



CHILDREN'S HOSPICE INTERNATIONAL®

Pioneering Children's Hospice and Palliative Care for 26 Years
www.CHIONline.org

CHI Programs & Services

Definition of Children's Hospice and Palliative Care

Developed by CHI in 1983, with Barbara McCann, JCHO

Glossary of Children's Hospice Terms (1984)

Standards of Children's Hospice & Palliative Care (1992)

Publications & Training Manuals

CHI has published training and information manuals (8 copyrighted to date) for health care providers and hospice administrators.



Toll-Free Help Line

CHI refers thousands of parents, family members, friends and health care providers each year to programs and services in their area

Website & Online International Children's Hospice Database (2003)

Children's Hospice & Palliative Care International Surveys

CHI surveys 10,000+ programs



Developed for CHI's 25th Anniversary Gala by Caldecott Award Winner, Chris Raschka

The Honorable Margaret Tutwiler
Chairman

Sponsor



“CHI'S ULTIMATE GOAL is to so ingrain the hospice concept into pediatrics that it isn't considered a separate specialty, rather, an integral part of the care for children and adolescents...”

Ann Armstrong-Dailey, 1983 American Academy of Pediatrics, San Francisco

CHI LOGO: When a child becomes aware of his or her pending death and is given the opportunity to “draw your feeling,” he or she often will draw a blue or purple balloon, released and floating free. Health care professionals have discovered that this is true regardless of a child's cultural or religious background, and researchers believe that it demonstrates the child's innate knowledge that a part of him or her will live forever.

CHILDREN'S HOSPICE INTERNATIONAL'S name was chosen because of the meaning of its acronym “CHI”:

Ancient Chinese for Life Force ? Greek for Christ ? Hebrew for Life

“AS THE PARENTS of a beloved child who died of leukemia, the President and I know beyond any doubt that Children's Hospice International does a compassionate service of invaluable worth.”

Barbara Bush, Former First Lady of the United States

CHI WORLDWIDE TECHNICAL ASSISTANCE PROGRAMS

CHI provides ongoing technical assistance to nations and programs developing children's hospice and palliative care services worldwide. The following countries are among those:

Argentina	Germany	Kuwait	Russia
Australia	Guatemala	Latvia	Scotland
Austria	Hong Kong	Mexico	Singapore
Belarus	Hungary	Namibia	South Africa
Bermuda	Ireland	Netherlands	Spain
Bulgaria	Israel	New Zealand	Sweden
Canada	Italy	N. Ireland	Switzerland
China	Japan	Pakistan	UK
Costa Rica	Jordan	Philippines	Ukraine
England	Kenya	Poland	Zambia
France	Korea (South)	Romania	Zimbabwe

NEW FROM OXFORD UNIVERSITY PRESS – 3RD EDITION OF HOSPICE CARE FOR CHILDREN, edited by Ann Armstrong-Dailey and Sarah Zarbock, forward by Nobel Prize winner Archbishop Desmond Tutu

“There are few more compelling concerns in health care than the ability to provide care to children with serious or life-threatening illness and their families. The 3rd Edition of *Hospice Care for Children* is a foundational work in an area of health care that deserves far greater attention and resources.”

*Russell K. Portenoy, MD, President
American Academy of Hospice & Palliative Medicine*

“The need for the publication is great as organizations around the world incorporate children and adolescents into their pediatric programs.”

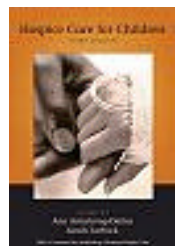
J. Donald Schumacher, PsyD, President, CEO, National Hospice and Palliative Care Organization

“The knowledge offered by the wisdom in this book is too important to ignore. It will help us not fail our children.”

David Abrams, President, Hospice Foundation of America

“As a father of a cancer survivor, I know the pain these families are experiencing. While nothing can provide complete relief for the suffering terminally ill children and their families must endure, having support from trained medical professionals can make a profound difference in the quality of life of the child and family. This book is designed to aid in understanding the needs of these children and their families and identify ways to provide quality of life for kids with life-threatening conditions.”

James P. Moran, Congressman (D-VA)



U.S. HEALTH POLICY CHANGES - CHI PACC® (2000)

With funding and bipartisan support from the U.S. Congress and technical assistance from the Centers for Medicare & Medicaid Services (CMS), CHI developed the CHI Program for All-Inclusive Care for Children with Life-Threatening Conditions and their Families® (CHI PACC®).

