FOR IMMEDIATE RELEASE
July 26, 2018

CONTACT:
Kirsten Fedewa
(For Children’s Hospice International)
Tel: 202.365.6936

NEWS RELEASE

CHI Founder Ann Armstrong-Dailey Applauds the Reintroduction of the ChiPACC Act of 2018
Says Legislation Will Provide More Compassionate, Cost-Effective Care for America's Children

ALEXANDRIA, VA – Ann Armstrong-Dailey, Founding Director of Children’s Hospice International (CHI) applauded the reintroduction of the Children’s Program of All-Inclusive Coordinated Care (ChiPACC) Act of 2018 in the United States Congress by Reps. Diana DeGette (D-CO), Michael McCaul (R-TX), G.K. Butterfield (D-NC), Jackie Speier (D-CA), and Mike Kelly (R-PA).

The legislation will amend XIX of the Social Security Act to provide states an option to cover under their Medicaid plan, a children’s program of an all-inclusive coordinated care (ChiPACC) to help children with life-threatening conditions and their families, alongside curative care from time of diagnosis.

Under the current Medicaid model, children with life threatening illnesses who qualify for hospice benefit are limited to the existing hospice services and other Medicaid services covered by their state. To be eligible to receive hospice benefits, one must be diagnosed as having no more than six months to live. Parents and medical providers are understandably often hesitant to make a hospice determination for a child. However, increased access to palliative and hospice benefit services from the time of diagnosis can drastically improve the quality of care and outcomes for this population of children. Palliative care has been shown to decrease the average lengths of stay in medical facilities and hospital admissions for this pediatric population.

Since 2005, the Secretary of Health and Human Services has approved home and community based waivers to operate the programs, based on a collaborative model of care developed by CHI. Initial data from these ChiPACC state waiver programs (CA, CO, FL, NY and ND) have found significant cost savings.

“Families with children facing life-limiting illnesses need all the support they can get, and they should be empowered to seek out that support,” the bill’s sponsors said in a joint statement. “We owe it to these kids and their loved ones to help ensure more compassionate care in their most trying times.”
“The ChiPACC Act of 2018 is in loving remembrance of Mattie J.T. Stepanek and Melinda Lawrence, who were perfect examples of why ChiPACC is needed. Mattie and Melinda were not expected to live past the age of two months; however both children defied the odds by living into their teens. During their lives, they were hospitalized many times, and in and out of terminal situations multiple times, which was extremely difficult for their families, as they faced challenges navigating access to pediatric palliative care services. Mattie and Melinda were spokespersons for CHI and ChiPACC. Each of them left lasting lessons of strength and perseverance for us to live by, which is why the ChiPACC program is dedicated their memories. They represent children and families nationwide who will benefit from ChiPACC services,” said Armstrong-Dailey.

“On behalf of millions of children like Mattie and Melinda, we thank Reps. DeGette, McCaul, Butterfield, Speier, and Kelly for their leadership on this legislation and encourage all Members of Congress to support this legislation to provide comprehensive, compassionate and cost-effective care for children and their families.” said Armstrong-Dailey.

Founded in 1983, CHI’s ultimate goal is to so ingrain the hospice/palliative care concept into pediatrics that it is considered an integral part of health care for children and adolescents rather than a separate specialty. Toward that end CHI developed ChiPACC, which goes beyond hospice and palliative care while incorporating these critical components from time of diagnosis of a life-threatening condition.

www.chionline.org

For additional information on ChiPACC please visit our website www.CHlonline.org