Overview and Importance of the Kentucky Pediatric Cancer Research Trust Fund

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Budget Review Subcommittee - Health & Family Services

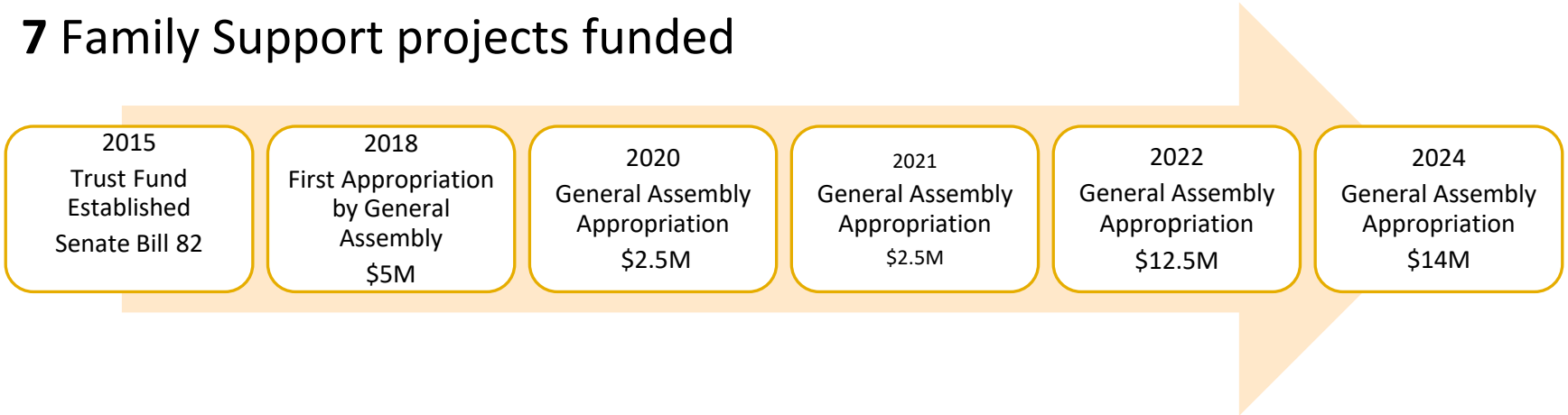
Wednesday, November 5, 2025

KPCRTF Timeline

The KPCRTF was established in 2015 by Senate Bill 82 and sponsored by Senator Max Wise (father of neuroblastoma survivor). This fund is the product of collaborative grassroots advocacy work of many Kentuckians. Kentucky serves as a national model for other states, replicating our success.

The KPCRTF is an independent board administered by the Kentucky Cabinet for Health and Family Services per statute KRS 211.595, KRS 211.596 and KRS 211.597

- Meets approximately four times yearly to review grant applications and progress reports
- **63** Research projects funded including Psychosocial projects
- **7** Family Support projects funded



