butterfly Program, Colorado Update, 2010</i> Brian Greffe, MD	<i>p. 25</i>
<i>The New Discipline of Pediatric Palliative Care</i> Kelly Cronin Komatz, MD, MPH, FAAP Kelly describes some of the challenges faced by pediatric hospice and palliative care, while also noting the successes of an academic-community partnership--in this case between Community PedsCare the pediatric palliative and hospice care program of Community Hospice of Northeast Florida, Wolfson Children's Hospital, the University of Florida School of Medicine Jacksonville, and Nemours Children's Clinic--and the results of a pilot evaluation confirming those successes.	<i>p. 26</i>
<i>The National Pediatric Palliative Care Collaboration: Innovative and Active</i> Christy Torkildson, RN, PHN, MSN In this article, Christy describes a new pediatric palliative care initiative that brings together a collaborative of organizations committed to promoting excellence in pediatric palliative and hospice care who can work together to advance common goals while avoiding duplication of effort.	<i>p. 31</i>
<i>Reader's Corner</i>	<i>p. 28</i>
<i>Items of Interest</i>	<i>p. 30</i>
<i>Calendar of Events</i>	<i>p. 31</i>

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



MODELS OF PEDIATRIC HOSPICE AND PALLIATIVE CARE IN THE UNITED STATES

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*This article was adapted from the Module "Pediatric Palliative Care: Delivery Models" developed by Christy Torkildson and Claire Vesely for the online curriculum for Pediatric Palliative Care authored by **Children's Project on Palliative/Hospice Services (ChiPPS)** a program of the National Hospice and Palliative Care Organization.*

It is the goal of this article to discuss various ways pediatric palliative care (PPC) is provided to children and families in the United States. Several articles within this issue of the ChiPPS e-Newsletter highlight the efforts organizations, coalitions, collaborations, states, and the nation are making in the provision of Pediatric Palliative Care. It is our hope to highlight results of those efforts but first we give you a brief background on pediatric palliative care in the U.S.

"Children should not die." This is an oft-heard phrase in the world of pediatrics and PPC; however as Francis Bacon stated, "It is as natural to die as to be born." In the United States there are approximately 2 million children living with a life-threatening condition or a complex chronic medical condition (Torkildson, 2008; Hellsten, 2009). There has been a steady increase in this population over the last decade as the medical community has found therapies to both cure some children and palliate others for longer periods of time.

Hope never ends for a child, although what is hoped for may change. Early research has shown that the integration of the PPC model into the care of the medically-fragile child enhances quality of life for children and their families, decreases inappropriate hospitalizations, and optimizes healthcare dollars. The PPC model embraces the child and family from diagnosis through bereavement support. It also encourages quality of life considerations whether the child is undergoing curative, life-lengthening therapies or is in hospice care. Despite its proven advantages, however, palliative care is not an integral part of most healthcare programs in the United States.

Ideally, care is concurrent – consistent care across the continuum with a dual focus, which for children is either cure-directed or life-prolonging care along with palliative care. Providing concurrent care requires careful planning and coordination. How we share caring for children with complex medical conditions, providing a supportive framework so children and families are aware of all options can be extremely difficult – but not impossible! Issues of providing care while focusing on the child's and family's goals for care, across settings, can seem daunting; understanding differences and practical realities in different systems is key. In general, and in very simplistic terms, the hospital provides acute care, which is focused on cure. Hospice and palliative care is typically home-based with an interdisciplinary approach, and is usually visit-based. Home Care is usually centered on a skilled nursing need and is often goal-oriented and directed towards wellness.

Often children with life-threatening conditions are followed by community-based pediatricians as primary care providers (PCPs) together with multiple sub-specialists who are usually based in acute care centers. This can lead to fragmentation of care and poor communication across settings; and often goals of care



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Organization



are isolated to the body system under care at the time. As a child progresses towards death, however, it is becoming more common for PPC teams to function as the primary care provider. And while this is encouraging, PPC *should* be an integral part of the care of any child with a life-threatening condition beginning at the time of diagnosis. There is a real gap between care and services available for dying adults and dying children, in a variety of different realms.

There are several barriers to hindering care for children with serious illnesses and conditions. Most can be grouped under the following broad categories: regulatory, financial, cultural and educational. Regulatory barriers include insurance or lack of, including the Medicare Hospice Benefit that was developed for the older adult and never for children. The hospice benefit under which children are covered is almost always under the Medicaid umbrella and is subject to the individual state plan of benefits. The hospice benefit is very specific and often does not provide for life-prolonging or curative therapies concurrent with hospice care. Most third party payors or private insurance providers model their benefits after the Medicare and Medicaid plan of benefits. In addition, much of palliative care is classified as "supportive" care and is almost never covered by a third-party payor.

Cultural views and beliefs can also be a barrier; a discussion of cultural barriers is beyond the scope of this article. There are a variety of resources available at www.nhpc.org/pediatrics and in previous issues of this e-Newsletter. Educational barriers impact healthcare providers (HCPs) as well as patients and families. Many HCPs have limited exposure and experience with PPC, including advance care planning (Ferrell, 1999; Baker, 2007; Roth, 2009). Although we have made great strides in educating professional healthcare providers we have a long way to go.

All of the above listed barriers impact access to care. An additional important barrier to access is our own fear of taking care of dying children. I know I am preaching to the choir, if you are reading this e-Newsletter you are interested in, if not working in, pediatric palliative care. However, pediatric palliative care is challenging. Many providers have limited expertise; the pediatric world sees a wide realm of unknown diagnoses and conditions, often with uncertain prognoses and complex symptom management issues. Advance care planning can seem impossible.

PPC can be provided in a variety of settings, following different and similar models of care. PPC was first recognized as a specialty in the United Kingdom in 1987 and was recognized as a formal subspecialty in the U.S. in 2008. In 1982 the first pediatric palliative care, hospital based service, opened at Great Ormond Street Hospital in London and the first children's hospice house, Helen House, opened that same year. Helen House provides respite, pain and symptom management, and end-of-life care for children and their families. In 2009, there were 42 such houses in the U.K. alone. In the U.S. there was 1 – the George Mark Children's House (GMCH), which opened in March of 2004. On March 29th, 2010, Ryan's House, opened in Phoenix, Arizona. However GMCH had to close its inpatient services due to lack of funding that same week.

Although the U.K. has a national health service, palliative care is often a community supported service especially if based at a children's hospice house, such as Helen House. In the U.S., palliative care when focused on pain and symptom management may be reimbursable; however as noted earlier the hallmarks of palliative care such as identifying goals of care, communication, advance care planning, education, and advocacy are typically not reimbursable.

In addition to the hospital-based consult service and the "hospice house," there are a variety of settings providing PPC services. These settings can be either hospital or unit based. Some examples include:

- Inpatient and outpatient settings
- Home health and hospice agencies
- Perinatal services



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- Neonatal intensive care units
- Pediatric intensive care units
- Emergency rooms
- Medical home settings
- Inpatient, community-based facilities

The following are examples of programs, services, and innovative organizational partnerships expanding access and services:

