



## Kentucky Public Health

Prevent. Promote. Protect.

# MEETING MINUTES

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

**Meeting Location: Novak Center for Children, 411 East Chestnut Street, 8<sup>th</sup> Floor, Louisville, Kentucky**

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

**Present:**

- *Salvatore Bertolone, MD, UL Retired*
- *Jamie E. Bloyd, MPA, Pediatric Cancer Survivor Parent Representative*
- *Kim Boland, MD, UL Department of Pediatrics*
- *John D’Orazio, MD, UK Children’s Hospital Representative*
- *Thomas Hogan, RaiseRED*
- *Kay Howard, UL Department of Pediatrics*
- *Shawn Jones, Nate’s Wish*
- *Gil Liu, MD, CHFS Secretary Representative Proxy*
- *Janet C. Luttrell, KDPH, Chronic Disease Prevention Branch*
- *Reagan Miller, RaiseRED*
- *Joanna Mroczkowska, PH.D., UL Pediatric/Hematology and Oncology*
- *Spencer Moorman, Norton Children’s Hospital*
- *Brad Nunn, Leukemia & Lymphoma Society Representative*
- *Jino Park, UL Student*
- *Ashok Raj, MD, Norton Children’s Cancer Institute Representative*
- *Ethan Sammons, RaiseRED*
- *Heather Shaw, Survivor/Parent Representative*
- *Nico Thom, RaiseRED*
- *William T. Tse, MD, Norton Children’s Cancer Institute*
- *William W. Tse, MD, UL Brown Cancer Center*
- *Nicholas Yikes, RaiseRED*
- *Kristy Young, American Cancer Society Representative Proxy*

**Welcome and Introductions:**

- Jamie Bloyd welcomed everyone in attendance and called the meeting to order.
- Jamie introduced Kristy Young who is representing the American Cancer Society in place of Erica Palmer Smith.

*Action Items: None*

## Previous Meeting Minutes:

- The January 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 Brad Nunn seconded the motion. The minutes were approved by the board as written.

*Action Items: None*

## New Business:

- University of Louisville Introduction
  - Kim Boland thanked everyone for coming and everyone for what they do for children with cancer.
- James Graham Brown Cancer Center Update
  - Dr. Jason Chesney explained the direction of the James Graham Brown Cancer Center in childhood cancer research. They are currently trying to come up with approaches to become a hub for offering patients access to novel immunotherapies. The next phase of their plans includes ways to stimulate immune system with CAR-T cells. They currently need to build out their GMP (good manufacturing practices) facility (clean room). They plan to convert one into CAR-T cell laboratory. They are committed to making this work. Dr. Chesney expressed that this project would not happen without the support of the PCRTF funding.
- Update of RaiseRED
  - William Lampe explained that RaiseRED just finished their 2018/2019 season. They raised more than \$680,000 with 974 participants. They are currently transitioning to a completely new board for 2019/2020. Fifty percent of funds raised are used for research and 50% for clinic needs such as gas cards and parking cards.
  - Spencer Moorman thanked and praised the workers of RaiseRED.
  - Dr. Raj praised Spencer Moorman for the work she does.
  - Dr. Liu challenged the RaiseRED workers to step up to a higher level by also participating in the PCRTF advocacy day scheduled for February 20, 2020.
- Nate's Wish
  - Dr. Shawn Jones provided the history behind Nate's Wish.
  - Nate's Wish is a 501(c)(3) charitable organization founded by Jeff and Stacy Richard in honor of their five year old son, Nate, who died of ALL.
  - A children's book with Nate's story has been written and is given to children with cancer along with a teddy, blanket, pillowcase, books, water jug, all in a backpack.
  - This organization started at Vanderbilt University and was funded by a middle school basketball tournament in Paducah, Kentucky.
  - Shawn connected them to the University of Louisville two years ago where they distributed 90 backpacks.
  - They would like to expand to the University of Kentucky.
  - They will ship backpacks anywhere in the country.
- Election of 2019 President and Vice President
  - Jamie Boyd spoke to why she would like to continue on as president of the PCRTF Board. Brad Nunn said he would accept the position of Vice President if so elected.
  - Brad Nunn made a motion to elect Jamie Boyd as the 2019 board President. Dr. John D'Orazio seconded the motion. Motion was unanimously approved.
  - Jamie Boyd made a motion to elect Brad Nunn as the 2019 board Vice President. Dr. Ashok Raj seconded the motion. Motion was unanimously approved.
- Dream Projects for Next Biennium
  - Jamie Boyd explained that she would like to get suggestions from the board on projects for the next biennium.
  - Dr. D'Orazio suggested putting out a call asking for suggestions.
  - Dr. Liu suggested staying local and to be sure to focus on accountability. He loves the blend of different types of projects and emphasized the importance of having a diverse portfolio.

He also emphasized the importance of showing return on investment of state dollars and how we are able to use the funds to bring in additional funding and partnerships.

