

Interstate Compact to Award Prizes for the Cure for Major Diseases

Ohio House Bill 345 (2018), also known as the “Cure Bill,” introduced by Speaker Pro Tempore Jim Butler, will allow the creation of a multistate compact to offer monetary prizes for curing deadly diseases such as cancer, Parkinson’s disease and Alzheimer’s disease. States that join the compact will pool money to fund the prize, with the aim of incentivizing additional research into cures rather than long-term treatments.

“Anybody in the world that has something that is proven to cure a disease—based on the criteria the compact will lay out—will be eligible for the prize,” said Butler. “It has to be less than one year for the course of treatment. True cures are a short period of treatment that results in the disease being eradicated from your body. That’s the idea.”

An interstate compact like the one created by the Cure Bill is a legal and administrative mechanism that allows states to work collaboratively to address issues that span state boundaries. Compacts have been successfully used to provide disaster relief across state lines during emergencies, manage shared natural resources such as rivers and ensure the children of military members have smooth transitions between schools when they move to a new state.

“Interstate compacts are a tool for state governments to cooperatively solve problems that affect multiple states, without the need for federal intervention,” said Dan Logsdon, director of the CSG National Center for Interstate Compacts. “Compacts allow states to be agile in the way they address issues and use their shared knowledge and resources in innovative ways.”

In order to receive the prize money offered by the Cure Bill’s compact, the patent for the cure would have to be turned over to the compact commission, which would work with a manufacturer to produce and distribute the cure. The prize money will be equal to the five-year tax savings—from Medicaid and other

sources—to the member states resulting from curing the disease. The commission would get a loan for the prize money when a cure is found, and then each state in the compact would pay its actual one-year savings in public health expenses annually until it has fulfilled its prize responsibility.

Federal and foreign governments can also join the compact as nonvoting members. Manufacturers, producers and providers in noncompacting states will pay a royalty, no more than the cumulative five-year public health expenses, which Butler said gives states an extra incentive to join the compact.

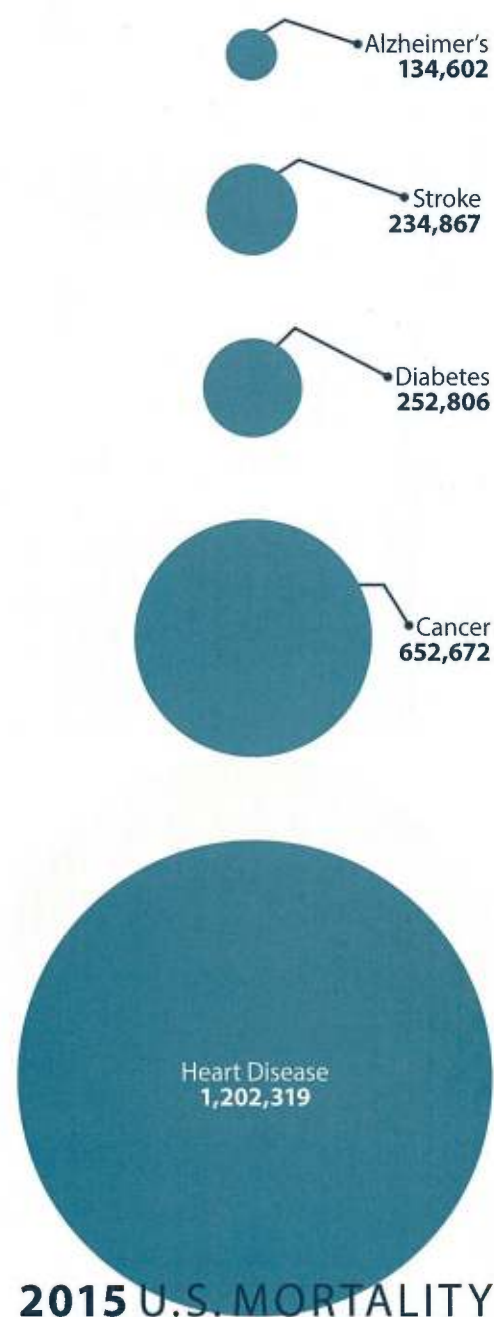
The compact will go into effect when six states join, so Butler has been reaching out to legislators in other states educate them about how the compact would work.

“I’ve had an overwhelmingly positive response in many states, and many are planning to introduce it in their states,” he said.