- As noted within this e-Newsletter several states are pursuing the provision of palliative care for their children and families. One such example is the Massachusetts PPC program, designed to complement existing services to meet the needs of eligible children with life-limiting illnesses and their families or guardians. Children can be eligible whether they are "on" Medicaid or not and the services provide all the "core" services mentioned earlier: consultation, collaboration, case management, education, and advocacy. The Massachusetts program is available to ANY child up to age 19 diagnosed with a POTENTIALLY life-limiting condition. There are no restrictions on life expectancy and the program does not preclude seeking other treatments or supportive therapies.
- Pediatric Palliative Care Waivers are designed to address a gap in the State Plan Services usually under Medicaid. These are demonstration programs that target specific populations, usually in specific geographical locations. Several states have implemented or are working on pediatric palliative care waivers. Those with existing waivers include Florida (the first), Colorado and California (*please see the individual articles in this issue detailing these programs*).
- The Northern California Collaborative for Pediatric Palliative Care (NCCPPC) is a collaborative group of community members, families, and healthcare professionals advocating for the needs of children, their families, and the staff who care for them. NCCPPC is committed to continuity, standards, and excellence of care across settings for children with life-threatening illnesses and members represent all members of the interdisciplinary team as well as settings such as acute care hospitals, home care and hospice agencies, inpatient facilities, and parent advocacy organizations. Specific goals for this organization include networking for providers who cover an extremely large and diverse geographical area; education for professionals, consumers, and third-party payors; development and sharing of clinical practice tools for consistent implementation across settings; and providing a "clearinghouse" for support and services for northern California.
- Coalitions are usually state-wide groups with a focus on advocacy, education, and services. Examples include the Children's Hospice and Palliative Care Coalition based in Watsonville, CA (www.childrenshospice.org); the Pennsylvania Children's Hospice and Palliative Care Coalition (PA-CHaPPC) (www.pa-chapcc.org/), and although not a state, the District of Columbia Pediatric Palliative Care Collaboration (DCPPC)(www.dcppcc.org/).
- It is true that great things often start with one person who is able to gather other voices in their efforts. Research has elucidated the essential elements of advocacy. In general, advocates are usually prompted by a catalyst, a trigger event which is a turning point that illustrates gaps in services. The Moment by Moment Foundation (www.momentbymoment.org) and Liam's Foundation for Pediatric Palliative Care (www.liamlawsonfoundation.org) are two examples of the work of a single voice or a few united voices that changed lives by their advocacy for PPC. Moment by Moment was started by a single professional photographer who could only think of one thing she could do for a dear friend who faced the death of her newborn son – the gift of memories with photographs. This photographer now manages over 250 professional photographers who donate their time and talents to provide free photo shoots for any child and family facing a life-threatening condition (*you can read more about*



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National Hospice and Palliative Care Organization



Moment for Moment in the next issue of this e-Newsletter, which will be focused on *Legacy*). The Liam Lawson Foundation grew out of the experience of one family living through the life and death of a child. Since 2003 this foundation has fought to ensure the provision of palliative care services to all children with life-limiting conditions and has been instrumental in a model telemedicine project to provide palliative care support to all who need it in their home.

- Home care and hospice agencies require different licensing, although one organization may have both licenses, providing different services under each license. Home care agencies traditionally are skill-based (i.e., the patient requires a nursing skill such as wound care, assessment, or education); care is goal-oriented and time-limited and provided in the patients' home. Home care is most often visit-based; however in some instances shift care in the home is provided usually for the most medically fragile and technology dependent. Funding is typically through Medicaid and can be dependent on medical as well as financial need. Hospice agencies in the U.S. are usually home-based, community providers. Most single license hospice providers are adult oriented that either have a separate pediatric program, or provide care for a small number of children annually. The first, home-based, pediatric hospice program in the U.S. is EDMARC, founded in 1978 in the Tidewater region of Virginia (www.edmarc.org).
- One of the most common types of provider for pediatric palliative care is the hospital-based consult service. Many of these programs have grown to include outpatient and inpatient services as well. Examples include the Haslinger Pediatric Palliative Center at Akron Children's Hospital in Akron, Ohio (www.akronchildrens.org/cms/subsite/e72d31b7552f899a/); the Children's Institute for Pain and Palliative Care at the Children's Hospitals and Clinics of Minneapolis, MN (www.childrensmn.org/Services/PainPalliativeCare/), and the Compass Care Program at UCSF Children's Hospital in San Francisco, CA (www.ucsfchildrenshospital.org/services/compass_care/index.html)

This is a brief sampling of models of care and PPC services available in the U.S. The *Module "Pediatric Palliative Care: Delivery Models"* (Torkildson & Vesely, in press) will be available online in 2010 along with the 9 other modules focused on pediatric palliative care. Availability will be noted on the NHPCO website and in this e-Newsletter. We hope some of the articles in this issue of the e-Newsletter help you identify ways and resources to provide pediatric palliative care. We welcome your comments and suggestions.

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National Hospice and Palliative Care
Organization



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THE IMPACT OF THE ROBERT WOOD JOHNSON FOUNDATION PROGRAM PROMOTING EXCELLENCE IN END OF LIFE CARE ON THE STATUS OF PEDIATRIC PALLIATIVE CARE IN THE UNITED STATES

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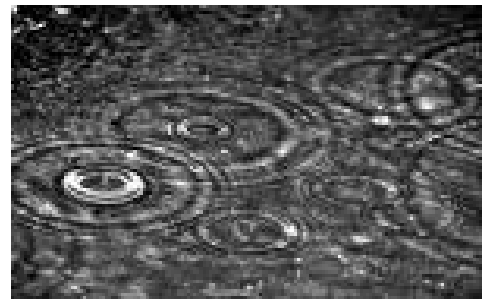
It was 1994. Two things happened pertinent to this topic. I and the other ethics committee members at Cardinal Glennon Children's Medical Center/Saint Louis University were involved in yet another ethical crisis at end of life of a nonverbal child where the parents' request to "do everything" seemed like prolonging suffering to the bedside caregivers. The second event was the return to our neonatal follow-up clinic of a baby with severe anomalies that we all expected to die shortly after discharge. He didn't. We had provided excellent discharge planning for his medical problems but had not provided the psychosocial and spiritual support that the family needed. We knew that we could do better for both of these children and their families. I volunteered to lead a process to describe what best practice would look like for the interdisciplinary care of the dying child. I considered myself mid career and this project really energized me both intellectually and emotionally. Not long after we developed a pilot process, Sr. Judith Carron, our director of Pastoral Care and head of the Ethics Committee heard from not one but two colleagues the same day who told her of a call for proposals for demonstration projects for a Robert Wood Johnson Foundation (RWJF) grant in their Promoting Excellence in End of Life Care program. It was a sign.



I assembled a wonderful core group of talented and experienced pediatric caregivers and off we went in pursuit of a grant. We were too naïve to understand the enormity of actually achieving nirvana - a close to half million dollar grant from one of the most prestigious organizations on the planet. But our passion and a great collaboration with Dr. Elena Andresen of the St. Louis University School of Public Health resulted in being named one of 26 programs funded, and one of only 2 pediatric programs, from over 700 applicants. That started an amazing personal and professional journey.

I was asked (well, begged actually) to comment on the impact of the RWJF program. I was trying to find the right analogy. Springboard? Catalyst? This one seemed the most apt: Raindrops on a pond with ever widening and intersecting circles.

The RWJF Promoting Excellence in End of Life Care program team headed by Ira Byock, MD, and Jeannie Twohig, MPA, provided nurturing, nudging, and networking. We were paired with research mentors. We had educational sessions on research, communications, marketing, advocacy, sustainability, etc. Dr. Byock recommended my participation in the original NHPCO ChiPPS (Children's Project on Palliative/Hospice Services) work, a program with which I am still involved and on the leadership council. I was introduced to many if not most of the physicians involved in pediatric palliative care at the time. What a wonderful and generous source of support and inspiration.





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We had much in common with the other pediatric program: the Seattle Children's group headed by Ross Hayes, MD, and Russ Geyer, MD. Their group contributed to Linda Seaman's great handbook: *Pediatric Pain and Symptom Management Algorithms for Palliative Care*. They developed/adapted decision making, family satisfactions, post death interview, and provider survey tools. They collaborated with third party payors to provide co-case management and flexible administration of benefits based on the needs of the patient/family. A decision-making tool based on that developed by Jonson, Siegler, and Winslade was used to enhance patient/family ethical decision making. Their project resulted in no increase in costs and in an improvement in health related quality of life and family satisfaction. According to Seattle Children's executive vice president Patrick Hagan, the Promoting Excellence grant pushed the facility in a direction it was already inclined to go, becoming more family-centered and patient-focused. Seattle Children's now has a pediatric palliative care program. Dr. Hays, who is now board certified in Hospice and Palliative Care, is the Clinical Director. Russ Geyer, Ross Hays and I were all contributors to *Palliative Care for Infants, Children, and Adolescents: A Practical Handbook*, 2004, edited by Carter and Levetown.

