



**Kentucky Public Health**

Prevent. Promote. Protect.

## MEETING MINUTES

**Meeting Name: Pediatric Cancer Research Trust Fund Board**

**Meeting Location: DPH Commissioner's Conference Room, Frankfort, Kentucky**

**Meeting Date & Time: July 23, 2019; 9:00 a.m.**

**Present:**

- *Jessica Blackburn, University of Kentucky*
- *Jamie E. Bloyd, MPA, Pediatric Cancer Survivor Parent Representative*
- *John D'Orazio, MD, UK Children's Hospital Representative*
- *Eric Durbin, Kentucky Cancer Registry*
- *Robert Emmons, University of Louisville*
- *Michael Huang, University of Louisville*
- *Markos Leggas, University of Kentucky*
- *Janet C. Luttrell, KDPH, Chronic Disease Prevention Branch*
- *Devon McFadden, KDPH, Division of Prevention & Quality Improvement*
- *Brad Nunn, Leukemia & Lymphoma Society Representative*
- *Ashok Raj, MD, Norton Children's Cancer Institute Representative*
- *Heather Shaw, Survivor/Parent Representative*
- *William T. Tse, MD, Norton Children's Cancer Institute*

**Welcome and Introductions:**

- Jamie Bloyd welcomed everyone in attendance and called the meeting to order.

*Action Items: None*

**Previous Meeting Minutes:**

- The April meeting minutes were emailed to board members in advance of the April meeting for review.
- Dr. John D'Orazio moved that the minutes be approved and Dr. Ashok Raj seconded the motion. The minutes were approved by the board as written.

*Action Items: None*

**New Business:**

- Discussion of Projects for Next Biennium
  - Jamie Bloyd led a discussion about the vision of the PCRTF board regarding projects for the FY21/22 biennium.
  - The board expressed that they hope the process improves as we go along but also need to be flexible.
  - Each university discussed what projects considering submitting for funding.
  - Drs. Raj and D'Orazio gave a summary of how proceeding at their university.

- FY21/22 Applications
  - It was decided to extend the deadline for applications to September 9, 2019.
  - Only one application has been received as of July 23, 2019.
  - Dr. Michael Huang suggested having a set deadline each cycle for conformity.
- 2020 Legislative Session
  - Jamie and Janet met with CHFS personnel about what to include in the proposed legislation.
  - Legislation will ask for a change in board membership to include:
    - Representative from Kentucky Cancer Registry
    - Representative from Dance Blue
    - Representative from Raise Red
    - Two representatives from school interventionists
    - Two representatives of Psychosocial social workers
    - Two other representatives that are "doers"
  - Include in legislation update staggered terms; suggested language was provided by LRC as well as CHFS
  - Jamie will share draft legislation
  - Plan to ask for \$7.5 million.
- Childhood Cancer Awareness Month
  - Had a photo shoot with Patrick McSweeney and he is going with Jamie to Washington, DC.
  - Dr. D'Orazio will ask about employees who could help with advocacy.
  - Spencer Moorman and Dr. D'Orazio will locate families stories to share and connect to public relations department.
  - Jamie reported that a proclamation is being developed for Childhood Cancer Awareness Month.
  - Drs. Leggas and Rohr will help co-author an OpEd piece.
- President's Childhood Cancer Symposium
  - Jamie reported involvement and frequent meetings in Washington, DC regarding the President's new Childhood Cancer Data Initiative which calls for \$500 million in new funding in the National Cancer Institute.
  - Dr. Durbin and Jamie were invited to the President's CCDI Symposium to present a poster presentation on leveraging data infrastructure and the high incidence of pediatric brain tumors in certain areas of Kentucky as part of the Kentucky Pediatric Cancer Research Trust Fund. Dr. Durbin reported that it has been a challenge to put together the data for the Childhood Cancer Data Initiative.

*Action Items:*

- *Jamie will share with board members the draft of the proposed legislation.*
- *Dr. D'Orazio will ask about employees who could help with advocacy.*
- *Spencer Moorman and Dr. D'Orazio will locate families stories to share and connect to public relations department.*

**Old Business:**

- Board Reappointments
  - Janet reported that all board reappointments have been processed and are in the approval process.
- 2018 and 2019 Annual Report Update
  - Janet Luttrell reported that the 2018 annual report has been approved and submitted to the Governor and legislature. A copy is provided in board members packets.
  - The 2019 annual report is currently being developed.
- Contributions/Funding Report
  - Janet provided in board members packets a short report showing fiscal years 2018, 2019 and 2020 expenses, revenues, and balances to date.

*Action Items: None*

**Other Business/Updates:**

- Grantees provided the board members with reports on each of their projects. Copies of their presentations are attached to these minutes.

*Action Items: None*

**Next Meeting Date**

- The next board meeting is scheduled for September 10, 2019 at 10 a.m. at the Capital Annex Room 125, Frankfort, Kentucky with a 1 pm Appropriations and Revenue Committee Meeting with room to be determined.