# Enacting Targeted Policies to Improve Childhood Cancer Outcomes

Population Health Sciences

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September is Childhood Cancer Awareness Month, when we focus attention on a disease that strikes approximately 15,270 children every year and kills 1,790, making it the leading disease-related cause of death for kids between the ages of 1 and 19. It is not enough that we just bring recognition to the disease, we must also leverage that attention into action by working to improve outcomes.

As a former engineer and cancer researcher, I understand well that before rushing toward solutions, you have to truly understand the root causes of a problem to ensure that solutions are effective. In 2016, I had the great fortune to work in collaboration with others in the childhood cancer advocacy community to identify some of the unique challenges faced in developing new therapies for kids with cancer. It was a wonderful learning opportunity for me, opening my eyes to the many ways cancer in children is different from adults, and reinforcing why our approach to treating childhood cancer, conducting research and caring for kids after they finish treatment has to be different.

While general cancer research and advances in cancer care can help kids with cancer, the only way to guarantee specific progress is to focus efforts on the *unique needs* of kids with cancer, a focus that is a core strength at Children's Hospital of Philadelphia.

Just three months ago, Congress passed the Childhood Cancer Survivorship, Treatment, Access and Research (STAR) Act into law, with the goal of addressing the specific challenges noted in the bill's title through targeted provisions. One core provision aims to foster more efficient drug development by overcoming the current limited

access to tumor tissue samples, which are used by researchers to identify common weaknesses that can be exploited as targets of drugs. The broad category of childhood cancer is made up of dozens and dozens of unique cancers, so getting enough samples of any given cancer requires thousands—or even tens of thousands—of total samples. While large academic cancer centers primarily serving adults might be able to collect this magnitude of adult tumor samples on their own, no single pediatric cancer center can do the same, hence the need for a shared resource.

It is also expensive to collect and house the specimens along with accompanying clinical information, but in the adult space this cost is seen as an investment that may be commercialized for its value to drive drug development. On the other hand, childhood cancer drugs are not often viewed as commercially lucrative, so biorepositories for childhood tumors must rely on government or philanthropic funding sources to operate, which the STAR Act is charged with doing.

Another key aspect of the law involves improving the way that childhood cancer survivors are cared for. Administering cancer treatment while a child's body is still developing—in the form of radiation or chemotherapy—can lead to lasting damage. Around one-third of childhood cancer survivors aged 35 or older have developed a serious and debilitating condition or died as a result of their cancer or its treatment. The STAR Act includes a provision for government-sponsored pilot projects to develop better care models for childhood cancer survivors and their unique needs. The law also bolsters workforce development programs to ensure that health care providers are equipped with the specialized skills required to provide such care.

The STAR Act represents an important example of clearly identifying specific barriers to improving outcomes for kids with cancer and developing targeted policies and programs to address those barriers. While the STAR Act is now law, our work is far from over. The law still requires funding from Congress in order to be implemented and the American Cancer Society Cancer Action Network (ACS CAN) is working in concert with the broader childhood cancer advocacy community to ensure that Congress provides this funding. Once funded, it will be important to ensure that the knowledge gained from these initiatives feeds back into better care and better outcomes for our kids.

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