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## CHILDREN'S HOSPICE INTERNATIONAL

Mr. BENNETT. Mr. President, on May 23 of this year, Children's Hospice International celebrates its 22nd anniversary of helping children with life-threatening conditions find comfort and care through hospice care programs around the country and the world.

Several members of this distinguished body, including former Senate Majority Leader Robert K. Dole of Kansas and the late Senator Claiborne Pell of Rhode Island, were among the organization's early supporters because they recognized the need to provide comprehensive hospice care for children who are suffering from difficult medical conditions.

In 1977, there were no hospice care programs for children in the United States. In 1983, when CHI was founded by Ann Armstrong-Dailey, only four of 1,400 hospice programs in the United States were willing to accept children. Now, close to 450 of 3,000 U.S. hospices include child-specific services. And while that is good news, there is much more to be done.

Of the 10 million children in America who are living with a serious chronic condition, each year about 54,000 will die; another 1.3 million will live but could greatly benefit from hospice and palliative care.

Historically, hospice reimbursement guidelines, in Medicaid and most private plans, have required that patients forego all life-saving care before they can be admitted to hospice. They have also required the patient to be within the last 6 months of life. However, this does not work with pediatric patients for whom aggressive treatment is sought and life-expectancy cannot be estimated.

Families should not be expected to give up on hope for a cure in order to receive that help. Because of the unpredictable course of many serious childhood illnesses, it is often very difficult for doctors to know when a child is within 6 months of death. Parents should not have to choose between hospice care and the hope for a cure. Parents should not have to keep their child in a hospital or other facility simply because insurance will not pay for the child to receive the same care, at a lower cost, at home.

The most critical time for children and family members is at the point of diagnosis--when they need the intensive support and guidance that hospice and palliative care programs can provide.

Since 1997, CHI has worked with the Centers for Medicare and Medicaid Services, CMS, to set up the Program for All-Inclusive Care for Children and their Families, CHI PACC. CHI PACC programs provide a continuum of care for children and their families from time of diagnosis, with hope for a cure, through bereavement, if needed.

With Congressional support, a total of 18 States are already benefiting from this initiative through CHI PACC programs in six States and two regions. States

currently implementing CHI PACC are Colorado, Florida, Kentucky, New York, Virginia, and my home State of Utah, which will be among the first to implement this model.

Utah has been one of the leaders in this effort. Utah's Department of Health has spearheaded the effort in Utah, and the Primary Children's Medical Center in Salt Lake City, UT has been a central point of developing these pediatric palliative services to assist families from the point of diagnosis.

The New England Region is also preparing to implement CHI PACC to serve six States--Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island and Vermont. The Colorado program extends to patients in six additional States--Kansas, Montana, Nebraska, New Mexico, South Dakota and Wyoming. In Pennsylvania, the Department of Defense is working to adopt the CHI PACC model for its health care system. The goal of all of these efforts is to prove the effectiveness of the CHI PACC model so that it can be adopted universally through Medicaid, S-SCHIP and private insurers.

As we approach Memorial Day, it should be noted that Children's Hospice International is a living memorial to Ensign Alan H. Armstrong and his shipmates lost aboard the U.S.S. Frank E. Evans during the conflict in Vietnam. Armstrong is the brother of CHI Founder Ann Armstrong-Dailey. I deeply appreciate Ensign Armstrong's service to our country.

I commend Children's Hospice International on its 22nd anniversary as it seeks to remove the roadblocks in private and public insurance programs that prevent these children and their families from receiving the care and support they need.

I too believe in the vision that Ann Armstrong-Dailey, along with original honorary board members Barbara Bush, and Senators Claiborne Pell and Robert Dole, put forth 22 years ago when they launched this very important effort to provide dignified care and support to children with life-threatening conditions and their families.