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RECOGNIZING **CHILDREN'S HOSPICE INTERNATIONAL** ON ITS 22ND ANNIVERSARY ON  
MAY 23, 2005

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HON. JAMES P. MORAN

of virginia

in the house of representatives

Wednesday, May 25, 2005

Mr. MORAN of Virginia. Mr. Speaker, I rise today to commemorate the 22nd anniversary of Children's Hospice International, a ground-breaking, non-profit organization based in Alexandria, Virginia.

Since 1983, Children's Hospice International (CHI) has been a champion of children with life-threatening conditions--and their families--by calling for the U.S. healthcare system to do more to meet their medical and emotional needs.

In 1983, only four of 1,400 hospice programs in the United States were willing to accept children.

Since then, great progress has been made--and now, aided by the efforts of Children's Hospice International, 450 of about 3,000 hospices include child-specific services.

But CHI's work is far from done. The standards and training it has developed for pediatric hospice programs need to be universally adopted by hospice, palliative care, and home care programs. CHI is also working to include the hospice perspectives in all areas of pediatric care and education.

Of the 10 million children in the United States who are living with a serious chronic condition, each year about 54,000 will die without hospice services--and another 1.3 million children's lives could greatly benefit from this care.

CHI is seeking to eliminate the roadblocks in private and public insurance programs that prevent these children and their families from receiving the full range of services they need.

Historically, hospice and reimbursement guidelines--in Medicaid and most private plans--require that patients forego all life-saving care before they can be admitted to hospice, and that the patient be within the last six months of life. CHI has worked with the Centers for Medicare and Medicaid Services (CMS) to facilitate State implementation of CHI PACC programs that will reduce the impact of these requirements on children and families.

These restrictions simply do not work with patients in pediatric care.

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

A parent should never have to choose between hospice care and the hope for a cure. And, because of the unpredictable course of many serious childhood illnesses, it is often very difficult for doctors to determine when a child is within six months of death.

Since 1997, CHI has worked with CMS to set up the Program for All-Inclusive Care for Children and their Families (CHI PACC).

Unlike traditional hospice/palliative care models, a CHI PACC program provides a continuum of care for children and their families from time of diagnosis, with hope for a cure, and through bereavement if a cure is not attained.

This program will allow states to receive federal reimbursement for a more coordinated service package than is generally provided under Medicaid, including counseling for children and families, respite care, and bereavement services. States operating CHI PACC programs through the Medicaid Home and Community-Based Waiver authority will also be able to serve children in families who earn too much to typically qualify for Medicaid.

With Congressional support, a total of 16 states are already benefiting from CHI PACC. Six states have their own CHI PACC Medicaid program in development. These are Colorado, Florida, Kentucky, New York, Utah and my state of Virginia. In addition, the New England Region is also working toward implementing CHI PACC to cover four states--Maine, Massachusetts, New Hampshire and Vermont. The Colorado program will also cover a region, providing services to patients in six additional states--Kansas, Montana, Nebraska, New Mexico, South Dakota and Wyoming.

While the CHI PACC model creates a core set of standards and principles have been developed, the model itself is flexible, allowing states to tailor-make different approaches to running the program.

Currently, about 30% of the children who have life-threatening conditions qualify for Medicaid. All of these children and perhaps many more will benefit from this model of care.

And with the support of my good friend, Mr. Murtha of Pennsylvania, the Department of Defense is working to adopt the CHI PACC model for its health care system. 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.

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-CHIP and private insurers.

Projections from the states developing CHI PACC programs indicate that they not only expect these programs to be budget neutral, but they hope they will actually save the taxpayers money.

Since 1983, Children's Hospice International has provided new hope to the millions of children with life threatening conditions and their families.

It is in recognition of these efforts that I want to express my personal gratitude for the work of Children's Hospice International--and to congratulate them on their 22nd anniversary.

Mr. Speaker, I would like to also submit for the Record, a poem by young Mattie J.T. Stepanek, a New York Times best selling author who passed away last summer, after a valiant fight with dysautonomic mitochondrial myopathy. Mattie volunteered for many years to be CHI's spokesperson--he is a hero and inspiration to us all CHI PACC is a living memorial to Mattie.

#### A New Hope

I need a hope--a new hope.

A hope that reaches for the stars, and that does not end in violence or war.  
A hope that makes peace on our earth, and That does not create evil in the world.

A hope that finds cures for all diseases, and That does not make people hurt,  
In their bodies, in their hearts, Or most of all, in their spirits.

I need a hope--a new hope, A hope that inspires me to live, and To make all these things happen.

So that the whole world can have A new hope, too.

--Mattie J.T. Stepanek, 1999.