



Children's Hospice International

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Children's Hospice International gains Congressional support of their Program for All-Inclusive Care for Children with Life-threatening Conditions and their Families

CHI PACC[®] State Directors meet in Washington to further healthcare campaign

Alexandria, VA – Continuing to wage the campaign to close a serious gap in the healthcare system, Children's Hospice International (CHI) and a team of leaders from the CHI Program for All-Inclusive Care for Children and their Families[®] (CHI PACC[®]) were on Capitol Hill this week promoting their program and garnering further Congressional support for the all-important but often forgotten healthcare issue -- pediatric palliative care.

Leaders of six state CHI PACC[®] demonstration model programs from Colorado, Florida, Kentucky, New York, Utah and Virginia met with their Congressional delegations in an effort to gain ongoing support for CHI PACC[®] with the goal of taking the program to all fifty states within the next four years. "Families are brought into the fold as full and active participants of the care-giving process," said Rep. James P. Moran. (D-VA), "it is a model that should be replicated around the world for how to care for the terminally ill."

Since FY2000, federal appropriations have been awarded to CHI through the Centers for Medicare & Medicaid Services (CMS) for the demonstration model programs in these six states. To date 21 additional states – including California, Indiana, Maine, Massachusetts, Nevada, New Hampshire, Pennsylvania, Rhode Island and Vermont – have indicated a strong interest and a desire to participate in the project.

In 2002, Congressman John Murtha (D-PA) sponsored a \$1.5 DoD appropriation, making possible a CHI partnership with Walter Reed Army Medical Center for the DoD/CHI PACC[®] pilot project at Walter Reed, based on CHI PACC[®] standards and core principles. "The importance of the CHI PACC[®] program can't be overstated." Mr. Murtha said yesterday, "it's integral to the healthcare needs of all of our children."

CHI, the Alexandria, VA-based non-profit -- now in its 20th year working to provide palliative support services to children with life-threatening conditions and their families -- was singled out in the 2003 Institute of Medicine of the National Academies report "When Children Die" as the first organization to focus its efforts on "providing resources to support the development of hospice services specifically for children." The IOM report goes on to cite as critical elements of a successful pediatric/palliative healthcare program the provision of support – emotional and technical -- from time of diagnosis through treatment and extensive bereavement counseling. As

the core of CHI PACC[®] has always been the provision of these specific support services, the findings of the IOM report reaffirm the need for CHI PACC[®].

CHI's pioneering spirit led to the development of CHI PACC[®] in 1996, when Ann Armstrong-Dailey, CHI Founding Director and CEO, approached Senator Robert Bennett (R-UT), Congressman James P. Moran (D-VA) and Terry Pratt, Director of Integrated Services at CMS (then HCFA) for their guidance and help in overcoming the barriers in care for children with life-threatening conditions and their families.

Yesterday, Congressman Moran was awarded a CHI Certificate of Appreciation from the six state CHI PACC[®] leaders. Armstrong-Dailey said "Congressman Moran has been our good friend from the very beginning and without his unwavering and continuing support, CHI PACC[®] would not exist today."

"This award hits close to home," Moran said. "I became involved with CHI because of my youngest daughter's bout with a malignant brain tumor. She was given little chance of survival. My daughter did survive, but in this time of crisis I learned how truly valuable CHI is to families and children in similar situations."

The humanitarian purpose of CHI PACC[®] is to develop flexible, compassionate approaches to fill the comprehensive needs of children with life-threatening conditions and their families, from time of diagnosis – with hope for a cure – through treatment, providing a continuum of care. CHI PACC[®] also provides extensive bereavement counseling if a cure is not attained. Moreover, economic studies of CHI PACC[®] have shown that once the program is established in state children's hospitals, hospices and home health agencies it becomes budget neutral. Since CHI PACC[®] support services are there for the child and family at all times, the savings in unnecessary emergency room visits and medical charges alone more than pay for the program.

To learn more about CHI, CHI PACC[®] and other services please visit the new CHI web site www.chionline.org.

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