

# ALLIANCE FOR CHILDHOOD CANCER

## 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

Cancer Research and  
Prevention Foundation/ Hope  
Street Kids

Candlelighters Childhood  
Cancer Foundation

Chai Lifeline

Children's Brain Tumor  
Foundation

Children's Oncology Group

CureSearch National Childhood  
Cancer Foundation

Lance Armstrong Foundation

National Children's Cancer  
Society

National Coalition for  
Cancer Survivorship

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

April 28, 2008

Senator Daniel Akaka  
United States Senate  
Hart Senate Office Building 141  
2nd and C Streets, N.E.  
Washington, DC 20510

Dear Senator Akaka,

The Alliance for Childhood Cancer, representing twenty national patient advocacy groups and professional medical, health and scientific organizations, urges you to become a co-sponsor of "The Pediatric, Adolescent, and Young Adult Cancer Survivorship Research and Quality of Life Act of 2007" (S.2877). We believe this legislation is an important step forward in enhancing research and programs for young cancer survivors that will lead to improved health for the growing number of survivors of childhood cancers.

The population of survivors of childhood cancers has grown exponentially over the years. In 1960, only four percent of children with cancer survived more than five years compared to 270,000 survivors of childhood cancers as of 1997. As many as two-thirds of these survivors are experiencing late effects of treatment, and one-fourth experience effects that are serious or life threatening. With so many survivors experiencing these late effects, it is critical that resources are made available to all childhood cancer survivors, especially those in minority or underserved communities. The 2003 Institute of Medicine report, "Childhood Cancer Survivorship: Improving Care and Quality of Life" and subsequent IOM reports on cancer survivorship have outlined a number of recommendations to address childhood cancer survivors' needs, including more research, long-term follow-up guidelines, provider education and awareness, and improved access to long-term care services. This legislation would address many of these recommendations by: 1) establishing clinics for comprehensive long-term follow-up services for survivors; 2) providing grants to improve access to care for survivors of childhood cancer; and 3) developing Centers for Disease Control and Prevention cancer control programs aimed at providing guidance to states and encouraging them to improve systems of care for survivors of childhood cancer.

The Alliance for Childhood Cancer advocates efforts to advance research and policies to improve the diagnosis, treatment, care, and survivorship of children and adolescents with cancer, as well as enhance public awareness. We hope you will become a co-sponsor of this important piece of legislation to help childhood cancer survivors. If you have any questions, please contact Tara Leystra at [tara.leystra@asco.org](mailto:tara.leystra@asco.org) or 703-299-1050.

Sincerely,

Craig Lustig, MPA  
Co-Chair

Edwin Forman, MD  
Co-Chair