

ALLIANCE FOR CHILDHOOD CANCER

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

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American Society for
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Radiology/Oncology

American Society of
Clinical Oncology

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Association of Pediatric
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Association of Pediatric
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Cancer Research and
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Candlelighters Childhood
Cancer Foundation

Chai Lifeline

Children's Brain Tumor
Foundation

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CureSearch National Childhood
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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 23, 2008

Representative Thomas Allen
United States House of Representatives
Independence and New Jersey Avenues, S.E.
Longworth House Office Building 1127
Washington, DC 20515

Dear Rep. Allen,

The Alliance for Childhood Cancer, representing twenty national patient advocacy groups and professional medical 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" (H.R. 4450). 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 or 703-299-1050.

Sincerely,

Craig Lustig, MPA
Co-Chair

Edwin Forman, Md
Co-Chair