

KENTUCKY

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NPCR and ECC Efforts Lead to Better Awareness and Support for Research into Kentucky's High Incidence of Childhood Brain Cancer

NATIONAL PROGRAM OF CANCER REGISTRIES SUCCESS STORY

SUMMARY: Pediatric brain and central nervous system tumors (PBCNST) are the most common solid tumors in children and are the leading cause of disease-related death in children in the United States. Data from NPCR and the Pediatric and Young Adult Early Case Capture Program indicate that the incidence rates of PBCNST in Kentucky are significantly higher than in the United States as a whole and are even higher among Kentucky's Appalachian children [1]. NPCR and ECC data have been utilized by key stakeholders to inform state legislators about the benefit of additional research to better address this and other high incidence childhood cancers in Kentucky. As a result, the Kentucky Cancer Registry (KCR) will lead a PBCNST study with specific aims to: 1) to identify potential environmental exposures associated with Kentucky's high rates; 2) to assess whether Kentucky-specific mutations and mutational signatures exist that may be related to PBCNST, and to determine whether known genetic risk factors for PBCNST are present among Kentucky children; and 3) implement informatics infrastructures for data sharing with national PBCNST consortia. These initiatives can continue to be sustainable through evidence-based decision making at the state and national level.

CHALLENGE: Known risk factors for PBCNST are limited, while factors specific to Kentucky children remain understudied. There may be unidentified risks unique to Kentucky children, including both environmental and genetic factors. To understand and eventually eliminate such cancer disparities among Kentucky children, population-based research is needed to gain a more thorough understanding of the epidemiology and etiology of the disease. However, the number of research studies for pediatric cancers are limited compared to the number of studies on adult cancers.

SOLUTION: The Kentucky Cancer Registry (KCR) compiled data from the NPCR and ECC program to describe Kentucky's childhood cancer burden and this data was used by key stakeholders to inform the state legislature. Led by Ms. Jamie Bloyd, mother of a childhood cancer survivor, stakeholders made a commitment to evidence-based decision making in their efforts to inform decision makers about the importance of research needed to address Kentucky's childhood cancer burden and disparities.

RESULTS: In 2015 the state legislature established the Kentucky Pediatric Cancer Research Trust Fund (PCRTF). Establishment of the PCRTF created an opportunity for the KCR to bring together a multi-disciplinary team of pediatric oncologists, epidemiologists, biostatisticians and biomedical informaticists to develop a proposal for a population-specific study to identify factors associated with the high incidence of pediatric PBCNST in Kentucky. The proposal leverages the infrastructure provided by the KCR, its Virtual Tissue Repository and the NIH Kids First Data Resource Center (DRC, led by Dr. Adam Resnick at the Children's Hospital of Philadelphia, who has agreed to provide tumor next generation sequencing services at no cost to the project.) The specific aims of the study are: 1) to identify potential environmental exposures associated with Kentucky's high rates; 2) to assess whether Kentucky-specific mutations and mutational signatures exist that may be related to PBCNST, and to determine whether known genetic risk factors for PBCNST are present among Kentucky children; and 3) implement informatics infrastructures for data sharing with national PBCNST consortia. KCR's was one of five proposals that were awarded funding in a proclamation signed by Kentucky's Governor Matt Bevin on September 19, 2018.

SUSTAINING SUCCESS: This success story highlights the importance of utilizing registry data and working closely with stakeholders, decision-makers and the research community to affect change in the population. We view this as a first step towards addressing Kentucky's high pediatric cancer incidence rates. As a result of these efforts, our collaborators in the private sector, legislature and research community are more aware of the burden and challenges of pediatric and young adult cancers in the state. Kentucky's Cancer Action Plan has also been enhanced to include measurable objectives related to childhood cancer survivorship and cancer treatment at the most qualified facilities in the state. KCR will continue to utilize NPCR and ECC data, along with data from this important research study as evidence for the benefit of research to address the state's childhood cancer burden.

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