Overcoming barriers to appropriate care for children with life-threatening conditions, CHI PACC allows children and families to pursue curative and traditional hospice/home care services concurrently. These services are covered under Medicaid and hopefully private insurance will follow suit.

Currently two (2) states are implementing CHI PACC programs through CMS waivers – Colorado and Florida. California, Maryland, New Jersey, New York, and North Dakota currently are working toward CMS waivers for CHI PACC. A growing number of states are planning CHI PACC initiatives. CHI also is working with the U.S. Department of Defense to develop CHI PACC within the military health care system for military personnel and their families.

A number of U.S. government agencies and foreign countries are interested in CHI PACC (including USAID, U.S. Department of State, and PEPFAR).

ChiPACC Bill HR 722

Because of the increased quality of care for children and families, as well as cost savings for state and federal Medicaid programs, combined with the time it takes states and programs to develop CMS waivers in order to implement; Congressman James P. Moran is sponsoring the Children's Program of All-inclusive, Coordinated Care (ChiPACC) Bill which will make the program a Medicaid State Option.

CHI 19TH WORLD CONGRESS

CHI 18th World Congress
Singapore
September 7-9, 2007

CHI 19th World Congress
San Francisco
November 16-19, 2008

CHI 20th World Congress
Cape Town, South Africa
September, 2009



THE NEED

Current models of care for children, including hospice/ palliative care programs, are neither sufficient nor sufficiently available to adequately address the needs of children with life-threatening conditions and their families.

Research suggests that – for each child diagnosed with a life-threatening condition – approximately 300 people around them are directly impacted. (This includes the child and family members, the health care professionals providing their care, the coworkers of the parents, their friends, neighbors, and their communities.)

There are two primary roadblocks that stand in the way of appropriate care provision. Current hospice and reimbursement guidelines require that the patient:

1. Forego all curative treatments before they can be admitted into the hospice program
2. The patient must be within the last 6 months of life

This simply does not work with pediatric patients. It has been established that the most critical time for children and family members is at the time of diagnosis.

These challenges spurred CHI to develop the CHI Program for All-Inclusive Care for Children and their Families® (CHI PACC®) – which allows support and services to be provided in a continuum of care from the time of diagnosis, with hope for cure, through bereavement.

THE STATS

- The U.S. Government Accounting Office (GAO) estimates that, of the approximately 72 million children in the U.S., 10 million live with a serious chronic condition.
- 1.3 million of those children and families – in addition to the families of the 54,000 children that die each year – could benefit from children's hospice/palliative care.
- In addition, there are millions more children and families worldwide in dire need of this important care.

CHI – MEETING THE NEED

Clinical Support

- CHI Program for All-Inclusive Care for Children and their Families® (CHI PACC®), currently implemented in Florida and Colorado; with increasing interest from other states and the U.S. Department of Defense for military families
- Technical assistance to developing children's hospice and palliative care programs worldwide (e.g. Mission for the Children of Chernobyl)
- International exchange and Residency programs*
- Research studies

Education & Training

- World Congresses, 2008 19th World Congress in San Francisco
- Publications and Implementation Manuals (*six copyrighted*)
- *Hospice Care for Children*, Oxford University Press
- Speakers and Conference Planning
- Comprehensive Education and Training Program
- Library/Resource Center
- School outreach program*
- Educators' Guide to *The Purple Balloon*

Funding/Grant Source

- Scholarship & Research Funds*
- Seed money for program start-up

Public Policy & Awareness

- Children's Program of All-inclusive Coordinated Care (ChiPACC) Bill
- CHI Public Policy and Advocacy Committee
- Congressional Exhibit
- World Tour*
- Video, featuring former First Lady Barbara Bush, others

International Resource

- Web-based international database of children's hospice and related resources
- International survey of children's hospice programs and services
- Toll free helpline: 800.2.4.CHILD & Referral Service

Special Events & Activities

- Fantasy Flight to the North Pole
- Run for the Children
- *The Secret Garden*, garden party
- International photo contest and exhibit

"The CHI PACC program uses innovative approaches to enable families to play a more active role in the health care decisions of their loved ones."

Tommy G. Thompson,
Former Secretary
U.S. Department of Health
& Human Services

"CHI PACC is an innovative, new model of care for children that allows us to lighten the heavy burden of Families."

Michael O. Leavitt, Secretary
U.S. Department of Health
& Human Services