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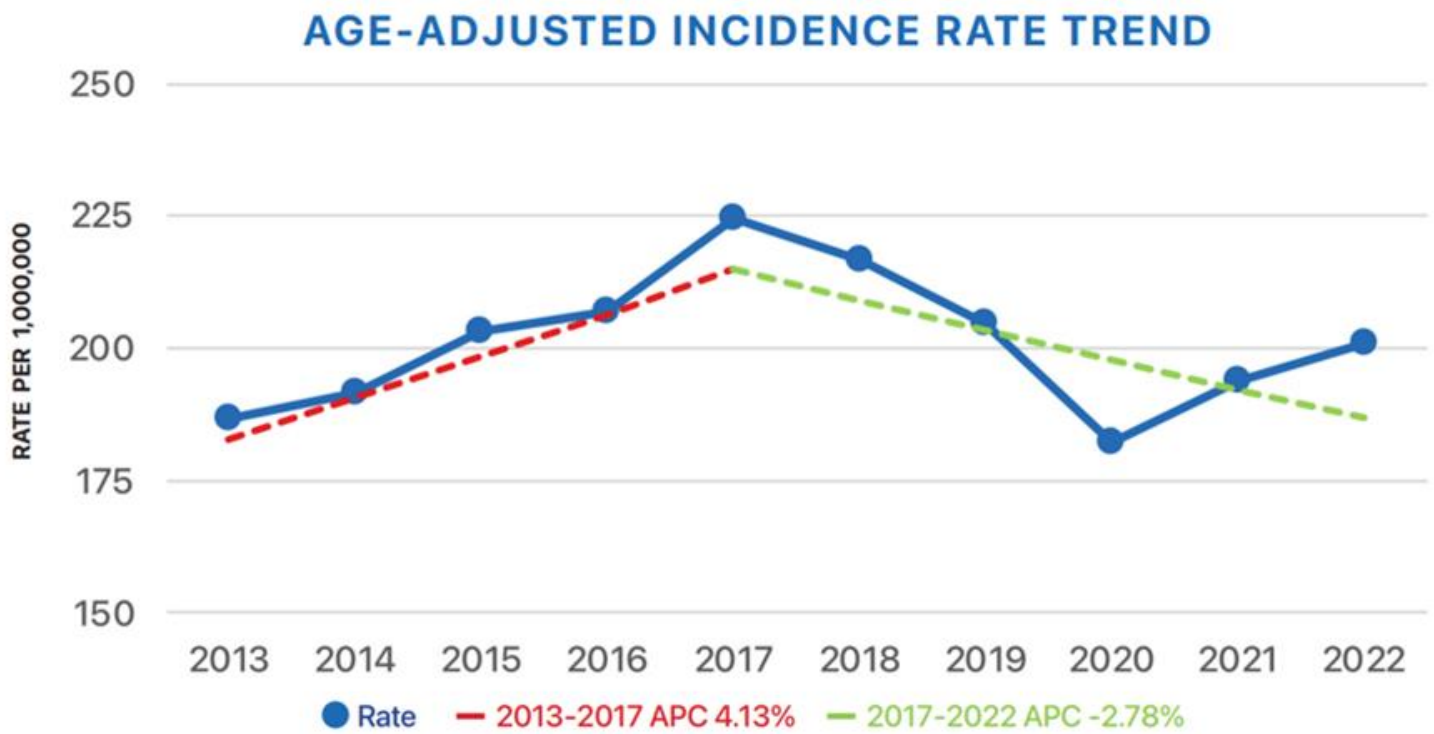
Kentucky Statistics



The age-adjusted incidence rates of childhood cancer in Kentucky increased with a 4.13% annual percent change (APC) from 2013 through 2017 and then decreased by 2.78% annually through 2022. The trend lines shown in the figure and the APC rates are based on the results from the JoinPoint Trend Analysis software package developed by NCI SEER.
https://surveillance.cancer.gov/joinpoint

- 2,775 children and adolescents were diagnosed with cancer in Kentucky (2013-2022).
- Kentucky children have the 5th highest cancer incidence rate compared to other states.
- Pediatric cancer rates are higher in Kentucky than the the overall United States in ten out of eleven major cancer types.
- Brain tumors have recently overtaken leukemia as the most lethal childhood cancer.

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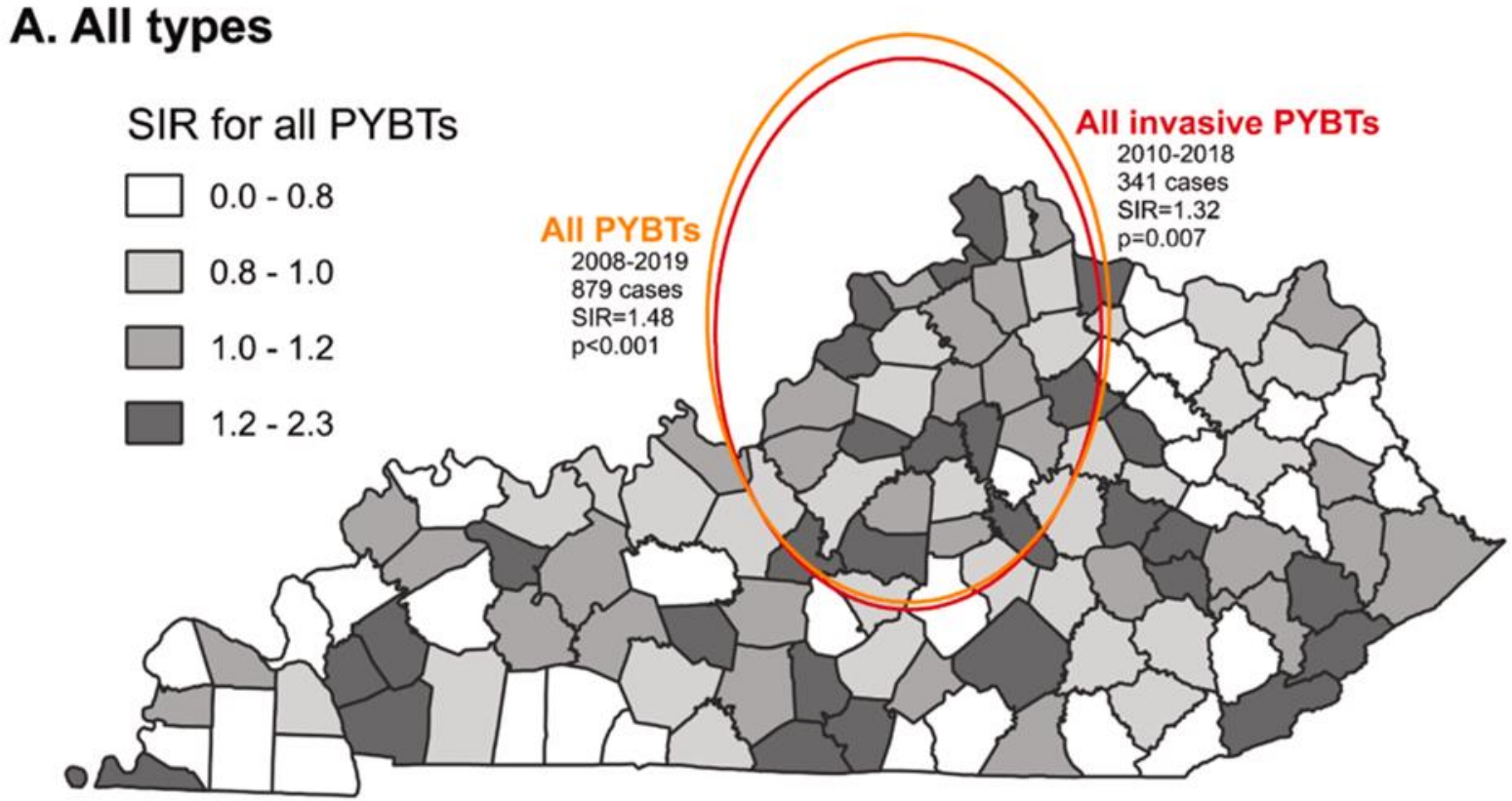
CANCER REGISTRY

