

MEETING MINUTES

Meeting Name: Pediatric Cancer Research Trust Fund Board Meeting Location: UK Lee Todd (Biopharm) Building, Room 570CR, Lexington Meeting Date & Time: January 8, 2019; 9:00 a.m.

Present:

- Susanne Arnold, Markey Cancer Center
- Dr. Jessica Blackburn, UK
- Jamie E. Bloyd, MPA, Pediatric Cancer Survivor Parent Representative
- Allan Butterfield, Markey Cancer Center
- John D'Orazio, MD, UK Children's Hospital
- Dr. Eric Durbin, Kentucky Cancer Registry
- Courtney Emery, UK DanceBlue
- Mark Evers, MD, Markey Cancer Center
- Leigh Anne Fall, Markey Cancer Center
- Jill Kolesar, Markey Cancer Center
- Dr. Markos Leggas, UK
- Janet C. Luttrell, KDPH, Chronic Disease Prevention Branch
- Jake Maynard, Survivor
- Spencer Moorman, Norton Children's Hospital
- Jennifer Mynear, Dance Blue
- Erica Palmer-Smith, American Cancer Society Representative Proxy
- Ashok Raj, MD, Norton Children's Cancer Institute
- Dr. Jurgen Rohr, UK
- Dr. Daret St. Clair, UK
- Heather Shaw, Survivor/Parent
- Tracey Sparks, KDPH, Chronic Disease Prevention Branch
- William T. Tse. MD, Norton Children's Cancer Institute
- William W. Tse, MD, UL Brown Cancer Center
- Connie Gayle White, MD, KDPH,

Welcome and Introductions:

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

Action Items: None

Previous Meeting Minutes:

- The September meeting minutes were emailed to board members in advance of the January 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:

- 2019 Legislative Session
 - Jamie Bloyd discussed the board priority to get to know the new legislative members during the upcoming legislative session. February 13 is Pediatric Cancer Advocacy Day, which will be used to meet the legislators.
 - Erica Palmer-Smith discussed the American Cancer Society (ACS) focus areas for the session. February 21 is ACS Day at the Capitol.
 - Jamie Bloyd is working with the Cabinet for Health and Family Services staff and legislative officers to put together a campaign to highlight the pediatric cancer checkoff box.
- PCRTF Board Reappointments
 - Ms. Bloyd announced that all current board members appointments will expire on October 1, 2019. Anyone wishing to serve a second four-year term should complete an application. Those not wishing to serve again should notify Ms. Luttrell and Ms. Bloyd..
- Update on DanceBlue
 - Ms. Jennifer Mynear talked about DanceBlue, which is celebrating their 14th year. They have raised over \$11 million to share with the Markey Cancer Center. Their focus for the future will now be on research.
- Update on KY Childhood Cancer Report
 - Dr. Eric Durbin from the Kentucky Cancer Registry presented the first Kentucky Childhood
 Cancer Report for the years 2007 2016. This report looks at trends over time and reports
 on incidence and compares state rates to national rates. This report will go to print fairly
 soon and will be hand carried to Governor Bevin by Ms. Bloyd. Please send Dr. Durbin
 names of anyone who should receive a copy.

Action Items:

- Ms. Luttrell will email all board members the application for reappointment.
- All board members should send Dr. Durbin names of anyone who should receive a copy of the KY Childhood Cancer Report.

Old Business:

- NCI-designated Markey Cancer Center Highlight
 - Dr. Mark Evers talked about the Markey Cancer Center and their tremendous growth over the last several years. A big driver of this growth is their NCI designation which was initially awarded in 2013
 - According to US News and World Report, the Markey Cancer Center ranked #50 nationally in 2017 and moved up to #38 in 2018.
 - Kentucky ranks first in the nation in incidence rate for all cancers and first in the nation in overall cancer mortality rate. Kentucky also ranks #6 in childhood brain and central nervous system tumors at 40.1 and even higher in Appalachia at 42.5
 - Markey Cancer Center works with 41 other NCI Cancer Centers worldwide.
 - Their goal is to conquer cancer in the Commonwealth with a 50% reduction and to drop from #1 national in cancer mortality.
 - Markey Cancer Center aspires to be a comprehensive cancer center.
- UK Trust Funded Research Projects Update
 - Dr. Jurgen Rohr, Dr. Jessica Blackburn, Dr. Eric Durbin, and Dr. Daret St. Clair each updated the board about their funded projects.
 - Each Powerpoint presentation is attached to these minutes as Appendix A-D.
- 2018 Annual Report Update
- Ms. Bloyd reported that the 2018 annual report is in the final phase of being drafted and should start the approval process at CHFS in the next week.

- Contributions/Funding Report
 - Ms. Luttrell reported that during 2017 \$23,406 was donated to the check-off box. In 2018 \$20,529 was donated to the check-off box and \$2.5 million in state appropriations was added to the account. To date only \$109.07 has been spent of these funds to pay for the PCRTF logo.
 - A question was asked about the carryover of FY19 funding since contracts were not approved until halfway through the year. Ms. Luttrell check on this and reports that these funds do not expire and will be carried over from year to year.
 - Action Items: None

Other Business/Updates:

 Meeting attendees were taken on tours of the Metabolomics Facility, the Blackburn Lab/Zebrafish Facility, and the DanceBlue Pediatric Hematology/Oncology Clinic.

Action Items: None

Next Meeting Date

- The next board meeting is scheduled for April 23, 2019 at 9 a.m. at the University of Louisville, Louisville, Kentucky
- Dr. Raj and Drs. Tse will notify us with exact information.
- The meeting was adjourned at 11:30 a.m.