The compact will identify diseases to target for eradication based on factors such as fatality rates, the severity of the illness and the cost of treating the disease. The compact commission will establish criteria for cures, including a 95% survival rate through at least five years with no more than one year of treatment.

Butler’s inspiration and passion for the cure compact stems from losing both his parents to cancer in their 50s.

“Well before I entered government service, 20 years ago, my mother was diagnosed with metastatic breast cancer, and I went to find any potential hope for a cure for her by looking through all the clinical trials that existed and all the treatments that existed,” he said. “And there was nothing at all that might cure her from all the clinical trials that were out there. It was very disappointing.” □



Closing the Gap Between Adult and Childhood Cancer Research

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CANCER IS THE SECOND-LEADING CAUSE OF DEATH AMONG CHILDREN AGES **1-14** YEARS (AFTER ACCIDENTS).

There is a large disparity between the amount of funding the federal government allocates for adult and 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.

The American Childhood Cancer Organization, or ACCO, a CSG Associate, is advocating to make up that difference at the state level through their Why Not Kids initiative. The initiative is based on successful efforts in Kentucky to close the gap between budget allocations for adult and childhood cancer research, treatment and support.

Why Not Kids was formed after this disparity became very personal to Jamie Ennis Boyd, ACCO director of Government Relations and External Affairs, when her five-year-old son was diagnosed with aggressive stage 4 lymphoma during the Kentucky legislative session in March 2014. A lobbyist at the time of diagnosis, Boyd 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 that in the last three biennial state budgets,


more than \$15 million had been allocated to adult cancer research. The Kentucky Legislature had never 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 then-Gov. Matt Bevin, state leaders in Kentucky set a national precedent for state engagement in the fight against childhood cancer by appropriating first-time funding of \$5 million. The funding resulted in the revelation that a 40-county area in Kentucky has children with 87% higher incidence of pediatric brain tumors than what would be expected.

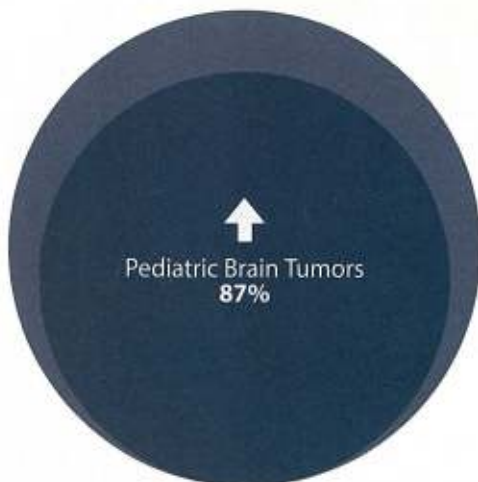
For Wise, the effort to fund childhood-specific cancer research also hit close to home.

"Our third child, Carter, was diagnosed with stage 4 Neuroblastoma at six months of age," said Wise. "Carter underwent his treatment protocol and chemotherapy at Kosair Children's Hospital. At that time, I was not a legislator, but our family vowed that we would always be advocates for childhood cancer research and awareness."

Wise said he believes Kentucky will continue to dedicate funding specifically to childhood cancer research.

"We are talking about children...many of whom have likely not yet had the experience to play in an organized sporting event, perform in a high school musical, attend a prom or unfortunately do the many other activities and lifetime experiences that so many others get to," he said. "The federal dollars for pediatric cancer are scarce compared to various other diseases and advocacy efforts." 

