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**Docket:** IRS-2010-0017

Requirement for Group Health Plans and Health Insurance Issuers to Provide Coverage of Preventive Services under the Patient Protection and Affordable Care Act

**Comment On:** IRS-2010-0017-0002

Interim Final Rules for Group Health Plans and Health Insurance Issuers Relating to Coverage of Preventive Services; etc.

**Document:** IRS-2010-0017-0036

Comment on FR Doc # 2010-17242

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**General Comment**

See attached file(s)

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**Attachments****IRS-2010-0017-0036.1:** Comment on FR Doc # 2010-17242

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September 17, 2010

The Honorable Kathleen Sebelius  
Department of Health and Human Services  
200 Independence Avenue, SW  
Washington, DC 20201

Dear Secretary Sebelius:

The Children's Cause for Cancer Advocacy (CCCA) appreciates the opportunity to comment on the interim final rules for group health plans and health insurance issuers related to coverage of preventive services under the Patient Protection and Affordable Care Act (PPACA) as published in the Federal Register: July 19, 2010 (Volume 75, Number 137).

CCCA is the leading national advocacy organization that works to facilitate development of less toxic, more effective pediatric cancer therapies; to expand resources for childhood cancer research and specialized care; and to address the unique needs and challenges of childhood cancer survivors. One program offered by CCCA is a series of survivorship conferences held around the nation to educate childhood cancer survivors and their families about the unique challenges they face.

Today, the rate of survival among children diagnosed with cancer is 80 percent, with more than 320,000 childhood cancer survivors living among us. While this rate of survival is encouraging, the use of toxic therapies to save the lives of children with cancer has significant long-term health consequences that are unique to this population. In fact, two thirds of survivors have at least one chronic or late-occurring complication of their cancer therapy, with about one third having serious or life-threatening complications that diminish their quality and length of life. Late effects include second cancers, cardiac and pulmonary disease, musculoskeletal changes, cognitive dysfunction, psychosocial challenges, obesity, thyroid disease, and bladder disease.

Just yesterday, at a Childhood Cancer Summit on Capitol Hill, the Pediatric Cancer Caucus received testimony from Dr. Kevin Oeffinger, Director of the Adult Long-Term Follow-Up Program at Memorial Sloan Kettering, on the subject of childhood cancer survivors' long-term health challenges. The statistics are startling. A study of 9,535 young adult survivors of childhood

cancer revealed moderate to extreme adverse health outcomes for

- general health at a rate of 10.6%;
- mental health at a rate of 17.2%;
- functional impairment at a rate of 11.8%;
- limitations in activity at a rate of 13.5%;
- post-cancer pain at a rate of 10.2%; and
- post-cancer fears and anxiety at a rate of 13.2%.

The good news is that many of these health issues are preventable or very treatable if detected early. Clearly, the diligence of childhood cancer survivors in seeking appropriate follow-up care, including preventive services, from doctors and institutions that understand the possible and probable health consequences of the therapies children with cancer receive is critical to preserving the health and productivity of these individuals for the remainder of their lives.

Given the relatively small population of childhood cancer survivors, most pediatricians, family practitioners, and other primary care physicians do not have experience treating these patients and are likely unaware of the unique vulnerabilities of this population. The most appropriate and successful setting to receive preventive, follow-up care is in a survivor clinic or institution where clinicians understand the relationship between the course of pediatric oncology drugs and the associated long-term effects .

It is with these facts in mind that CCCA provides the following comments on the Departments' interim final rules.

The Interim rules establish that plans and issuers are not required to cover preventive services provided by out-of-network providers and may impose cost-sharing requirements for preventive services provided by out-of-network providers. We understand that this decision is based on the need to preserve the cost-effectiveness of in-network care and encourage providers to pursue in-network agreements. While we support these principles, we are concerned that if appropriate care for childhood cancer patients is not available in-network and cost becomes a barrier, that access to high quality, appropriate and coordinated care will be compromised, thereby jeopardizing the long-term health of this population, many of whom have years of life ahead of them.

Many of the preventive services covered by the PPACA provision, based on the current recommendations and ratings of the United States Preventive Services Task Force, are applicable to follow up care for childhood cancer survivors, including blood pressure and cholesterol screening, diabetes screening for hypertensive patients, cancer screenings, adolescent depression screening, counseling related to tobacco cessation and obesity counseling. These services may be provided as part of a comprehensive survivorship follow-up care program that is coordinated in survivorship clinics in line with specific patients risk profiles. If cost-sharing is applied to these services based on the providers'

network status, there is a significant risk that appropriate care will not be received by these individuals. Therefore, the benefits associated with increased access and utilization of preventive care, including earlier treatment of disease, healthier workers, and savings due to lower health care costs, will not be realized by a population of cancer survivors that is in greater need of these services and has significant years of life ahead – factors that exacerbate this loss.

While the preferable solution is for plans to engage survivor clinics and institutions providing comprehensive follow-up care to childhood cancer survivors and ensure they are able to offer the services in-network, we know that will not always be the case. Given the relatively small number, high risk, and life years associated with the childhood cancer survivor population, we believe it would be cost effective to eliminate cost barriers to appropriate, high-quality preventive services in special survivorship clinics or an otherwise informed and appropriate setting of care regardless of in-network status.

Thank you for your consideration of our perspective and for your support of childhood cancer survivors. We thank the Department of HHS and other departments for the opportunity to comment on the interim final rules implementing special cost-sharing protections related to preventive services and goods.

Sincerely,



Lori A. Salley  
Executive Director