- Janet Luttrell stated that all current project directors need to keep in mind that we will need to show each projects progress in the FY19 annual report.
- Dr. Raj suggested that we need to harness all emerging technologies.
- Brad Nunn elaborated that the projects initial focus was on finding and funding projects to improve outcomes and reduce suffering of Kentucky kids battling cancer..
- Spencer Moorman suggested that we show the legislature a visual that moves them and to capitalize on the mark Kentucky is making nationally.
- Dr. Salvatore Bertolone suggested to make the following points the board keystone:
  - Young adults on pediatric protocols survive better than on adult protocols. Get agreement from UK and UL to make it a rule to use pediatric protocols for pediatric cancer patients 15 and over.
  - At a national level, develop regional protocols and financially “marry” with other researchers around the country.
- Jamie Bloyd suggested to increase the focus on surveillance
- Shawn Jones suggested keeping the message clear, concise and consistent. He would be glad to help with filing a resolution with the American Medical Association.
- Dr. Liu noted that grants acquired through pilot data, which are acquired through the PCRTF need to see additional funding based on Kentucky seed funds. Suggested hiring a professional writer for grant funding.
- FY 21/22 RFA
  - Janet Luttrell presented a draft of the FY21/22 Request for Applications that has received approval from the Department of Public Health. Board members received this draft ahead of the meeting to review and be prepared to comment. Dr. D’Orazio noted that a six week time frame to prepare a good grant application isn’t enough. It was suggested to change the deadline for application to the end of July. All agreed to this change.
  - Dr. Raj moved to approve the FY21/22 Request for Applications with deadline amendment to July 29, 2019. Dr. Liu seconded the motion. The motion was unanimously approved.
- Cincinnati Children’s Hospital Proton Radiation Facility Tour and Meeting – June 21
  - Jamie Bloyd announced that on June 21, 2019 board members are encouraged to join her for a tour of the Cincinnati Children’s Hospital Proton Radiation Facility. Northern Kentucky legislators are being invited to attend as well.
- 2020 Legislative Session
  - During the 2019 legislative session PCRTF combined forces with Kentucky Youth Advocates for advocacy day at the capital. PCRTF currently has February 20, 2020 reserved for next legislative session, but Kentucky Youth Advocates has reserved February 23. Jamie has also reserved the tunnel for the last week of session. Jamie posed the question to board members as to whether they want to combine forces with KYA again or have a stand alone PCRTF day. Members decided they would rather do both.
  - Dr. Bertolone suggested to bring childhood cancer survivors to the event and to testify and to start lining people up now.
  - Kristy Young noted that the American Cancer Society will be asking for funding for all cancers for the next biennium.
  - Jamie Bloyd suggested that UK and UL marketing could help get out stories.

*Action Items:*

- *Board members should email Jamie Bloyd and Janet Luttrell as to whether they will attend the June 21 tour of the Cincinnati Children’s Hospital Proton Radiation Facility.*
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**Old Business:**

- 2019 Legislative Session

- Janet noted that the amount of funding coming into the PCRTF through the check box has been dwindling. She also noted that she has been working on a flyer to use for distribution to help increase awareness.
- Jamie noted that she is looking into how to make donations through a link of the PCRTF webpage.
- Board Reappointments
  - Janet Luttrell reported that she has received all the necessary paperwork from board members and will now begin the approval process for reappointments.
- UL Research Project Updates
  - Dr. Raj presented the Eflornithing/DMFO Pilot Study update. Slides are attached.
  - Dr. William W. Tse presented the Acute Myeloid Leukemia update. Slides are attached.
  - Dr. William T. Tse presented the Neuroblastoma Brain Tumors update. Slides are attached.
- 2018 Annual Report Update
  - Janet Luttrell reported that the 2018 annual report has been reviewed by CHFS and asked for revisions which she is currently making and then will resubmit for approval.
  - Will begin 2019 annual report in June 2019 with goal to have approved by September 2019 to have ready for legislative session.
- Contributions/Funding Report
  - Janet Luttrell reported that all contracts have received approval and all projects have been given the go ahead to begin work.
  - Janet noted that during 2017 the check box brought in \$23,406, during 2018 \$20,419.93 and thus far for 2019 \$6,946.
  - We currently have \$74,083.48 in pending invoices. After paying these invoices PCRTF will have a balance of \$2,443,143.12.

*Action Items: None*

#### **Other Business/Updates:**

- Meeting attendees were taken on tours of the Cellular Therapy Research Lab, the GMP Facility, the Brown Cancer Center, the Novak Center for Children's Health and Norton Children's Hospital after the board meeting was adjourned.

*Action Items: None*

#### **Next Meeting Date**

- The Cincinnati's Children's Hospital Proton Radiation Facility Tour and Meeting is scheduled for June 21, 2019.
- The next board meeting is scheduled for July 22, 2019 at 10 a.m. at the Department for Public Health, Frankfort, Kentucky
- Dr. D'Orazio moved to adjourn the meeting at 10:30 a.m. Dr. Raj seconded the motion. The motion was unanimously approved.