Clusters of Pediatric, Adolescent, and Young Adult Brain Tumors (Ages 0-29)



Standardized incidence ratios (1995-2019), and significant high rate-clusters.

Christian, W. J., Walker, C. J., McDowell, J., Huang, B., Tucker, T. C., Villano, J., & Durbin, E. B. (2024). Geographic and temporal trends in pediatric and young adult brain tumors in Kentucky, 1995–2019. Cancer Epidemiology, 88, 102499.

Project Inherited Cancer Risk
A Statewide Program

Drs. John D'Orazio (UK) and Michael Ferguson (UL)

- Clinical study of children and young people with genetically increased risk of cancer
  - Next-gen focused exome sequencing of more than 120 cancer-relevant genes
- Results reviewed by the Pediatric Germline Molecular Tumor Board
- Positive results identifies the need for cascade testing of affected family members:
  - Including cancer-preventive actions and early detection of asymptomatic tumors
- More than **260** patients enrolled to date
  - **8%** positive exome sequencing results

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Trauma-Informed Procedural Pain Intervention

Drs. Lauren Hayes (UL) and Meghan Marsac (UK)

- **Poorly managed pain** can lead to high levels of **traumatic stress**, greater functional **impairment**, and **poorer quality of life** for children with cancer.

- Developed an **evidence-based psychological intervention** to mitigate adverse outcomes by supporting children in coping with painful procedures.

- **Multi-site clinical trial** to test the effectiveness of TIPPI is in progress.
  - **30 patients** enrolled in the trial to date.

- **Broadening the scientific knowledge base** regarding pediatric cancer pain management and translation of evidence-based care in clinical practice.

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Return on Investment

- Federal Grants totaling **$4,000,000** awarded to Kentucky
- First Good Manufacturing Practices (GMP) pharmaceutical facility
  - Clinical grade novel CAR-T immunotherapy produced
- Multi-centered national Medulloblastoma Phase 1 trial
- Top talent fund to attract leading childhood cancer researchers and providers
- Prioritization of Psychosocial research projects
- Monetization included in a grant award contracts
- Funded projects resulted in **111** presentations and publications
  - **63** Presentations
  - **30** Publications
  - **18** Research publications

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KPCRTF ASK:

Cancer remains the leading cause of death by disease in children. Kentucky children are diagnosed at a disproportionately higher rate than other states, prioritization of childhood cancer research warrants continued expansion.

We are requesting an increase to **$15 million** over the next two years, **$7.5 million** each year, to build on current project momentum, expand transformative research and support new initiatives.

More than 47 application totaling $21 million have been received for the next budget cycle.

Thank you for your thoughtful consideration in supporting the KPCRTF and being a national leader in state support of childhood cancer research.

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