The efforts at Cardinal Glennon Children's Medical Center resulted in the FOOTPRINTS program, a pediatric palliative care model focusing on anticipatory guidance, advance care planning, and care coordination. There have been 572 children cared for in the FOOTPRINTS program since 1999. Yearly enrollment has increased exponentially. There are currently 350 children and their families in the program. Advance care planning tools that we developed are accessible for use by other programs. Care coordinators are now routinely involved in advance care planning as appropriate in the neonatal ICU, hematology/oncology and bone marrow transplant units, neurology, and in the Fetal Care Institute.



With Dr. Andresen's help and the funding from RWJF, we were able to contribute some much needed pediatric palliative care research.

Education has been and continues to be a primary focus, because one of the identified barriers to quality pediatric palliative care is the lack of trained pediatric palliative care providers. FOOTPRINTS staff are heavily involved in the orientation and education of pediatric residents. There have been over 6000 participants at FOOTPRINTS sponsored educational activities. Although I left Missouri 6 years ago, I continue to speak about pediatric palliative care issues at local, regional, and national venues. I remain a member of the leadership council of ChiPPS and have contributed to the pediatric standards and the pediatric palliative care curriculum. You will find many articles in the ChiPPS newsletter with my name attached. At my current hospital, we just completed our perinatal palliative care project and are beginning a pediatric palliative care project.

Because of RWJF, the FOOTPRINTS program was nationally recognized and awarded a **Citation of Honor** as part of the 2003 Circle of Life Awards honoring innovation in palliative and end-of-life care. Because of RWJF, we were able to energize others. There is a coordinator of community outreach. There is now a FOOTPRINTS across Missouri program and there have been over 100 collaborations or mentoring activities with programs across the country and as far away as Australia. The raindrop circles are reaching very far here. Current and past FOOTPRINTS personnel interact with several national organizations including the American Academy of Pediatrics, ELNEC (End-of-Life Nursing Education Consortium), IPPC (Initiative for Pediatric Palliative Care), , NHPCO (National Hospice and Palliative Care Organization) via the ChiPPS initiative, Resolve through Sharing and Supportive Care Coalition.



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National Hospice and Palliative Care
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Cardinal Glennon Children's Medical Center has continued to support the program financially as the missions are closely aligned. Volunteers and donors are critical to the program's success and sustainability. The Saint Louis University Department of Pediatrics is also highly supportive. The role of the program in resident education is incalculable.

So how did the RWJF program impact pediatric palliative care nationally? On a personal level, I can say that without the RWJF program, I would probably still be providing good basic palliative care to my patients, but I would not have been pushed beyond the physical boundaries of my NICU to the work that I continue to do on a local, regional, and national level. The program gave the grantees the resources to develop and refine programs that may have otherwise remained dreams. I would say that it gave the field a jump start, and heavy infusion of energy and resources. It connected people who could really move the field forward and gave them tools to be effective. It provided a secure base for future growth. It provided us all the opportunity and probably the obligation to move from local to global in the effort to ensure that quality pediatric palliative care is the expected standard of care for all children with life limiting and life threatening conditions.

Over ten years later, the field is flourishing. (Just so we don't get complacent, the status of pediatric palliative care in the US is still way behind US adult hospice and palliative care, and pediatric palliative care in the United Kingdom.) With the collaboration of other dedicated professionals and families, we all can be satisfied that we have made a great start. I am certain however, that we never would have gotten this far, this fast without the Robert Wood Johnson Foundation and the wonderful people of the Promoting Excellence in End of Life Care program.

Resources and References

Seattle Children's and Cardinal Glennon Children's Medical Center tools:

www.promotingexcellence.org/childrens/

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National Hospice and Palliative Care Organization ChiPPS National Update, 2010

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Despite all the incredible efforts of many organizations and professionals, children are still dying without hospice or palliative care. According to the NHPCO's [Facts and Figures: Pediatric Palliative and Hospice Care in America](#), more than 53,000 children in the United States die each year. Yet NHPCO's Children's Project on Palliative/Hospice Services (ChiPPS) estimates that although 8,600 children are eligible for palliative care services on any given day **only 5,000 of those 53,000 children receive hospice services**, and usually only for a brief period of time.

In an ongoing effort to close that gap, NHPCO's ChiPPS leadership council and workgroups have created the following resources to teach healthcare professionals how to provide palliative care to children and teach hospices how to care for children and their families.

- **Pediatric Standards of Hospice and Palliative Care** –The Standards along with an online organizational self-assessment are now available online for hospices to use to determine their readiness to care for children. These Standards were recently approved to receive the Affirmation of Value by the American Academy of Pediatrics, an organization of 60,000 pediatricians committed to the attainment of optimal physical, mental, and social health and well-being for all infants, children, adolescents, and young adults.
- The above-mentioned **NHPCO Facts and Figures: Pediatric Palliative and Hospice Care in America**, is an essential resource for policy makers, researchers, and others working to improve care for children with life-threatening conditions and their families.
- The **Pediatric Palliative Care Online Training Series**, which was written in 2009 and is currently being designed, will provide instant access to educational resources for pediatric care providers around the world. The series offers 10 online educational modules written by leading pediatric palliative/hospice care experts. The modules will begin to be available through NHPCO's E-Online in 2010.
- The 3rd annual **ChiPPS Pediatric Intensive** at NHPCO's annual Clinical Team Conference, scheduled for **September 13-15, 2010**, offers a complete track of sessions training hospice professionals how to care for seriously ill children and their families. www.nhpco.org/ctc2010
- **ChiPPS Pediatric Palliative Care Newsletter** is now distributed to more than 2,500 pediatric palliative care and hospice professionals and others invested in improve care for seriously ill children.



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- **Pediatric-related consumer education materials** are available for loved ones caring for a seriously ill child on the Caring Connections website, www.caringinfo.org, and/or to purchase via [NHPCO's Marketplace](#).

These tremendous resources are the essential steps to ensure that children throughout the country have access to quality pediatric palliative care, but there is much work yet to be done particularly in the policy arena. To help address state and national policy issues that affect children who are seriously ill and their families, NHPCO conducts quarterly networking calls with designated pediatric statewide leaders. With the pediatric provision in the newly-signed healthcare reform bill, which NHPCO championed, ongoing coordination between and among state leaders is more important than ever. NHPCO will continue facilitating conversations among state leaders working with their state government officials to implement strategies and resources that will benefit all children and their families.

For more information about NHPCO's pediatric resources, visit www.nhpco.org/pediatrics.

* * *



CENTER TO ADVANCE PALLIATIVE CARE

www.capc.org

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The Center to Advance Palliative Care (CAPC) provides healthcare professionals with the tools, training, and technical assistance necessary to start and sustain successful palliative care programs in hospitals and other healthcare settings. The following highlights training and technical assistance we are providing to pediatric palliative care programs.

Palliative Care Leadership Centers™

The Palliative Care Leadership Centers (PCLC) are a network of leading palliative care programs that provide the curriculum, tools, and expertise to address the specific needs of teams that are planning, starting, or growing a palliative care program. Teams experience personalized, comprehensive training tailored to the needs, goals, and challenges of individual palliative care programs – along with 12-months of mentoring follow-up. **PCLC Peds** is appropriate for teams from children's hospitals and pediatric programs within a hospital. Go to www.capc.org/palliative-care-leadership-initiative to learn more about PCLC training and the PCLC Peds leaders, Akron's Children's Hospital and Children's Hospitals and Clinics of Minnesota.

