



Overview and Importance of the Kentucky Pediatric Cancer Research Trust Fund

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Interim Joint Committee on Families and Children Committee Meeting

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KENTUCKY

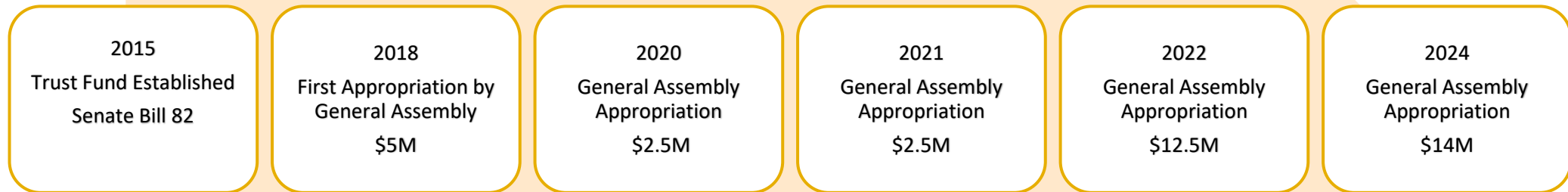
PEDIATRIC CANCER RESEARCH TRUST FUND

Kentucky Pediatric Cancer Research Trust Fund (KPCRTF)

- The KPCRTF was established in 2015 by Senate Bill 82 and sponsored by Senator Max Wise (father of a neuroblastoma survivor). This fund is the product of a collaborative and grassroots effort that has become successful because of the work & advocacy of many Kentuckians

KPCRTF Timeline

- Independent board administered by the Kentucky Cabinet for Health and Family Services per statute KRS 211.596 and KRS 211.597
 - Meets approximately four times yearly to review grant applications and progress reports
 - 44 Research projects funded including Psychosocial projects



KPCRTF Mission

- To make childhood cancer a state health priority that provides all Kentucky children access to innovative cancer research, development, and precision treatments — with less toxicity — while encouraging psychosocial support to navigate complex issues throughout the trajectory of care, including long-term survivorship.



