



**2017 APOSW Position Statement for
Universal Health Coverage/Access to Affordable Care/Palliative Care/Psychosocial Care¹**

APOSW supports public policies which ensure that children, adolescents, and young adult survivors with cancer and their families can access high quality, affordable, and timely health care. APOSW supports health care as a human right as outlined by the World Health Organization (WHO) Constitution and Palliative Care as a human right also recognized by the WHO.

Moreover, APOSW supports passage of The Childhood Cancer Survivorship, Research, Access, Treatment (STAR) Act of 2017, now pending before Congress (H.R. 820/S. 292) and adoption of the 15 Psychosocial Standards of Care for Children with Cancer and their Families², supported by the Congressional Childhood Cancer Caucus.

In conjunction with and as a member of the Alliance for Childhood Cancer, a coalition of more than thirty national (childhood) cancer patient advocacy, professional, medical and scientific organizations, APOSW urges lawmakers to protect coverage for children, adolescents, and young adults with cancer and their families, as changes to the Affordable Care Act (ACA) and other health care programs are debated. APOSW strongly urges that any changes to existing Health Care Policy in the U.S. must ensure uninterrupted health care access for children, adolescents, and young adults with cancer.

Cancer is the leading disease-related cause of death for children aged 1-19, with nearly 15,000 children diagnosed each year. Despite this fact, many childhood cancers can be successfully treated. By 2020, there will be at least 500,000 childhood cancer survivors in the U.S. However, research now clearly documents that survivors experience serious long-term and late effects of their disease and therapies, affecting their health and welfare, and which require lifelong surveillance and treatment.

Treatment for childhood cancer is expensive, requiring access to ongoing specialty care, often for years. Families cannot forego insurance coverage because of the costs of their children's care. The ACA provides important financial protections and assistance for families facing the crisis of a childhood cancer diagnosis. These protections are critical to saving children's and adolescents' lives without bankrupting families or placing them in dire financial need.

The Affordable Care Act also includes many insurance market reforms that have been vital to childhood cancer patients, survivors, and their families, including protections for patients in clinical trials. Prior to the passage of the ACA, childhood cancer patients (including adolescents and young adults) and survivors were often denied coverage. Recent data show that 41 states allowed pre-existing exclusion periods of six months or more for individuals purchasing insurance, potentially devastating for newly diagnosed children with cancer, many of whom incur the bulk of health care expenses during the first six months of treatment and for long term survivors. Specifically:

- Current law includes limits on the amount a privately insured patient must pay out-of-pocket in copays, coinsurance, and pre-deductible expenses.

- Under the ACA, insurers are prevented from denying or retroactively denying coverage to children or adults with pre-existing health conditions or charging people with preexisting conditions more than those without.
- Because nearly two-thirds of childhood cancer patients experience late effects, such as heart and lung disease, treatment-related secondary cancers, endocrine dysfunction and infertility, they require continued coverage for their chronic healthcare needs.
- Survivors' lasting impairments make it especially important to preserve the ACA's prohibition of lifetime caps or annual limits on coverage.
- Prohibition of annual limits on coverage and lifetime caps is also extremely important for bone marrow transplant candidates and recipients and all patients with high risk disease and/or who suffer multiple infections, complications, relapses, etc. incurring multiple hospitalizations and/or PICU stays.
- Insurers are no longer allowed to cancel coverage when a child becomes sick.
- Under the ACA, survivors can also receive continued care by allowing them to remain on their parents' health insurance plans up to age 26 -- a vital time before many can enter the workforce to obtain their own coverage.
- Under the ACA, cancer patients are entitled to have coverage for the routine costs of their care if they participate in clinical trials; vital since the vast majority of children with cancer are treated in the context of clinical trials, a fact responsible for children's increased survival.

There is growing research indicating children living in poverty have poorer treatment outcomes and lessened chance for survival³. In addition, since nearly 25% of children with cancer are covered by Medicaid, maintaining Medicaid coverage and adequately funding state programs is critical. Specifically:

- Under current law, families with incomes between 100 and 400 percent of the federal poverty level (FPL) can receive premium tax credits to purchase health insurance.
- In addition, families with incomes between 100 and 250 percent of the FPL can receive cost-sharing subsidies to help with out-of-pocket costs.
- Proposals that would alter current federal policies that guarantee Medicaid benefits and eligibility could threaten care and survival for children.

Principles that should be preserved in the health care debate include:

- **Access:** Children, adolescents, young adults, and survivors of childhood cancer should have access to high-quality, timely health care at each point across the cancer care continuum from diagnosis through survivorship or end-of-life care.
- **Affordability:** High-quality health insurance and prescription medications should be affordable (including premiums and out of pocket costs) for all individuals regardless of income, using public programs and subsidies when needed. **Clinical Trials:** Children with cancer should have access to clinical trials, and insurers should not limit or drop coverage due to participation in a trial.
- **Consumer Insurance Protections:** Insurance companies should not be able to place lifetime limits on coverage, rescind coverage (except in cases of fraud), drastically raise premiums without justification, or discriminate based on pre-existing conditions or genetic information.
- **Coverage:** Young adults should be eligible to remain covered under their parents' insurance plan until the age of 26; prohibition on lifetime caps for coverage need to remain in place.

- Disparities: Federal health programs should be required to collect and report racial, ethnic, and language data to help understand and reduce persistent health disparities which affect treatment outcomes and quality of life.
- Mental Health Services: There should be mental and behavioral health care parity with access to trained and licensed mental health care providers who deliver affordable care.
- Non-discrimination: Patients should not be discriminated against based on health or any other characteristic.
- Prevention: All childhood cancer patients and survivors should have access to supportive, preventive, and survivorship care with appropriate follow-up, screenings, nutrition counseling, and opportunities to engage in an active and healthy lifestyle.
- Palliative Care: Children, adolescents, and young adults with cancer and their families should have access to integrative palliative care across the continuum of care within health care facilities, in their homes, and communities, with appropriate funding and training for health care workers, bereavement care, and support for parents and siblings.

¹ Statement adapted from letter addressed to Congress by the Alliance for Childhood Cancer (February 2017); from a position statement on access to care adopted by AOSW (January 2017) <http://www.aosw.org/AOSW/media/Main-Site-Files/About/Documents/POLICY-PRINCIPLES-FOR-HEALTH-CARE-ACCESS-AND-INSURANCE.pdf>; and a policy statement by The Worldwide Hospice Palliative Care Organization on palliative care for children (August 2016) <http://www.thewhpc.org/resources/item/whpca-position-paper-on-palliative-care-for-children>

² Standards for Psychosocial Care for Children with Cancer and Their Families, *Pediatric Blood and Cancer*, **62** (S5), December 2015: S419-S895. Accessed at <http://onlinelibrary.wiley.com/doi/10.1002/pbc.v62.S5/issuetoc>. Articles are free and downloadable at www.mattiemiracle.com/standards

³ Bona, K; Blonquist T; Neuberg, D; Silverman, L; Wolfe, J. "Impact of Socioeconomic Status on Timing of Relapse and Overall Survival for Children Treated on Dana-Farber Cancer Institute ALL Consortium Protocols (2000-2010)." *Pediatric Blood and Cancer*, February 2016; DOI: 10.1002/pbc.25928.