CAPC National Seminar

Building New Paradigms in Palliative Care

October 21 – 23, 2010; Phoenix, AZ

www.capc.org/support-from-capc/capc-seminars/phoenix-2010/seminar

This Level I/II Seminar is designed to help programs develop solutions to programmatic issues and challenges. In addition to focusing on core operational elements that are integral to program success and sustainability, this seminar offers new cutting-edge content and topics through plenary sessions, small group breakout sessions, office hours, and special events. There are three flexible tracks and the **Peds track** is geared to pediatric palliative care programs at any level of maturity. Topics include:

- Making the Case
- Clinical Models and Staffing
- Financing Pediatric Palliative Care Programs
- Pediatric Palliative Care in the Community
- Team Dynamics
- Integration into the Intensive Care Unit



Children's Project on Palliative/Hospice Services

National Hospice and Palliative Care
Organization



AAP (PROVISIONAL) SECTION ON HOSPICE AND PALLIATIVE MEDICINE (PSOHPM)

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The American Academy of Pediatrics represents 60,000 pediatricians, pediatric subspecialists, and pediatric surgeons. The mission of the AAP is to attain optimal physical, mental, and social health and well-being for all infants, children, adolescents, and young adults.

Through the generosity of the Lord Foundation, the AAP produced an award-winning documentary DVD and associated educational guide on pediatric palliative care, "Cameron's Arc."

In May 2008, the AAP established the Provisional Section on Hospice and Palliative Medicine (PSOHPM) to create a professional home for pediatricians and pediatric subspecialists who are interested in learning about Pediatric Hospice and Palliative Medicine (PHPM). The Section was established to assure that all infants, children, adolescents, and young adults who might benefit from comprehensive palliative care services, as well as their families, receive the highest quality of care, across the entire continuum of sites of care, in as timely a manner as possible.

PSOHPM has 215 physician members and approximately 100 additional interdisciplinary and family participants on our open list serve. Our accomplishments and ongoing commitments include quarterly newsletters, in-person educational opportunities, and collaboration with other national organizations active in Pediatric Palliative Care. We plan to move forward in developing print, audio, multi-media, and web-based education targeting medical students, residents, fellows, and practicing pediatricians. Other plans include the revision of the current AAP Pediatric Palliative Care Policy as well as new policies relevant to PPC over time and advocacy for improved reimbursement and research to enable the broad availability of evidence-based PPC.

Final approval of the PSOHPM to become a full section of the AAP is anticipated this summer. With that approval is the possibility of the expansion of Section membership to include non-physician affiliate members, providing an opportunity to inform the activities and direction of the Section. More details on criteria for affiliate membership will be available July 1, 2010. Current members of the AAP can join on our website at www.aap.org/Sections/Palliative/ and anyone can join our list serve from that site as well. Please contact Madra Guinn-Jones, MPH with any questions at mjones@aap.org.

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PENNSYLVANIA UPDATE, 2010

Katey Lawson, RN, Bereaved mother

President, Liam's Foundation

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In the past five years, Pennsylvania has made tremendous progress in advancing the pediatric palliative and hospice care (PPHC) movement across the state. Initially, and on opposite sides of the state, three grassroots movements began to take shape and create the foundation for the wonderful statewide network of parents and professionals we have today. In western Pennsylvania, the Pittsburgh Pediatric Palliative Care Coalition (PPPCC) and Helping Hands/Healing Hearts (HHHH) identified the needs that were not being met in their region. In eastern Pennsylvania, Liam's Foundation for Pediatric Palliative Care had just begun a similar effort. Unlike most organizations that are provider driven, the majority of the membership in the Pennsylvania's three work groups is comprised of bereaved parents. It is also important to note that many of the parents were also medical professionals. In this sense, the unique composition made the Pennsylvania groups uniquely qualified to speak with some very specific concerns from both vantage points.

At different points in time, each of these organizations met individually and independently with Secretary Estelle Richman of the Department of Public Welfare to express their concerns on the state of healthcare for children and families living with life limiting/life-threatening diseases or conditions. The Secretary not only listened, she convened Pennsylvania's first **Pediatric Palliative and Hospice Care Task Force** in January 2008. Two hundred members from across all pediatric healthcare disciplines joined with the parent efforts and over the course of the next 10 months defined and drafted the state's first comprehensive report on the issues related to end-of-life care for children. The purpose of this task force was to identify barriers to access and availability of PPHC, identify solutions to these barriers, and make recommendations aimed at filling the gaps of care and services, as well as funding, for the children and families in need of pediatric palliative and hospice services. The full report is a 700-page comprehensive document including 12 subcommittee chapters, an executive summary and a Co-Chair's Corner. It can be found at www.dpw.state.pa.us.

One of the five recommendations put forth from the PPHC task force report was to establish a **statewide coalition** of parents and professionals who would develop a website for people to access information, find available resources, and locate palliative care physicians, etc. This coalition, named Pennsylvania Children's Hospice and Palliative Care Coalition (PA-CHaPCC) evolved directly out of the PPHC task force membership and welcomes new members. CHaPCC has three active work groups presently: Legislative Action/Advocacy, Website Development, and Regional Centers of Expertise.

The Legislative Action/Advocacy work group members keep law makers informed and continue to work with state legislators regarding the importance of access, availability, education, and funding of PPHC programs and services. The Website Development work group members work on developing the CHaPCC website at www.pa-chapcc.org. This project will continue to be a work in progress as we develop our statewide resource map by county, a physician directory, and an advocacy page, among others. The Regional Centers of Expertise work group is working towards developing these centers to be the focal point of the clinical, educational, and community outreach opportunities for both parents and professionals.

On a national level, Liam's Foundation will continue to participate in the quarterly ChiPPS policy meetings to keep us and our state legislators informed of other states' activities. We look forward to continuing the work that has been started and creating a strong network of parents and professionals, programs and services, information, and advocacy for the benefit of all whom are touched by our most precious children.



ILLINOIS UPDATE, 2010

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During 2008 the Illinois Hospice and Palliative Care Organization surveyed all state hospices to determine the availability of community-based, pediatric services. Hospice providers in 67 of the 102 Illinois counties reported the ability to accept pediatric patients. Most of these programs, however, were restricted by the reimbursement criteria of traditional Medicaid hospice, and served between 0-2 children per year. Several philanthropic pediatric palliative care programs were identified, where care was provided contemporaneously with curative therapies and without prognostic limitations. These progressive programs demonstrated a sizeable daily census; all the providers, however, were located in the Northeast portion of the state.

The Make-A-Wish Foundation estimates that 1,185 Illinois children between the ages of 2.5 and 18 are diagnosed each year with a potentially life-limiting illness; the 2005 Illinois mortality statistics report that 1,674 children died of natural, non-trauma related causes that year. As in many states, pediatric providers in both the hospital and community realize that tremendous improvements are needed in care delivery for Illinois children with life-limiting illnesses. The diversified demographics of Illinois amplify the predicament. Challenges in care delivery are different for providers in Chicago's metropolitan community than for healthcare personnel working downstate, within principally rural areas. Even within the greater Chicago area, children with life-limiting illnesses are cared for at various, non-affiliated, referral centers and seek community-based care from an assortment of hospice providers throughout the region, thereby intensifying the fragmented nature of care.

In response to the observed need, a statewide Coalition of nonprofit hospices was formed, whose members work collaboratively to improve the delivery of pediatric palliative care in Illinois. A hospital-based, interdisciplinary, palliative team operates as an advisor for Coalition projects. The primary focus of the Greater Illinois Pediatric Palliative Care Coalition is to improve access to quality care for all Illinois children with life-limiting illnesses. In pursuit of this overall goal, the Coalition operates with four primary objectives: (1) education (strengthening existing programs and facilitating program development); (2) quality assurance (creating tools to promote superior care and assess satisfaction); (3) increased access (implementation of a state program to fund pediatric palliative care); and (4) resource allocation (sharing trained pediatric staff, educational curriculum and bereavement programming).

Additionally, emerging state policy seeks to promote increased availability of pediatric palliative care. A bill is currently moving through the Illinois General Assembly that instructs regarding the creation of community-based, pediatric palliative care programming. Thus far, the legislature has warmly received this bill, introduced by Senator Dale Righter and entitled the Pediatric Palliative Care Act. The Governor's office, along with delegates from the Illinois Department of Healthcare and Family Services, were moved by the need for improved care delivery for children with life-limiting illnesses and are engaged in the legislative process.



