

Member Organizations

American Academy of Pediatrics

American Cancer Society Cancer Action Network

American Childhood Cancer Organization

American Society of Clinical Oncology

American Society of Pediatric Hematology/Oncology

Association of Pediatric Hematology/Oncology Nurses

Association of Pediatric Oncology Social Workers

B+ Foundation

Children's Brain Tumor Foundation

Children's Cause for Cancer Advocacy

Children's Oncology Group

CureSearch for Children's Cancer

Leukemia & Lymphoma Society

National Children's Cancer Society

Pediatric Brain Tumor Foundation

Sarcoma Foundation of America

Society of Pediatric Psychology

St. Baldrick's Foundation

Partner Organizations

American Brain Tumor Association

American Pediatric Surgical Association

American Psychological Association

American Society for Radiation Oncology

Cancer Support Community

Chai Lifeline

Livestrong Foundation

National Brain Tumor Society

National Coalition for Cancer Survivorship

Patient Advocate Foundation

May 14, 2013

The Honorable Jackie Speier U.S. House of Representatives 211 Cannon House Office Building Washington, DC 20515

Dear Congresswoman Speier:

The Alliance for Childhood Cancer, a coalition of national patient advocacy groups and professional medical and scientific organizations, would like to share our support for the *Childhood Cancer Survivors' Quality of Life Act* and express our gratitude for your leadership on this critical child health issue. The Alliance for Childhood Cancer aims to advance policies that improve the diagnosis, treatment, and survivorship of children and adolescents with cancer, and we believe this legislation represents an important step forward in enhancing research and programs for young cancer survivors.

The population of survivors of childhood cancer has grown exponentially in the last 50 years and today there are more than 360,000 survivors of all ages in the United States. Unfortunately, as many as two-thirds of these individuals are likely to experience at least one late effect of their disease or treatment, and one-fourth experience effects that are serious or life threatening. Second cancers, heart and lung damage, osteoporosis, financial pressures, psychosocial issues, neurocognitive effects, and employment and fertility problems are among the many challenges faced by childhood cancer survivors.

The 2003 Institute of Medicine (IOM) report, "Childhood Cancer Survivorship: Improving Care and Quality of Life" outlined a number of recommendations to improve the outlook and quality of life for this unique population. The Childhood Cancer Survivors' Quality of Life Act would establish vital programs to improve care for childhood cancer survivors, consistent with the recommendations of this landmark IOM report. In particular, this legislation will enhance research on late effects and health care disparities; create pilot programs to evaluate model systems of care and identify the most effective ways to provide follow-up care to survivors; authorize grants to establish clinics to provide comprehensive, long-term follow-up care; and strengthen the emphasis on psychosocial care for childhood cancer survivors.

The Alliance for Childhood Cancer thanks you for sponsoring the *Childhood Cancer Survivors' Quality of Life Act* and we applaud your ongoing commitment to improving the lives of children diagnosed with cancer, survivors, and their families. We look forward to working with you to pass this important bill to help ensure a brighter future for childhood cancer survivors. If you have any questions, please contact Kristen Mizzi with the Children's Cause for Cancer Advocacy at kmizzi@childrenscause.org.

Sincerely,

American Brain Tumor Association

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