

Agency for Health Care Administration • Florida Department of Health • Florida Hospices and Palliative Care, Inc



### **A Support Program for Children With Life-limiting Conditions**

hildren's Hospice International Program for All-Inclusive Care for Children and Their Families<sup>™</sup> (CHI PACC<sup>®</sup>).

While advances in medicine have significantly increased our ability to cure or manage potentially life-limiting illnesses, ten of thousands of children each year are diagnosed with fatal or potentially fatal medical conditions. According to a report released by the National Institutes of Medicine in 2002, these children and their families often fail to receive compassionate and consistent support that meets their physical and emotional needs.



Florida Department of Health Florida Hospices and Palliative Care, Inc.

To address these needs, Florida has initiated a demonstration

program in seven areas of the state that provides specialized support services to children with potentially life-limiting illnesses. **Partners in Care-Together for Kids (PIC-TFK)** is a partnership of health-care organizations that enables children enrolled in the Children's Medical Services Network with potentially life-limiting conditions to benefit from the palliative care services provided by a hospice without being enrolled in a hospice program.

#### What is palliative care?

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Palliative care is an approach that improves the quality of life of patients and their families who are facing a potentially life-limiting illness, through the prevention and relief of suffering by means of early identification, assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Hospice is known for its expertise in providing palliative care and other support services.



#### What is the goal of the PIC-TFK Program?

The program's primary goal is to provide a continuum of curative and supportive care for children and their families from the time that a child is diagnosed with a potentially life-limiting condition, with hope for a cure, through the bereavement process, if needed. By providing early and continual intervention and consistent supportive care, the frequency of hospital admissions and emergency room visits for these children may be reduced while the quality of life for the child and family is increased.

#### Isn't hospice care already available for seriously ill children?



Although hospice is available for children, current state and federal regulations restrict hospice care to terminally ill patients who are not expected to live more than six months and are no longer seeking curative medical care. Health care providers managing the care of children with serious medical conditions often cannot state with any certainty that a child is within six months of death, and families of children with potentially life-limiting illnesses should not be required to give up on efforts to cure their children in order to benefit from palliative care services. The PIC-TFK Program can provide palliative care to eligible children and their families at any time following diagnosis of a potentially life-limiting medical condition without compromising hope for a cure.



#### Who is eligible to receive PIC-TFK services?

Children who meet the following criteria may be eligible for PIC-TFK services:

- Enrolled in the Children's Medical Services Network (CMSN)
  - Diagnosed with a potentially life-limiting condition by a CMSN physician
- Reside within an area of the state participating in the demonstration program.

#### What types of support and services are offered by PIC-TFK?

In addition to curative medical services provided through Children's Medical Services Network, palliative care services provided by the PIC-TFK Program include the following:

- Pain and symptom control
- Therapeutic Counseling for Child and Family
- Expressive Therapies for Young Children
- Respite Care
- Specialized Nursing Care
- Specialized Personal Care
- Bereavement Counseling



#### Who provides PIC-TFK services?

The services offered through PIC-TFK are provided in partnership with Children's Medical Services by the staff of a hospice that has been selected to participate in PIC-TFK and has completed specialized training in pediatric palliative care. Although hospice team members provide these services due to their expertise in pediatric palliative care, children receiving PIC-TFK services are not hospice patients. Curative treatment will continue to be provided through the Children's Medical Services Network.



## Are there any requirements for the families who participate in PIC-TFK?

Participation in the PIC-TFK Program is voluntary and there are no additional costs incurred by the families who participate in the program. Because the effectiveness of PIC-TFK is being evaluated for possible statewide expansion, participating families may be contacted by official evaluators, to answer questions about their experience with the PIC-TFK Program.

#### Who administers the PIC-TFK Program and how it is funded?



PIC-TFK is a partnership between the Agency for Health Care Administration, the Florida Department of Health, and Florida Hospices and Palliative Care, the state hospice organization. The program is guided by a statewide committee and PIC-TFK advisors comprised of physicians and health care professionals from Children's Medical Services, hospices, children's hospitals and children's institutes, as well as parents of children with special health care needs. PIC-TFK is developed through the Children's Hospice International Program for All-Inclusive Care for Children and Their Families<sup>™</sup> (CHI PACC<sup>®</sup>) and is supported by a federal grant to Children's Hospice International for its CHI PACC<sup>®</sup> Program. The CHI PACC<sup>®</sup> Program supports states' efforts to waive federal regulations that prohibit children from accessing inhome hospice and palliative care while undergoing curative treatment.



#### Who do I contact to find out more about the PIC-TFK Program?

To find out more about the PIC-TFK Program in a specific demonstration area contact the Children's Medical Services Office directly at the number provided on the back of this brochure. For general program information contact the Florida Department of Health's Children's Medical Services Network office at 850-245-4444 or Florida Hospices and Palliative Care's toll-free line at 800-282-6560.

# Demonstration Sites



For general program information, contact Florida Hospices and Palliative Care at 800-282-6560.

Demonstration Area	Counties Served	Children's Medical Services Office	Participating Hospice
Pensacola	Escambia, Okaloosa, Santa Rosa & Walton	Pensacola 850-484-5040	Covenant Hospice, Inc. 850-433-2155
Jacksonville	Baker, Clay, Duval, Nassau & St. Johns	Jacksonville 904-360-7070	Community Hospice of Northeast Florida 904-268-5200
Gainesville	Alachua, Bradford, Columbia, Dixie, Gilchrist, Hamilton, Lafayette, Levy, Putman, Suwannee, Union	Gainesville 352-334-1400	Haven Hospice 352-378-2121
St. Petersburg/ Clearwater	Pinellas	St. Petersburg 727-893-2775	The Hospice of the Florida Suncoast, Inc. 727-523-3458
Fort Myers	Glades, Hendry & Lee	Fort Myers 239-433-6723	Hope Hospice 239-482-4673
West Palm Beach	Palm Beach	West Palm Beach 561-881-5040	Hospice of Palm Beach County, Inc. 561-848-5200
Miami	Miami-Dade & Monroe	Miami North 305-349-1330 Miami South 305-669-6931	Catholic Hospice 305-822-2380

**Cover Photo** by Ingrid Damiani. Courtesy of Community Peds Care, a palliative and hospice care program for children and their families at Community Hospice of Northeast Florida. Funded by the Community Hospice Foundation.