NEW FUNDING 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.**



CSG Shared State Legislation

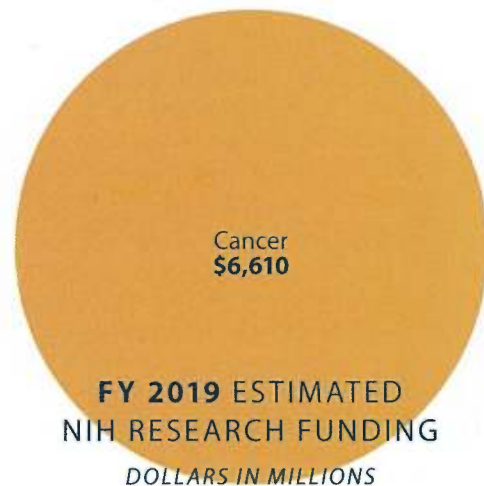
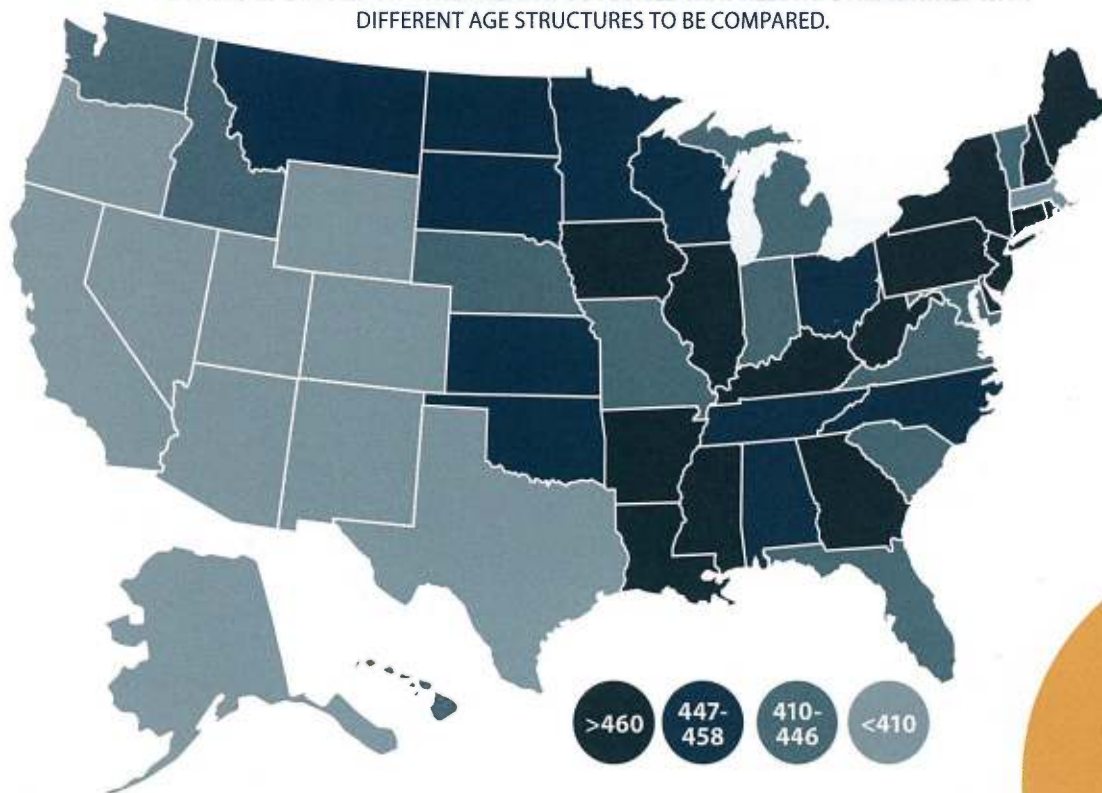
The Council of State Governments Shared State Legislation—or SSL—program is a member-driven process outlining innovative legislation on topics concerning multiple states. The SSL program gives state officials a simple way to keep up with how other states are addressing issues they too may be facing. The CSG SSL Committee, made up of state officials, meets twice annually to review recently adopted state legislation. The committee then selects legislation to be included in the annual SSL volume, which is published online for dissemination to state leaders and staff.

CSG does not promote or advocate for the enactment of state legislation, nor does it draft model legislation. Rather, the program's goal is to facilitate the sharing of legislative ideas among CSG members. The consideration or dissemination of such legislation by the SSL Committee does not constitute an endorsement.

RATE OF NEW CANCERS BY STATE

DATA IS FROM 2016, THE LATEST YEAR FOR WHICH DATA IS AVAILABLE.

RATES ARE THE NUMBER OF CASES (OR DEATHS) PER 100,000 PEOPLE AND ARE AGE-ADJUSTED TO THE 2000 U.S. STANDARD POPULATION. AGE-ADJUSTMENT IS A STATISTICAL PROCESS APPLIED TO RATES OF DISEASE OR OTHER HEALTH OUTCOMES THAT ALLOWS COMMUNITIES WITH DIFFERENT AGE STRUCTURES TO BE COMPARED.



Source: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute; cdc.gov/cancer/dataviz, June 2019.

\$80.2 billion

The estimated direct medical costs for cancer in the U.S. in 2015.

11,060

The estimated number of new cancer cases that will be diagnosed among children ages 0 to 14 years in the U.S. in 2019.

Source: National Institutes of Health, report.nih.gov/categorical_spending.aspx.