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National Hospice and Palliative Care
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THE DISTRICT OF COLUMBIA PEDIATRIC PALLIATIVE CARE COLLABORATION (DCPPCC)

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These are indeed exciting days for pediatric palliative care in the District of Columbia. Though the national economic downturn has hit the DC government hard, as has happened in every other state in the nation, it has not stopped the forward progress of making pediatric palliative care available to an ever-growing population in need of this care, nor has it slowed the pace of pediatric palliative care educational program development for nurses, social workers, physicians, chaplains, and other healthcare professionals.

The vision and mission of the DCPPCC is to create an environment supportive of a healthcare delivery system that provides optimal care to children with life-threatening illnesses and their families in the District of Columbia across the spectrum of care settings. In support of this mission, the DCPPCC committed at its inception to professional and public education, advocacy for this population, and research that would develop or identify standards and best practices for quality palliative care for children.

In the next few months, regional/national healthcare professionals seeking information and education about pediatric palliative care can choose from a health selection of options including: the March 24th Grand Rounds at the HSC Pediatric Center, featuring Dr. Julie Hauer speaking about "The Agitated Child at the End of Life: Causes and Interventions;" the April 8th & 9th ELNEC-PPC at Children's National Medical Center; the November 5th & 6th fourth annual pediatric palliative care conference, "Quality of Life for the Children;" and a most exciting offering, the first east coast offering of the Seminar in Pediatric Pain Medicine and Management of Distressing Symptoms in Pediatric Palliative Care sponsored by the DCPPCC with course director Stefan Friedrichsdorf, MD, Medical Director of the Children's Institute for Pain and Palliative Care Service at Children's Hospitals and Clinics of Minnesota.

Advocates of pediatric palliative care in the District of Columbia continue to press ahead in their quest for a Medicaid waiver to provide financial reimbursement for the providers of clinical care for these most vulnerable of children. Progress on this front continues to be slow, but we are now planning to work with the legislative branch to achieve this objective.

Finally, we are beginning dialogue with home care organizations in an effort to move away from a home care model based primarily on hospice services, to a model that is based on supportive services (palliative care) delivered to patients and their families in their homes. The model that is being discussed and is evolving is one that will use a number of home healthcare organizations (under the supervision of a palliative care physician) that will send to patient homes nurses, and as needed social workers, child life specialists, spiritual care providers, etc. The patient will continue to be cared for by his/her own physician, while the home healthcare organization supplies the additional services that are needed to allow the patient to remain with family and friends in a setting of the patients' and the families' own choosing.



STATE OF OHIO UPDATE, 2010

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The Ohio Pediatric Palliative and End-of-Life Care Network (OPPEN) is a collaboration comprised of all of the pediatric acute care institutions in the state (including nine children's hospitals), several of the major hospice organizations providing care to children, as well as additional members from children's advocacy and family support agencies. OPPEN's vision is that every child with a life-threatening or life-limiting diagnosis, from prenatal to young adult, will have access to quality pediatric palliative care and hospice. The coalition's mission statement centers on: equity to ensure access regardless of ability to pay or geographic location; effectiveness of interventions and service delivery; education focused on increasing awareness, safety, and quality; timeliness, including service provision from time of diagnosis and concurrently with disease-modifying therapies; and advocacy. Specifically, OPPEN members have committed to work actively toward removing legislative and financial barriers that prevent patients and families/caregivers from receiving high-quality pediatric palliative and hospice care.

In 2007, OPPEN published a white paper exploring the then-current picture of pediatric palliative care and outlining a legislative approach focused on improving access to care for Ohio's children with palliative care needs. Although some states have pursued and received a Medicaid waiver in order to provide concurrent pediatric palliative care, OPPEN has decided not to take this path. Ohio history has demonstrated that waivers are vulnerable to limitation or elimination. OPPEN, instead, proposed a Medicaid Pediatric Palliative Care Benefit covering pediatric palliative care under Medicaid by changing Ohio's Medicaid State Plan. The benefit would create a tiered, individualized plan of care for children with life-threatening illness and their families, allowing them to navigate our currently fragmented healthcare system, and to receive high-quality pediatric palliative care and hospice services without foregoing curative or life-prolonging treatment. Background analysis shows that the proposed services represent neither additional expenses/new dollars nor new patients who are not presently qualified for Medicaid benefits. Instead, the plan seeks to reduce current expenditures for children with life-threatening conditions through multiple mechanisms, such as: reducing inefficiency and duplication of services; streamlining communication among providers and families; keeping children out of the emergency department and the inpatient setting when possible; and improving psychosocial adjustment in family members, resulting in increased productivity and decreased time lost from work.

That same year, OPPEN hosted a national pediatric palliative care conference, "Leaders, Learners and Families Hand in Hand: Building Pediatric Palliative Care Best Practice." The conference brought together almost 400 professionals for 3 days of learning and networking. During the conference, OPPEN hosted a "legislative lunch" to thank state policymakers for their advocacy for children and to invite them into a partnership to move forward a legislative benefit for children, as outlined in the white paper. In follow up, OPPEN members testified in front of the state senate's Health, Human Services and Aging Committee to garner support for the legislative benefit.

In 2009, OPPEN revamped the white paper and began conversations with interested state legislators to craft the benefit. OPPEN also established a toll-free Comfort Line which connects Ohio's providers and families to palliative care advice and resource information, and published a Pediatric Palliative Care Resource Guide to provide pediatric hospice and palliative care information to residents and healthcare workers in rural, isolated areas of the state. Through all of its initiatives, OPPEN's model supports an environment of compassionate caring for Ohio's most vulnerable children.



FLORIDA'S EVOLUTION OF PEDIATRIC PALLIATIVE CARE

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In Florida pediatric palliative care for children with life-limiting or life-threatening conditions has been in an increasing state of awareness and growth over the past five years. Historically, families coping with their child's life-limiting diagnosis could get state assistance for supportive services only if they chose a hospice plan of care. But state healthcare providers recognized the importance of – and emphasis on – quality of life for these children, which could be provided through palliative care. So, Florida became the first state in the country to develop and implement a Medicaid Waiver program for pediatric palliative care. Beginning in July 2005 the state was able to offer children with life-limiting conditions, and their families, a community program that provides a palliative focus of care, pain and symptom management that supports the child and family. This program, known as *Partners in Care: Together for Kids* (PIC), involves partnering with hospices in the state to provide supportive care through an interdisciplinary team of nursing, social services, medical, spiritual, and child life specialists.

Based on Children's Hospice International Program of All-Inclusive Care for Children and Their Families (CHI PACC), Florida's pediatric care model, PIC, was launched with approval obtained from the Center for Medicare and Medicaid Services. PIC is administered through the Florida Department of Health Children's Medical Services Network, and services are reimbursed through the Florida Agency on Health Care Administration (AHCA). Currently there are eight fully operational PIC programs within the State of Florida; several more have been approved with roll out of services throughout 2010.

About the *Partners in Care: Together for Kids* Program

Florida's PIC program allows children whose healthcare is covered through either Medicaid or the State Children's Health Insurance Program to receive palliative care. Admission into the program can occur at any time from the point of initial diagnosis of a life-threatening condition to the end-of-life stage of their illness.

Patients and their families are eligible to receive services from the PIC program if the patient is under 21 years of age and has been diagnosed with a "life-limiting condition." The patient must reside in the State of Florida and be enrolled in his or her regional Children's Medical Services Network (CMSN). The patient also must have Medicaid, Title XXI (Florida KidCare), or CMSN Safety Net funding.

The primary physician must refer the patient to the PIC program and certify a life-limiting condition. Annual renewal of this certification is mandated.

The Partners in Care program allows for full supportive services for the children and their families throughout the continuum of the illness. It provides supportive psychosocial and spiritual therapy, activity therapy, hospice nursing care through regular physical assessments, pain and symptom management



Children's Project on Palliative/Hospice Services

National Hospice and Palliative Care
Organization



from a palliative care physician, as well as personal care, volunteer services, and respite care of up to seven days or 168 hours per year.

