In addition to many decades of leadership in federal advocacy and international policy change, CSG’s newest associate, the American Childhood Cancer Organization (ACCO), is taking a leadership role in strategic state advocacy through an Amazon supported initiative called Why Not Kids. This movement is based on successful efforts in Kentucky that focus on working with state governments—educating them and informing them of their unique role and responsibility—to close the gap between budget allocations for adult and childhood cancer research, treatment and support.

“Childhood cancer is the leading cause of death by disease in children in the United States,” said Ruth Hoffman, mother of a childhood cancer survivor and chief executive officer at ACCO. “What’s more, two-thirds of children who do survive will develop long term late effects. One-fourth of those children will have a life-threatening side effect, including secondary cancers from toxicity of treatment. It’s clear the time to act is now and rapid progress is needed to bring cures and hope to children and families across the country.”

Although it is important to acknowledge significant recent accomplishments at the federal level, including passage of the Childhood Cancer STAR (Survivorship, Treatment, Access, and Research) Act, a large disparity still exists between the amount of funding the federal government allocates for adult and childhood cancer research. This makes state government funding of childhood cancer research urgent and imperative. For comparison in federal funding and drug development in adult versus childhood cancer research, in the past three decades only four new drugs have been developed specifically for childhood cancer while more than 185 have been developed for adults.

Why Not Kids was formed after this disparity became very personal to ACCO Director of Government Relations and External Affairs Jamie Ennis Bloyd when her five-year-old son was diagnosed with aggressive stage four lymphoma during the Kentucky legislative session in March 2014. A lobbyist at the time of diagnosis, Bloyd quickly understood the gap in state-level engagement and funding for childhood cancer.

Working with Kentucky Senate Appropriations and Revenue Chair Chris McDaniel and state legislative commission staff, she discovered in the last three biennial state budgets over $15 million had been allocated to adult cancer research. Never in the history of the commonwealth of Kentucky had the Legislature invested in broad-based support of pediatric cancer—causing her to wonder aloud, “if state funds have been allocated to adult cancer research—why not kids?” She soon learned no other state in the country had specifically invested in childhood cancer research either.

In 2018, led by Kentucky state Sen. Max Wise and Gov. Matt Bevin, state leaders in Kentucky recognized this urgent need and set a national precedent for state engagement in the fight against childhood cancer by appropriating first time funding of $5 million. This new funding has already resulted in the revelation that a cluster of a 40-county area in Kentucky has children with 87% higher incidence of pediatric brain tumors than what would be expected.

ACCO’s Why Not Kids efforts will be focused on incentivizing collaboration with state pediatric
oncology programs—eliminating silos—and implementing awareness and advocacy campaigns utilizing state cancer registry data/population-based incidence to inform funding decisions. Pilot sites have been selected based on the June 2018 CDC report on childhood cancer incidence by state, with further review by experts with over 50 years of combined experience in state-level cancer epidemiology and cancer registries. Currently only three states fund childhood cancer research specifically and 29 states have no mention of childhood cancer in their respective state cancer action plans.

September is Childhood Cancer Awareness Month and ACCO is ready to jumpstart efforts in the states in preparation for the 2020 legislative sessions. Armed with model legislation, best practices and the largest grassroots advocacy network of any childhood cancer organization in the country, ACCO works with state legislators and budget officials to make childhood cancer a top policy and funding priority in every state.

By:
Friday, September 20, 2019 at 09:13 AM
Tags:
Policy Area | Health | Insurance Coverage and Medical Care | Children

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Source URL: http://knowledgecenter.csg.org/kc/content/closing-gap-between-adult-and-childhood-cancer-research