

November 6, 2002

FOR IMMEDIATE RELEASE

Contact: Sue Kennedy
301/322-4156 or 301/346-2038
Sloane York
CHI Home Office
703/684-0330

Children's Hospice International World Congress Calls for All-inclusive Healthcare for Children with Life-threatening Conditions

US Congressman John Murtha & Joyce Murtha honored for their support

Alexandria, VA – Children's Hospice International (CHI) closed the three-day 14th World Congress with Windber Hospice in Johnstown, PA today with a presentation by Lisbeth Quesada Tristán, MD of Costa Rica. Dr. Quesada, winner of a 2002 CHI Lifetime Achievement Award: The Elisabeth Kübler-Ross Award for Outstanding Contribution spoke about her work *The Rights of a Child with a Terminal Illness*.

“Dr. Quesada and all the other Lifetime Achievement Award winners personify our mission” said Ann Armstrong-Dailey, Founding Director and CEO of CHI. “The work that each has done is what CHI is about.”

US Congressman John P. Murtha (D-PA) and Mrs. Murtha welcomed hundreds of World Congress participants at a reception in the Joyce Murtha Breast Care Center at Windber Medical Center on November 3rd and Mr. Murtha gave the opening address on November 4th at the University of Pittsburgh at Johnstown.

Promising to continue his fight in Congress for more cancer research and cutting edge healthcare programs, Congressman Murtha praised the work of CHI as an organization leading the way in healthcare. His recent effort resulted in the CHI Program for All-inclusive Care for Children (CHI PACC[®]) being singled out for \$1.5 million funding in the 2003 DoD Appropriations Bill. CHI will partner with Walter Reed Army Medical Center, Bethesda, MD to structure, implement and provide oversight of a program for military hospitals to serve children with life-threatening illnesses, diseases or conditions who have a parent or custodial care giver serving in the US Military.

Joyce Murtha, after whom the Windber Center was named, presented the CHI Lifetime Achievement Awards at a luncheon in her honor. “You are at the forefront of making a worldwide difference in the way healthcare is delivered to children with life-threatening conditions,” said Murtha. “It is through your work and relentless commitment to the welfare of a very precious population that your story is being heard by an ever growing audience.”

The 2002 CHI Lifetime Achievement Awards were presented to:

Chriss Nelson – The Charles A. Corr Award for Literature --for her book *Eagle Doctor* the life story of her adopted son Stephen who was born the profound disabilities and how he and his mom shared triumphs, defeat, frustrations and love throughout Stephen's 14 years.

Becky Bedore, MSN, RN – The Sister Frances Dominica Award for Innovative Program Development -- for her work as the driving force behind the establishment of pediatric hospice and home care programs in Minneapolis/St. Paul.

Toni James Manus, M.ED., MPH – the Earl A. Grollman Award for Bereavement – for founding the program *Creating a Living Legacy: Photography by Grieving Teens* to help bereaved teens cope with the loss of a loved one by using photography in conjunction with bereavement support counseling.

Lisbeth Quesada Tristán, MD – The Elisabeth Kübler-Ross Award for Outstanding Contribution -- for being the creator of the Palliative Care Movement in Costa Rica and an unparalleled force for change in the Costa Rican medical community. Dr. Quesada was nominated by Oscar Arias Sánchez, former president of Costa Rica and Nobel Peace Laureate.

The purpose of the 14th World Congress was to provide a platform for hospice and pediatric palliative care experts to present and discuss and share findings of their research and programs. The agenda also included opportunities for world health leaders to discuss the challenges today's healthcare system faces in meeting the specific needs of children. Included was a presentation on the groundbreaking CHI PACC[®] model which provides a continuum of interdisciplinary care for children from time of diagnosis of a life-threatening condition with hope for a cure, through bereavement if a cure is not attained.

CHI PACC[®] development started in the mid-nineties with the involvement of the Centers for Medicare & Medicaid Services and Congressman James Moran (D-VA) who first introduced CHI to the US Congress. It was Congressman Moran's support that began the funding of the six state demonstration projects. US Senator Bob Bennett (R-UT) first CHI PACC[®] in the Senate. These efforts produced a \$1 million appropriation for CHI to help demonstration states, working with children's hospitals, hospices, Medicaid departments and other stakeholders, develop comprehensive community-based programs to care for children with life-threatening diseases.

As projects developed so did support and other national leader such as US Senators Arlen Specter (R-PA), Edward Kennedy (D-MA), William Frist, MD (R-TN) and US Congressman Joel Hefley (R-CO) who enthusiastically stepped forward to champion legislation affecting palliative care.

At the 14th World Congress, Congressman and Mrs. Murtha were cited for their leadership, both in Congress and at home, in moving the CHI mission forward. Ann Armstrong-Dailey presented the Murthas with a replica miniature of a statue being created in their honor, to be place on the hill between the Windber Research Center and the Joyce Murtha Breast Care Center in 2003.

CHI, a non-profit organization, was founded in 1983 to provide resources, care, support, and advocacy for children with life-threatening conditions, as well as support for their families. CHI also offers education, training and technical assistance, with help from CMS, to the healthcare professionals caring for this special patient population. In 1983, of the 1,400 hospices in the United States, only four were able to accept children. Today, due largely to the work of CHI and its supporters, thousands of hospices around the nation are able to consider accepting children.

For more information about CHI and the 14th World Congress visit www.chionline.org.