While in the PIC program, the children are able to receive curative treatments for their disease, unlike the traditional hospice model of care. Because supportive care is offered, and needed, during the entire trajectory of the child's illness, PIC allows for seamless transition from one care setting to another, including the patient's home, hospital, day care, and schools. The family will receive bereavement services through the hospice agency providing PIC care if the child dies during their enrollment in the program.

Common diagnoses of patients enrolled in the Partners in Care program include: congenital anomalies, conditions arising from the neonatal period, neurological conditions, progressive neuromuscular and metabolic disorders, chronic progressive respiratory diseases, and severe cardiac diseases, to name a few.

Again, these diagnoses are inherently different from those seen in adult palliative and hospice medicine. Although similar in name, the diagnoses have different progressions in each individual child and are further unique depending on the age of the child, his or her developmental stage, and the child's environment related to the family and community.

According to a 2007-2007 Independent Assessment of the PIC program, a couple of the comments made by parents surveyed are:

"The program is awesome. I'm glad it's here. Without them we wouldn't know what to do. It makes it easier for us to deal with what we're going through...I think these services should be offered around the world!"¹

"I just can't imagine going through this all without them. I know they will be there for us when things get rough. They got to know us now when things are calm and I know they'll be there for him when he's ready to die. They're part of the network of support now."¹

Based on Florida's success, many states have looked to Florida as a partner as they pursue their own Medicaid Managed Care Waiver program. One inherent difficulty is that each state operates its Medicaid Managed Care programs differently so no two waiver programs will look the same. But the overall intent is the same: to make available the hospice philosophy of care – including a full interdisciplinary team approach of support – for children diagnosed with a "life-limiting illness" and their families while still allowing for curative treatment, if available.

To further advance the pediatric palliative care philosophy and its implementation throughout Florida, the state held, for its first time, an Initiative for Pediatric Palliative Care retreat. This retreat, held in October 2009 at Suncoast Hospice in Clearwater, brought together a broad spectrum of pediatric practitioners from all areas of the state. There were interdisciplinary teams/representation from state children's hospitals, hospices, and Children's Medical Services Network offices, as well as a team from Phoenix AZ. There were also a number of parents in attendance, giving their perspective on the importance and impact of pediatric palliative care and what it meant to them, their child, and their families.

This retreat, one of the last of many held throughout the country since 2005, was provided by an respected faculty of pediatric palliative care leaders and brings together interdisciplinary teams of pediatric healthcare practitioners from all care settings, as well as bereaved family members, to learn from each other.



Children's Project on Palliative/Hospice Services

National Hospice and Palliative Care
Organization



The health-care providers who participated brought with them much experience in working with children who had life-limiting and life-threatening conditions and their families. The participating families had either suffered the death of their child or currently have a child who will not live to adulthood.

The result of this conference included:

- A statewide directory resource of pediatric palliative care providers
- Case studies of successful PIC programs
- Networking between pediatric palliative care providers
- A renewed, stronger vision to further pediatric palliative care in the state

Lastly, as continued evidence of the furtherance of the provision of pediatric palliative care in our state, there is a new pain and palliative care service at Wolfson Children's Hospital, Jacksonville, in partnership with Community Hospital of Northeast Florida and University of Florida-Jacksonville. Known as QUILT, Quality in Life Team, this physician consult service, working with the interdisciplinary hospital team, completes the holistic approach to care which patients and families at Wolfson Children's Hospital can receive.

There is still work to be done in pediatric palliative care in Florida, but progress has been and continues to be made, with the momentum positive in continued movement forward, to the benefit of Florida's children with life-limiting and life-threatening conditions and their families.

¹Knapp, C., Madden, V., & Shenkman, E. Institute for Child Health Policy, Children's Medical Services Network, Partners in Care: Together for Kids Report, 2006-2007. P. 22.



PARTNERS FOR CHILDREN, CALIFORNIA UPDATE, 2010

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One of the first children to receive services from Partners for Children was a 17-year-old with muscular dystrophy. Wheelchair dependent with severe respiratory issues, he was facing some difficult decisions including whether or not he chooses to go on a ventilator. With support from his care coordinator, he was for the first time able to talk candidly with his family about how he would like to live out the rest of his life.

Five-year-old Malea has an anoxic brain injury and has been ventilator dependent from birth. Her mother, who speaks very little English, often has difficulty understanding the doctor's orders and as a result in the past whenever Malea appeared uncomfortable or her breathing shallow, her mother called 911. Since enrolling in Partners for Children, she has successfully been able to manage her daughter's care at home, avoiding dangerous, costly and unnecessary emergency room visits.

Partners for Children, a demonstration project of Department of Health Care Services (DHCS) and California Children's Services (CCS) in partnership with Children's Hospice and Palliative Care Coalition (CHPCC), got its start following the enactment of the Nick Snow Children's Hospice and Palliative Care Act in September 2007 and subsequent passage of a federal pediatric hospice eligibility waiver in December of 2008. The waiver allows children with life-threatening conditions to receive certain community-based hospice and palliative care services alongside curative treatment. Qualifying children must have full-scope, no-cost Medi-Cal coverage, an eligible medical condition*, be 20 years of age or younger, and reside in a pilot county.

Care coordination is the capstone for services provided by participating community hospice and home health agencies. Other services include expressive therapies such as music, art, and massage, 24/7 on-call nursing support, family education, family support, respite, and bereavement. The focus is on family-centered care, with goals and interventions flowing from the Family Centered Action Plan (F-CAP).

Collaboration is the watchword in this pilot project. Two new positions were created to assist in administering and managing the program. A dedicated CCS nurse liaison, with a caseload of no more than 50, is the first point of contact for families and oversees their care on behalf of the state. A community-based care coordinator, either a nurse or social worker, is employed by the agency, to coordinate the child's care across settings.

Thirteen counties over three years have the opportunity to participate in this landmark project. Currently three pilot programs are up and running with at least six others on tap to launch within the year. However, the economic challenges experienced across the nation, are impacting California hospice and home care providers. This is reflected in the fact that provider capacity is delaying enrollment in two of the first five counties, as two hospices that previously provided care for children have closed their doors, at least temporarily. CHPCC, in partnership with DHCS and CCS, is addressing this issue by working with pilot counties to initiate and form partnerships among community-based agencies and to create opportunities for education and capacity building.

The Partners for Children program has a rapid improvement process built in, so ongoing amendments to the Benefit can be reviewed and approved throughout the 3-year trial if needed. The program is designed to demonstrate how the provision of community-based palliative care services concurrent with curative treatment can enhance quality of life and quality of care while maintaining fiscal efficacy. The ultimate



Children's Project on Palliative/Hospice Services

National Hospice and Palliative Care
Organization



goal is to take the program statewide so that every county in California may one day offer these critical services to children with life threatening conditions and their families.

**The list of medical conditions that may qualify a child to receive services includes: cancer, cystic fibrosis, brain or head injuries, spinal muscular atrophy, Duchene's muscular dystrophy ventilator dependent, intestinal problems dependent upon IV nutrition, liver or bowel transplant, heart defects or conditions, problems following a transplant, leukodystrophies.*



Children's Project on Palliative/Hospice Services

National Hospice and Palliative Care
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THE BUTTERFLY PROGRAM, COLORADO UPDATE, 2010

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The Butterfly Program is a pediatric palliative and hospice program based at The Children's Hospital in Aurora, Colorado. The program represents a partnership between The Children's Hospital and Centura Health at Home, a locally-based hospice and home care organization. The Butterfly Program began accepting patients in June 1999 and to date has served over 400 patients and their families. In 2001, the program was selected to receive a 3-year grant from Children's Hospice International. This funding was instrumental in allowing the program to work with the state Medicaid agency in crafting a 1915c Home and Community Based Medicaid Waiver to provide pediatric palliative care services from the time of a life-limiting diagnosis for eligible children receiving Medicaid. This waiver is based on the CHI PACC (Program for All Inclusive Care for Children and Their Families) model of care. The waiver was approved by Centers for Medicare and Medicaid Services (CMS) in January 2007 for 200 slots and implemented state-wide in February 2008. There are currently over 70 children who have been enrolled in this state-wide waiver. Cost analysis of the waiver to date has not yet been completed.

