



January 19, 2017

The Honorable Michael McCaul
2001 Rayburn House Office Building
U.S. House of Representatives
Washington, D.C. 20515

The Honorable Jackie Speier
2465 Rayburn House Office Building
U.S. House of Representatives
Washington, D.C. 20515

The Honorable G.K. Butterfield
2080 Rayburn House Office Building
U.S. House of Representatives
Washington, D.C. 20515

The Honorable Mike Kelly
1707 Longworth House Office Building
U.S. House of Representatives
Washington, D.C. 20515

Dear Co-Chairs of the Childhood Cancer Caucus:

On behalf of the 13,000 children who will be diagnosed with cancer this year, and the almost 500,000 childhood cancer survivors, we write to urge you to protect the needs of these children and those who will be diagnosed in the years to come as you consider changes to the Affordable Care Act and safety net health care programs.

The Children's Cause for Cancer Advocacy was founded to ensure the needs and perspectives of children with cancer and survivors are integrated into federal health care, research and cancer policy. Cancer remains the leading disease killer of children and childhood cancer survivors experience serious long-term and late effects on their health and well-being.

We urge policymakers to protect children and adolescents with cancer and survivors as Congress considers the Affordable Care Act (ACA), Medicaid, and the Children's Health Insurance Program (CHIP). These programs currently cover over 40 million children and adolescents in our country, and any changes must consider the impact on these vulnerable populations. Specifically, any structural or policy reforms should not diminish coverage or access for children with cancer.

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Timely Access to Affordable, High Quality Cancer Care

Children with cancer have significant health care needs, ranging from accurate diagnosis and appropriate therapies for their specific diagnosis, to management of side effects during treatment, and long-term survivorship care to address the late and long-term effects of cancer and cancer treatments. Children in need of active treatment and appropriate symptom management, as well as survivors who need ongoing care including monitoring, follow-up services, and preventive services, could be adversely affected by significant disruptions in the insurance market. We support access to care for cancer patients across the continuum of their disease without a period of uncertainty in the insurance market that might result in loss of access to affordable insurance coverage and therefore access to care. For this reason, Children's Cause supports the following elements of health care coverage:

- *Access to parents' insurance coverage.* Children and adolescents affected by cancer must continue to have access to their parents' insurance coverage through age 26 as an option to ensure their continued care and subsequent quality of life and productivity.
- *Insurance market reforms.* Children and adolescents with cancer must continue to be eligible for pre-existing condition exclusions and exemptions from waiting periods to receive coverage. Insurers should also continue to be prevented from retroactively denying coverage and imposing lifetime and annual coverage limits.
- *Access to pediatric providers.* Children and adolescents suspected of having cancer must have access and timely referral to pediatric oncology specialists for screening, comprehensive initial evaluation, and diagnostic testing and treatment.

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- Early access to diagnosis and treatment is critical to improving survival and long term outcomes for pediatric cancer patients.
 - Children and adolescents with cancer require coverage of coordinated care from a multidisciplinary team of pediatric cancer specialists, including physicians, nurses, social workers, psychologists and other health care providers.
- *Survivors of childhood and adolescent cancer.* Survivors of childhood and adolescent cancer require coverage for long-term follow-up care by specialists with expertise in the late effects of their treatment and disease. As many as two-thirds of childhood cancer survivors are likely to experience at least one late effect of treatment, such as heart damage, bone malformations and secondary cancers.
- *Medicaid program.* Medicaid is essential to ensuring all children with cancer have coverage and access to care; covering more than a third of childhood cancer diagnoses. We must ensure that the vital services provided under this program to children in need are not compromised.
- *Affordable coverage.* For those not eligible for Medicaid, support for the purchase of health insurance should be made available to ensure that families can afford coverage for children and adolescents with cancer.

Along with the children and families we serve, thank you for your continued commitment and dedication to protecting the lives of children with cancer and we look forward to working with you as Congress continues deliberations.



Susan L. Weiner
Founder



George Dahlman
Chief Executive Officer

