

MEETING MINUTES

Meeting Name: Pediatric Cancer Research Trust Fund Board Meeting Location: DPH Commissioner's Conference Room, Frankfort, Kentucky Meeting Date & Time: December 2, 2019; 10:00 a.m. Present:

- Jamie E. Bloyd, MPA, Pediatric Cancer Survivor Parent Representative
- Jason Chesney, MD, Brown Cancer Center
- Angela Dearinger, MD, KDPH Commissioner
- Katie Anne Lester, Ronald McDonald House
- Janet C. Luttrell, KDPH, Chronic Disease Prevention Branch
- Devon McFadden, KDPH, Division of Prevention & Quality Improvement
- Spencer Moorman, University of Louisville
- Brad Nunn, Leukemia & Lymphoma Society Representative
- Jennifer Rogers, Markey Cancer Center
- Olivia Sievert, Proxy for Heather Shaw
- Tracey Sparks, KDPH, Chronic Disease Prevention Branch
- Daret St. Clair, MD, Proxy for John D'Orazio
- William St. Clair, MD, University of Kentucky
- Judy Theriot, MD, Proxy for CHFS Secretary
- William T. Tse. MD, Norton Children's Cancer Institute
- Connie Gayle White, MD, (Phone) KDPH Commissioner's Office
- Kristy Young, American Cancer Society

Welcome and Introductions:

• Jamie Bloyd welcomed everyone in attendance including new board members, Prayer was held and the meeting was called to order.

Action Items: None

Previous Meeting Minutes:

- The July meeting minutes were emailed to board members in advance of the December meeting for review.
- Dr. Daret St. Clair moved that the minutes be approved and Dr. Angela Dearinger seconded the motion. The minutes were approved by the board as written.

Action Items: None

New Business:

UK and UL's Vision for Pediatric Cancer Research in Kentucky

- Jennifer Rogers presented a short talk about UK's four current projects funded by PCRTF and how they plan to grow their vision of pediatric oncology research. The Powerpoint slides are attached to these minutes.
- Dr. Jason Chesney expressed UL's wish to become a national hub for pediatric cancer research, genetic testing and to treat Kentucky's children with cancer.
- 2020 Legislative Session
 - Child Advocacy Day will be held on January 23, 2020 at about noon
 - On March 16-20, 2020, the tunnel between the Capital Annex and Capital Building will feature the faces of children diagnosed with cancer.
 - PCRTF will have an advocacy day at the Capital on February 20, 2020.
 - Legislation is being introduced to update and expand the PCRTF board membership.
- Election of 2020 Officers
 - Jamie Bloyd was nominated by Brad Nunn to continue serving the PCRTF board as president.
 - Brad Nunn was nominated by Jamie Bloyd to continue serving the PCRTF board as vice president.
 - There were no other nominations.
 - Jamie Bloyd was elected as president and Brad Nunn was elected as vice president for 2020.
- Legal Opinions
 - Janet Luttrell reviewed with board members the two legal opinions that have been requested of CHFS.
 - Payment of stipend for physician reviewers of grant applications.
 - KRS 211.595(5) states that trust fund money "shall be used" for two purposes: (1) "to support pediatric cancer research and treatment for Kentucky patients," (2) "for the purpose directed in ... KRS 211.596 and 211.597." KRS 211.597(1) states that the Pediatric Cancer Research Trust Fund Board "shall (d) develop a written plan for the expenditure of trust funds..." This plan must include a "prioritized list of programs and research projects that the Board will address with funding available through the competitive grant program."
 - The Board needs subject matter experts to assist in developing a KRS 211.597 written funding plan and a prioritized funding list, due to its oncologists' conflicts of interest and lack of specialization. KRS 211.595 allocates funding for both of those purposes. Accordingly, the authorizing statutes allow funding for specialized experts and there is no reason to amend these statutes or the regulation.

Action Items:

None

Old Business:

- Financial Update
 - Janet Luttrell reported that a financial update was not available at this time due to a death in the family of KDPH staff person with this information.
- Discussion of FY 21/22 Grant applications
 - Jamie Bloyd explained that reviewers expressed the concern that there are twice as many grant applications this year as they reviewed previously.
 - Jamie suggested that during the meeting today board members will hear about each of the grant applications from UK and UL and then will narrow down the number of applications that will go to the Scientific Peer Review Panel (SPRP). She also suggested that specialists be asked to review those applications that require special consideration.
 - It was suggested that the board get a commitment from the SPRP for reviewing the next grant cycle applications.
 - UK and UL both agreed to help with the Request for Application re-write for FY 23/24.

- Each grant application from UK and UL were presented by the organization's representative and questions were answered.
- It was determined that:
 - Seven applications would go forward to the SPRP for review
 - UL CAR-T Cells Therapies
 - UK Molecular Tumor Board
 - UL DFMO Phase 2
 - UK MEDs
 - UL High Risk Pediatric Solid Tumors
 - UL Immuno Tumor Microenvironment
 - UK AML
 - Requests were made of four applications:
 - CSN Pediatric Brain Cancer Information/Resource Network
 - Are they willing to reduce funding amount to \$250,000 and if so please redo their proposal to reflect this reduction
 - UL GMP Facility
 - Are they willing to reduce funding amount to \$1,250,000 and if so to redo their proposal to reflect this reduction.
 - UL Psychosocial Roadmap
 - The board had some questions regarding this application and organization was asked to clarify their proposal.
 - UK Pediatric Brain and Central Nervous System
 - Are they willing to reduce funding amount to \$500,000 and if so to redo their proposal to reflect this reduction.
 - Five applications were eliminated from possible funding:
 - UL Pediatric Glioma
 - UK ALL
 - Nate's Wish in Kentucky
 - UK Genome-Wide DNA Arrays
 - UL Genetic Sequencing

Action Items:

- Janet Luttrell will send out emails to each applicant.
- Jamie Bloyd will work with SPRP.

Next Meeting Date

• The next board meeting is scheduled for January 7, 2020 at 10 a.m. at the KDPH Commissioner's Conference Room, 1st Floor KDPH Building, Frankfort, Kentucky.