In addition to the waiver, The Butterfly Program is currently representing pediatric palliative care on a state Medicaid project entitled, CIVHC (Center for Improving Value in Health Care). The palliative care task force meets on a monthly basis to craft a palliative care model for the state that will allow better healthcare to the people of Colorado for the best cost.

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THE NEW DISCIPLINE OF PEDIATRIC PALLIATIVE CARE

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Palliative care seeks to manage symptoms and relieve physical and emotional distress produced by chronic life-limiting conditions. Pediatric palliative care focuses on both the child-patient, as well as the child as a sibling, the family unit and extended care-givers as well as the community the child lives in. The mainstay of providing palliative care is quality of life.

Pediatric palliative care experiences its own unique challenges while focusing on the child due to continued growth and development from infancy through adolescence and through transition into adulthood. The child's social and emotional growth continues through the trajectory of his or her underlying chronic medical condition.

The challenges also include the community at large. The primary care physician must be prepared with the skills necessary to meet the medical needs of the chronically ill and medically-complex child. Insurance companies must cover the total cost of care related to the pediatric patient including medical, mental health psychosocial, and respite services. Hospitals must provide interdisciplinary service to provide smooth uninterrupted linkages between the inpatient setting and community-based services. Schools as well as other community locations need to nurture both the child and the family.

In order to provide a comprehensive continuum of care for pediatric palliative care it is imperative to develop partnerships within the community to ensure seamless transitions for the child and family when moving between the inpatient setting, the home, and the community-at-large. A well-defined partnership model is the academic-community partnership. This partnership allows for direct patient care between the community physician and the subspecialists and ensures a seamless continuum of care across the medical system. It also provides for the development of training programs, research, and education to sustain and build the pediatric palliative care program.

Community PedsCare the pediatric palliative and hospice care program of Community Hospice of Northeast FL demonstrates the successes of an academic-community partnership. Community Hospice of Northeast FL in collaboration with Wolfson Children's Hospital, University of Florida-Jacksonville, and Nemours Children's Clinic has successfully developed a comprehensive continuum of care from prenatal diagnosis of life-limiting condition, to newly diagnosed life-threatening diseases, to end-of-life care and bereavement in Northeast Florida.

Recently a summative evaluation of the Community PedsCare Program was conducted to evaluate the impact of a pediatric palliative care service on hospital utilization and costs. The study reviewed hospital cost and utilization of enrolled patients pre- and post-enrollment in the Community PedsCare Program. The study demonstrated a significant decrease ($p=.03$) in hospital utilization (length of stay) for patients after enrollment into Community PedsCare in comparison to their pre-enrollment utilization. There was a promising decline in diagnostic service charges post-enrollment ($p=.13$), but the overall decline in hospital charges was not statistically significant ($p=.34$).

Parents' perceptions on Health Related Quality of Life (HRQOL) were studied as well if their child was enrolled in the Community PedsCare Program. The authors piloted a Health Related Quality of Life tool



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for this study due to the limitations of generalizing other quality of life tools and the patient population served by the Community PedsCare Program. Family caregivers reported self-efficacy in their ability to tend to the care of their child but also reported a number of days of impaired functioning in the previous 30 days. Overall, the family caregivers scored positively to having improved health related quality of life related to their child's enrollment in the Community PedsCare Program.

Although there are many limitations to this initial pilot, it nonetheless demonstrates a promising decrease in hospital costs and utilization when a child is enrolled in a pediatric palliative care program. Furthermore, there is an improvement in key quality of life indicators for the family at large when parenting a child with a medically complex condition. It is our goal that continued collaboration with pediatric palliative care sites will increase the power of studies such as this one.

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THE NATIONAL PEDIATRIC PALLIATIVE CARE COLLABORATION: INNOVATIVE AND ACTIVE

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Growing realization of the need for and importance of pediatric palliative care has led multiple national, state and community organizations to pursue clinical, education, research and advocacy initiatives in this relatively new field. As these initiatives grow and multiply, it becomes crucial to discover complementary ways in which efforts can be linked together to promote quality, efficacy, efficiency, and access for all children with life-altering conditions and their families.

This was the premise for the start of the National Pediatric Palliative Care Collaboration (NPPCC), founded by the National Hospice and Palliative Care Association (NHPCO), the American Academy of Hospice and Palliative Medicine (AAHPM), the Center to Advance Palliative Care (CAPC), and the American Academy of Pediatrics (AAP). Dr. Sarah Friebert, winner of the 2009 Children's Miracle Achievement Award and Director of the Haslinger Family Pediatric Palliative Care Center at Akron Children's Hospital, is the Founding Chair of the NPPCC. Recently the Hospice and Palliative Nurses Association was added to the membership.

The purpose of the NPPCC is to provide a framework within which a working collaborative of organizations committed to promoting excellence in pediatric palliative and hospice care can work together to advance common goals while avoiding duplication of effort. Through enhanced communication and cooperation, each of the member organizations is committed to presenting a united voice for pediatric palliative care issues. The NPPCC mission also includes: coordinating activities which will improve care for children with chronic, complex, or life-threatening conditions and their families; championing public policy and regulatory initiatives; and cooperating to maximize return on investment and conservation of limited resources and funding opportunities.

As the collaboration matures, membership in the NPPCC will expand to include other national professional societies, associations, organizations, and/or foundations that meet established criteria. In particular, members need to represent more than a single institution or program, have an organized pediatric group or program with defined representation, and have an established commitment to pediatric palliative care. Each organization has full support of its governing body and meetings are hosted by different organizations for a year at a time. Monthly meetings occur by teleconference; later this year, an in-person strategic planning session will be held to expand the group's mission and vision moving forward.

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Reader's Corner

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Evidenced-based clinical practice guideline for management of newborn pain

Kaye Spence, David Henderson-Smart, Karen New, Cheryl Evans, Jan Whitelaw, Rowena Woolnough and the Australian and New Zealand Neonatal Network, published online 26 Jan 2010 in [Journal of Paediatrics and Child Health](#), [Early View](#) (Articles online in advance of print).

ABSTRACT

Aim: To facilitate the uptake of evidence and to reduce the evidence practice gap for management of newborn pain through the development of a clinical practice guideline.

Method: An audit of practice and an appraisal of clinical practice guidelines were undertaken to establish current practices and guideline availability for the management of newborn pain in 23 hospitals in Australia. Guidelines were appraised using the Appraisal of Guidelines for Research and Evaluation instrument. A literature search was undertaken to acquire the evidence for best practice for management of newborn pain.

Results: Neonatal units in 17 hospitals had clinical practice guidelines. Each was peer reviewed and assessed according to the domains of the Appraisal of Guidelines for Research and Evaluation instrument. There was lack of consistency across the guidelines. As a result, a best practice guideline was developed based on current best evidence and the Royal Australian College of Physicians recommendations. To facilitate an ongoing compliance with the guideline, an audit tool was included together with algorithms for procedural pain and pain assessment.

Conclusion: The clinical practice guideline can be used by clinicians in varying settings such as the neonatal intensive care and special care unit. The document can be used to support existing practices or challenge clinicians to close the evidence practice gap for the management of newborn pain.

Who is the audience for this information? All newborn bedside caregivers.

What is special about this article? If there are any organizations that haven't gotten on board with a newborn pain assessment and management guideline, this eliminates any barriers. There are straightforward instructions on using a pain assessment tool. I found the key performance indicators very helpful. All organizations are looking for outcome measures to demonstrate quality care. Here they are!

Where and how can I apply this information? This provides tools for any organization from a well newborn nursery to the most advanced neonatal ICU to develop or enhance their newborn pain guideline. Step up to the plate and don't let those folks "down under" get the best of us. Make sure that all newborns in the hospital or who are receiving home care services are having quality pain assessment and management.