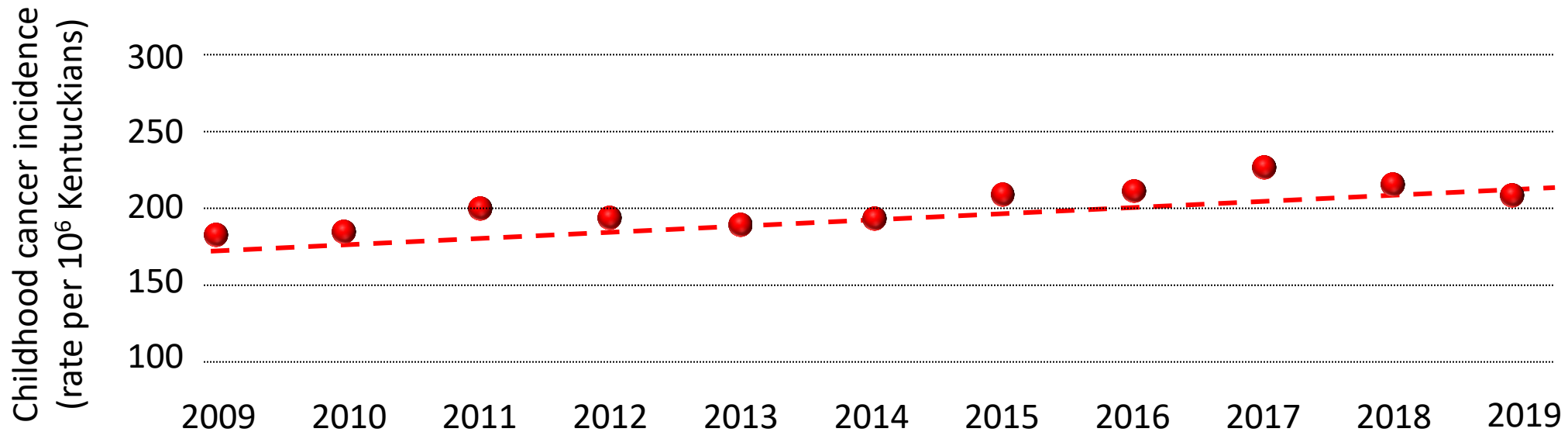
US Statistics

- Cancer is the leading cause of death by disease in children
- Each day, 47 children are diagnosed with cancer in the United States,
 - >17,000 US children are diagnosed each year
- > 80% of children diagnosed with cancer are alive at least five years after diagnosis
- Many pediatric cancer survivors have chronic health conditions and long-term side effects



Kentucky Statistics

- Almost 2,300 children and adolescents were diagnosed with cancer in Kentucky (2010-2019)



- 4th in the Nation for Pediatric Brain Tumors

KPCRTF Projects

- 44 Research and Clinical Care projects funded
- Investigators from the University of Kentucky and the University of Louisville
- Projects include many kinds of research
 - Basic (bench)
 - Translational
 - Clinical
 - Psychosocial
- Research on brain tumors, leukemias, solid tumors, and therapy side effects
- New collaborations between UK and UL



Four projects to highlight



Project Inherited Cancer Risk (D'Orazio, UK)

- About 10 percent of children who get cancer have a genetic mutation that explains their cancer
- Important to identify them because they could be at risk of further cancers, their treatment may need to be changed, and there could be other family members at risk
- “Project Inherited Cancer Risk” – clinical study to identify and manage children with increased cancer risk
- Open at the University of Kentucky since 8/21, expanding to University of Louisville
- > 200 patients tested with genetic findings that have impacted the children and their families

Childhood Brain Tumors in Kentucky (Durbin, UK)

- Dr. Eric Durbin (UK) and his team are taking a multi-faceted approach to try and figure out why
- ACCELERATE Consortium: UK, UL, WVU, UPenn
- Infrastructure has been successfully developed at UKY/KCR to acquire, harmonize, and integrate data
- Next generation sequencing (NGS) data linked with Kentucky Cancer Registry
- Link NGS reports with available clinical information for investigation.

DFMO for Brain tumors (Huang, UL)

- Phase II Trial of DFMO as therapy for Medulloblastoma
- Trial is now open at 17 different children's hospitals and academic centers throughout the country
- 23 patients have been enrolled
- Goal – test whether DFMO is effective effective in preventing relapse or further disease progression in medulloblastoma patients with high risk molecular features



Psychosocial Roadmap (Moorman, UL)

- Goal – provide comprehensive psychosocial support for patients and families
- Integration with the electronic health record (EHR)
 - psychosocial summary snapshot for teams to better inform care
 - documents support, resources, and services provided
 - improves care coordination and access to services across the entire trajectory of care
- Illustrates Kentucky’s prioritization of the whole person/patient, and their families
- Return on investment:
 - Led to 3 projects and five additional psychosocial providers/researchers
 - Puts Kentucky “on the map” for leading initiatives in psychosocial efforts, too
 - Multiple national presentations have highlighted this and other KPCRTF psychosocial efforts





Return on Investment

- Development of revised Childhood Cancer Action Plan – October 2024 release
- New treatments available to children in Kentucky
 - CAR-T therapy, Multicenter Phase 1 trial for Medulloblastoma (Mikey)
- 2023 Kentucky Pediatric Cancer Conference
 - Highlights
 - Tissue Donation now available for families at UK and UL/Norton Children's
 - Gift From a Child
- Leading the Nation
 - New Jersey passed Childhood Cancer legislation in 2021, modeled after KY
 - Participated in White House Cancer Moonshot meeting on 9/20/24

KPCRTF – Future Directions

- Make a positive impact for children and young adults with cancer in Kentucky through research, discovery and enhanced clinical care.
- Build collaboration and interaction between Norton Children’s and Kentucky Children’s Hospitals to develop statewide expertise.
- Serve as a national model for how other states approach childhood cancer research.





On behalf of the Kentucky children and families affected by pediatric cancer

Thank you!

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