

ALLIANCE FOR CHILDHOOD CANCER

August 25, 2008

Representative Deborah Pryce
United States House of Representatives
Cannon House Office Building 320
Washington, DC 20515

Dear Representative Pryce:

On behalf of the Alliance for Childhood Cancer, we commend you for introducing the Compassionate Care for Children Act of 2007 (H.R. 5192), which seeks to improve the quality of palliative and end-of-life care for children affected by life-threatening medical conditions and assure that their families have access to appropriate resources. The legislation represents a critical first step toward strengthening the training of professionals who deliver palliative care, enhancing services that are currently available, and improving scientific knowledge to guide development of new palliative care models.

In July 2003, the Institute of Medicine (IOM) released a report, "When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families," which detailed the significant shortcomings of the health care system in meeting the physical, emotional, and spiritual needs of children and their families throughout the course of the child's life-threatening illness. The Alliance applauds your efforts to work with experts in the field to address many of these recommendations through your legislation. Of particular note are provisions to improve the palliative care training of physicians, nurses, and other health care professionals who treat seriously ill children. In addition, we appreciate the inclusion of grants to create and expand pediatric palliative care, as well as research grants for pain and symptom management research.

Parents understandably find it difficult to make the choice between palliative care **or** disease treatment. The Alliance is pleased that the legislation provides for demonstration projects that will allow children to receive hospice care services without requiring certification that the child has less than 6 months to live, while also ensuring that parents will not have to forego disease treatment for their child. We also hope that based on the success of the demonstration programs that the Medicaid program and private insurers will adopt these policies.

The Alliance is pleased to see a number of enhancements in the bill including:

- Raising the age of eligible children from 18 to 21 years old;
- Adding an emphasis on the interdisciplinary approach to programs and services;
- To expand the types of programs eligible for grants to include schools of nursing, psychology and social work;
- To add emphasis on coordination of care services; and
- Requiring a symposium convening experts to evaluate the demonstration programs as well as continue to increase awareness on pediatric palliative care.

Alliance Members

Co-Chairs

Craig Lustig, MPA
The Children's Cause for
Cancer Advocacy

Edwin Forman, MD
American Academy of
Pediatrics

American Cancer Society

American Pediatric
Surgical Association

American Psychological
Association

American Society for
Therapeutic
Radiology/Oncology

American Society of
Clinical Oncology

American Society of Pediatric
Hematology & Oncology

Association of Pediatric
Hematology/Oncology Nurses

Association of Pediatric
Oncology Social Workers

Candlelighters Childhood
Cancer Foundation

Chai Lifeline

Children's Brain Tumor
Foundation

Children's Oncology Group

CureSearch National Childhood
Cancer Foundation

Hope Street Kids/Prevent
Cancer Foundation

Lance Armstrong Foundation

National Children's Cancer
Society

National Coalition for
Cancer Survivorship

National Patient Advocate
Foundation

Pediatric Brain Tumor
Foundation

Sarcoma Foundation of America

Society of Pediatric Psychology

The Children's Cause for
Cancer Advocacy

The Leukemia & Lymphoma
Society

The Wellness Community

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Again, we applaud your efforts to improve palliative care for children with life-threatening illnesses. We look forward to working with you on this critical legislation.

Sincerely,

American Pediatric Surgical Association
American Psychological Association
American Society of Clinical Oncology
American Society of Pediatric Hematology/Oncology
Association of Pediatric Hematology Oncology Nurses
Association of Pediatric Oncology Social Workers
Candlelighters Childhood Cancer Foundation
Chai Lifeline
Children's Brain Tumor Foundation
Children's Cause for Cancer Advocacy
CureSearch National Childhood Cancer Foundation
Hope Street Kids/Prevent Cancer Foundation
Lance Armstrong Foundation
Leukemia & Lymphoma Society
National Children's Cancer Society
National Coalition for Cancer Survivorship
Sarcoma Foundation of America
Society of Pediatric Psychology