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Items of Interest

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

1. **Pediatric Intensive at CTC.** Once again, ChiPPS has developed a pediatric session track that will be part of NHPCO's 11th Clinical Team Conference, Scientific Symposium and Pediatric Intensive ["Performing in the Key of E: Excellence in Interdisciplinary Care,"](#) September 13-15, 2010 at the Omni Hotel at CNN Center in Atlanta, GA.

The Pediatric Intensive provides sessions that enhance provider and professional capacity to confidently care for seriously ill children and their family caregivers. Session faculty includes palliative and hospice care professionals from across the country. Conference attendees may also take advantage of any of the concurrent sessions that are part of the CTC but the Pediatric Intensive provides a valuable opportunity to learn, share and network with colleagues concerned with the care of young people. Learn more and register online at www.nhpco.org/ctc2010.

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

3. **Reader's Corner.** Contributions to the Reader's Corner, like the one contained in this issue, include an abstract of the publication, a description of the audience for this information, comments on what is special about the publication, and suggestions as to where and how this information can be applied. We welcome suggestions for publications to include in our Reader's Corner and/or summaries and comments on such articles following the model in this issue. Please send all such suggestions to Christy Torkildson at torkc@sbcglobal.net.

4. **A Lion in the House, Teaching Modules.** A compelling set of **teaching modules** is now available from the Emmy Award-winning documentary about children with cancer, *A Lion in the House*. Based on real-life case studies, where things do not always go as one hopes, the stories offer a forum to consider and discuss approaches to help families navigate pediatric end-of-life. The module faculty is comprised of top educators in each subject area, including: Pediatric End-of-Life; Spirituality & Childhood Cancer; Nurse-Patient-Family Relationships; Disparities; and Siblings Stories. Each DVD module contains mini movies taken from the documentary that was shot over a course of six years, competencies & objectives, discussion questions, a recommended resource list, and a PowerPoint presentation. Modules can be obtained at Aquarius Health Care Media, 1-888-440-2963, www.aquariusproductions.com/lion.

5. **Pediatric Palliative Care Nursing Fellowship.** Pediatric Advanced Care Team (PACT), the pediatric palliative care service at Children's Hospital Boston and Dana-Farber Cancer Institute, is offering a Nurse Practitioner Fellowship (40 hours per week) July 2010 – June 2011. The position will provide opportunities to gain knowledge and experience collaborating with colleagues in the hospital and community to provide comprehensive compassionate care to children and families.



PACT is an interdisciplinary team dedicated to improving symptoms and quality of life in children with advanced illness, and their families. The team, which includes physicians, an advanced practice nurse and social workers, provides services at the hospital, in the outpatient setting, and in the community. The fellow will function as part of the core interdisciplinary team and will be responsible for consultation with patients, family members, and other medical providers. He or she will learn from interdisciplinary experts in the field of pediatric palliative care at Children's and Dana-Farber through formal and informal educational opportunities. This is an opportunity to work with one of the first pediatric palliative care teams in the country and to be a part of a unique interdisciplinary fellowship training, along with physician and social work fellows. This fellowship is a 12-month salaried position. For questions or to apply, please contact Marcie Brostoff, MS, RN, at 617-355-8564 or marcie.brostoff@childrens.harvard.edu.

6. Standards of Practice for Pediatric Palliative Care and Hospice Receive AAP

Affirmation of Value. We are pleased to announce that the [NHPCO Standards of Practice for Pediatric Palliative Care and Hospice](#) (Standards) have received the American Academy of Pediatrics Affirmation of Value! The Standards are a supplement to the NHPCO Standards of Practice for Hospice Programs and are designed to supplement the existing Standards and to set clinical and organizational precedents for hospice and palliative care programs providing care to infants, children, adolescents, young adults, and their families in the home, hospital, long-term care and respite setting. The Standards establish an important beginning to ensuring that children and their families receive high quality pediatric palliative care and hospice services. You can learn more about the Standards in the article, "[A Key Step in Advancing Care for America's Children,](#)" (PFD) from NHPCO's *NewsLine*, February 2009.

In recognition of the AAP affirmation, NHPCO is offering print editions of the Pediatric Standards to individuals active in ChiPPS at the NHPCO member price of \$34.99—a savings of 50%. For a limited time, **May 24 thru June 30**, you can call the [NHPCO Marketplace](#) at 800-646-6460 and reference promotional code "AAP" to receive the Pediatric Standards (item #821399) in print at the member price. Marketplace hours are Monday - Friday 8:30am - 5:30pm ET.

7. AAP Revised Policy Statement.

The American Academy of Pediatrics Council on School Health and Committee on Bioethics revised the policy statement, ***Honoring Do-Not-Attempt-Resuscitation Requests in Schools***. The statement was published in *Pediatrics* 2010;125:1073-1077; originally published online Apr 26, 2010; DOI: 10.1542/peds.2010-0452. The statement can also be found online at: www.pediatrics.org/cgi/content/full/125/5/1073

8. Sesame Street Primetime Special.

In association with Worldwide Pants Incorporated and Lookalike Productions, Sesame Street has produced a new primetime television special, ***When Families Grieve***, which aired in April 2010. Educational resources and more information can be found at: www.sesamestreet.org/grief.

Calendar of Events

ChiPPS provides a listing of conferences related to pediatric palliative care as a community service. A brief listing is included here however the complete listing is available to anyone and can be found at www.nhpc.org/pediatrics. Please e-mail Christy Torkildson at torkc@sbcglobal.net to have your pediatric palliative care educational offering listed.

What Matters Most: The Voice of Patients and Families in the Palliative Care Journey –



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DC Pediatric Palliative Care Collaboration hosts a panel presentation featuring a patient and family. Facilitated by Deborah Dokken, MPA (IPPC), and Kristen Caminiti, LICSW (PANDA Care Team, CNMC) June 8, 2010; 6:00pm at Children's National Medical Center, Washington, DC For information, email info@dcpcc.org or call 202-895-0191.

5th International Cardiff Conference on Pediatric Palliative Care, presented by ICPCN and Cardiff University. July 6-8, 2010; Cardiff, UK. Contact – PPC2010@cardiff.ac.uk.

2010 Pediatric Bioethics Conference – *Tiny Babies, Large Questions: Ethical Issues in Prenatal and Neonatal Care*. July 23-24, 2010; Seattle, WA. Contact Kathie Kohorn at 206-987-5379.

The Texas Pediatric Palliative Care Consortium (TPPCC), in collaboration with TAPM and TNMHO, will host the 2nd annual Pediatric HOPE conference, Friday and Saturday, July 30-31, 2010 in Austin, TX.

Pediatric Palliative Care at NHPCO's 11th National Clinical Team Conference – ChiPPS is proud to offer a pediatric intensive track that as part of NHPCO's 11th National Clinical Team Conference that will be held in Atlanta, GA (originally, this conference was scheduled for Nashville), September 13-15, 2010. More information is available at www.nhpco.org/ctc2010.

18th International Congress on Palliative Care – October 5-8, 2010. Palais des Congrès, Montréal, Canada.

Center to Advance Palliative Care Annual Conference – This conference includes a pediatric track. October 21-23, 2010; Pointe Hilton Tapatio Cliffs Resort, Phoenix, AZ. For more information visit www.capc.org.

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

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

Pregnancy Loss and Infant Death Alliance (PLIDA) and Association of SIDS and Infant Mortality Programs (ASIP) – November 4-7, 2010; Washington, DC. For more information, visit www.perinatalbereavementconference.org.

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Thank you for taking time to read this issue and for any feedback that you can offer us. If you are not on our mailing list and received this newsletter from a friend or some other source, please send an email message to chipps2@nhpco.org requesting to be added to our mailing list. If you are a member of NHPCO, you can go to the Communications Preferences tab in your individual member record online and "opt-in" for communications from ChiPPS. Member Services will be happy to help you adjust your communications preferences; contact them at 800-646-6460.

Visit the ChiPPS Web page at www.nhpco.org/pediatrics for further materials and resources of interest.

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