

# Participation in Pediatric and Young Adult Cancer Early Case Capture Program Leads to Investments in Cancer Resources in Kentucky

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## SUMMARY

Participation in the National Program of Cancer Registries' (NPCR's) pediatric and young adult cancer (PYAC) Early Case Capture Program led to the publication of an annual report of childhood cancer incidence in Kentucky. The report has been instrumental in securing recurring investments in PYAC resources in Kentucky.

## CHALLENGE

Due to the rarity of childhood cancer (fewer than 2% of all cancers), resources for surveillance and research are limited compared to adult cancers. But cancer is severely burdensome for children and their families, including side effects from treatment and lifelong economic and social costs. One out of six children diagnosed with cancer in the U.S. will not survive 5 years. Childhood cancer incidence rates are significantly higher in Kentucky and Appalachian Kentucky. Innovative approaches can inform policy makers and interest holders to bolster investments in surveillance and research.

## SOLUTION

The Kentucky Cancer Registry (KCR) started participating in the NPCR PYAC Early Case Capture Program in 2011. Participation led KCR to develop an annual report on childhood cancer in Kentucky. The report includes data tables and graphics by sex, age, and International Classification of Childhood Cancer site groups. To help deal with the small number of cases and unstable rates, data tables present 10 years of statewide data. Age-adjusted rates are generated by site group, sex, diagnosis year, and geographic regions. The annual incidence trends for all sites are also presented. Incidence rate comparisons are made between Kentucky, Appalachian Kentucky, the United States (U.S.), and other U.S. states. An annual publication is printed and also placed on the KCR website for wide dissemination.

## RESULTS

The publications have been well received by public health professionals, childhood cancer advocates, and government authorities. Organizations have referenced the data during annual Childhood Cancer Advocacy Day visits in Kentucky. The Kentucky legislature has appropriated \$36.5 million to childhood cancer research (2018 to 2026). Managed by the Kentucky Pediatric Cancer Research Trust Fund, this funding has supported 53 studies in basic science, clinical research, epidemiology, psychosocial support, a statewide pediatric molecular tumor board, and a statewide germline screening program. Also, an ongoing investigation into the high rates of brain and central nervous system tumors in Kentucky and Appalachia led to the establishment of a regional data sharing consortium.

## CONCLUDING REMARKS

The NPCR PYAC program led to publication of the statewide PYAC cancer burden report in Kentucky. This is an important first step toward identifying potential disparities and prioritizing evidence-based research objectives. Due to the rarity of the disease, the calculation of stable rates by cancer type, sex, race, and sub-regions must include multiple years of incidence data. Our approach for increasing childhood cancer awareness could be used to inform childhood cancer surveillance and research efforts in other states.



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