

# Health Care Reform Affects Pediatric Cancer Patients & Survivors



The current health care law has several provisions that help ensure children with cancer have access to quality treatment and care, and that survivors of childhood cancer are able to obtain and maintain affordable health insurance. These provisions and protections are essential in any health coverage system that intends to provide meaningful care for pediatric cancer patients and survivors.

## *How are Childhood Cancer Patients Insured?*

The American Cancer Society estimates that 14,660 new cases of cancer were diagnosed in 2016 among children and adolescents age 0-19.<sup>1</sup> Outcomes for children diagnosed with cancer have greatly improved over the past 50 years for most types of cancer – the average 5-year survival rate of childhood and adolescent cancers is 83 percent.<sup>2</sup> However, some cancer types have much lower survival rates and remain fatal. As of January 1, 2013, there were an estimated 408,283 survivors of childhood and adolescent cancer in the U.S.<sup>3</sup>

Young adults who have cancer or survived childhood cancer are particularly vulnerable to being uninsured for several reasons: they are unable to work or must reduce hours because of their treatment or side effects; they must move closer to their treatment facility or near a caregiver; or premium costs are unaffordable. Before 2010, young adult cancer survivors also had significant problems finding and affording health insurance because plans were allowed to reject them or charge more because of their pre-existing condition.

## *What Provisions Help Childhood Cancer Patients & Survivors Get and Keep Health Insurance?*

- **No Pre-Existing Condition Exclusions:** Since 2014, insurance plans have not been allowed to deny an individual coverage because they have a pre-existing condition, like cancer. Prior to this prohibition, it was common for cancer survivors to be denied coverage because of their cancer history.
- **Dependent Coverage:** Since 2010, insurance plans have been required to offer coverage to policy holders' dependent children up to age 26. This provision is crucial to providing health insurance options for young adult cancer survivors.
- **Medicaid Expansion:** Since 2014, states have had the option of expanding Medicaid eligibility to all individuals who earn an annual income of up to 138 percent of the federal poverty level. This expansion has been very important in covering low-income adults, including survivors of childhood cancers. Also, research shows that if parents are insured; their children are more likely to be insured, stay insured, and use health insurance effectively – like getting recommended preventive services.<sup>4</sup> Therefore Medicaid expansion is also very important in insuring the parents of childhood cancer patients.

## *What Patient Protections Help Childhood Cancer Patients & Survivors Once They Are Insured?*

- **No Annual or Lifetime Caps:** Insurance plans are no longer allowed to have annual or lifetime limits on the amount they spend on a patient's health care. Before this protection was in place, cancer patients – including children – frequently reached their maximums and had to

pay out-of-pocket for the rest of their treatments.

- **No Rescissions:** Insurance plans are no longer able to kick a child or adult off their plan after they are diagnosed with a serious illness like cancer.
- **Out-of-Pocket Spending Limits:** Current law includes limits on the amount a privately-insured patient must pay out-of-pocket in copays, coinsurance and pre-deductible expenses. As cancer treatment can be very expensive, most cancer patients meet their out-of-pocket maximums, and these provisions keep treatment from becoming unaffordable.
- **Coverage Standards:** As most individuals – especially children – do not know they have cancer or expect a cancer diagnosis when they enroll in health insurance, current standards for minimum essential coverage and essential health benefits ensure that children have access to a robust set of benefits that includes cancer treatments.
- **Preventive Services:** Current law requires most insurance plans to cover preventive services and cancer screenings with no cost-sharing. As treatments for childhood cancer continue to affect children into adulthood, and as survivors need to monitor for and prevent cancer recurrence and secondary cancers, this provision helps survivors of childhood cancer get the preventive services and screenings they need.

### *Patient Story – Taylor, Ohio*

At 12 years old, Taylor from Ohio was undergoing treatment for acute myeloid leukemia (AML) when her family discovered she was approaching her insurer's \$1 million lifetime insurance cap. Desperate for a solution, her parents filed a request to raise the maximum benefit and eventually were able to successfully raise the cap to \$1.5 million. However, even this new higher maximum would have been insufficient to cover all of the ongoing treatment and the lasting side effects of Taylor's disease and treatment.

Thankfully Taylor, now a college freshman, is in remission, and doing well. Due to the provision allowing children up to age 26 to remain on their parents' insurance plans and the elimination of lifetime and annual caps, Taylor has quality insurance coverage. However, because of her pediatric cancer history and other chronic conditions, she will need ongoing medical care for the rest of her life.

It is important to ensure that people like Taylor are able to maintain access to uninterrupted insurance coverage that includes recommended cancer screenings and follow-up care.

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<sup>1</sup> American Cancer Society and Alliance for Childhood Cancer. *Translating Discovery into Cures for Children with Cancer*. 2016. Available at <http://www.cancer.org/acs/groups/content/@editorial/documents/document/acspc-048347.pdf>.

<sup>2</sup> Ibid.

<sup>3</sup> Howlander N, Noone AM, Krapcho M, et al (eds). SEER Cancer Statistics Review, 1975-2013, National Cancer Institute. Bethesda, MD, [http://seer.cancer.gov/csr/1975\\_2013/](http://seer.cancer.gov/csr/1975_2013/), based on November 2015 SEER data submission, posted to the SEER web site, April 2016.

<sup>4</sup> Rosenbaum S, Whittington RPT. The George Washington University School of Public Health and Health Services. *Parental Health Insurance Coverage as Child Health Policy: Evidence from the Literature*. June 2007. Available at [http://publichealth.gwu.edu/departments/healthpolicy/CHPR/downloads/Parental\\_Health\\_Insurance\\_Report.pdf](http://publichealth.gwu.edu/departments/healthpolicy/CHPR/downloads/Parental_Health_Insurance_Report.pdf).