INTERIM JOINT COMMITTEE ON HEALTH AND WELFARE AND FAMILY SERVICES

Minutes of the Fourth Meeting of the 2018 Interim

September 19, 2018

Call to Order and Roll Call

The fourth meeting of the Interim Joint Committee on Health and Welfare and Family Services was held on Wednesday, September 19, 2018, at 10:00 a.m., in Room 129 of the Capitol Annex. Representative Addia Wuchner, Co-Chair, called the meeting to order at 10:08 a.m., and the secretary called the roll.

Present were:

Members: Representative Addia Wuchner, Co-Chair; Senators Ralph Alvarado, Tom Buford, Danny Carroll, Julian M. Carroll, David P. Givens, Denise Harper Angel, Stephen Meredith, Reginald Thomas, and Max Wise; Representatives Danny Bentley, Larry Brown, George Brown Jr, Daniel Elliott, Joni L. Jenkins, Mary Lou Marzian, Chad McCoy, Russ A. Meyer, Kimberly Poore Moser, Melinda Gibbons Prunty, Steve Riley, and Russell Webber.

Guest Legislators: Representative John Blanton.

Guests: Brandon J. Smith, Executive Director, Office of Legislative and Regulatory Affairs, Cabinet for Health and Family Services; Honorable Paul Sherlock, Retired Jefferson County Family Court Judge; Jaime Pittenger, MD, FAAP, Program Director, Pediatrics, Associate Clinical Professor, UK HealthCare, Department of Pediatrics; Scott Lengle, Lieutenant, Kentucky State Police; Steve Shannon, Executive Director, Kentucky Association of Regional Mental Health-Mental Retardation Programs; Elizabeth Caywood, Deputy Commissioner, Department for Community Based Services, Cabinet for Health and Family Services; Jill Seyfred, Executive Director, and Joel Griffith, Director of Programs and Prevention Services, Prevent Child Abuse Kentucky; Jamie Ennis Bloyd, MPA, President, Cancer Pediatric Research Trust Fund; Eric B. Durbin, DrPH, MS, Director of Cancer Informatics, Kentucky Cancer Registry; John D'Orazio, MD, PhD, Pediatric Hematology/Oncology, University of Kentucky, Kentucky Children's Hospital; Ashok Raj, MD, Chief of Pediatric Hematology/Oncology, Bone Marrow Transplant Unit, University of Louisville Norton Children's Hospital; Tommy Howard, parent; Steve Davis, Inspector General, and Stephanie Brammer-Barnes, Regulation Coordinator, Office of Inspector General, Cabinet for Health and Family Services, Beth Gamble, PhD, MSN, RN, CNE, Education Consultant, Kentucky Board of Nursing; Adam Meier, Secretary, Cabinet for Health and Family Services; Dawn Radcliff, RN, graduate student; Phyllis Sosa,

Jennifer Dudinskie, and Janet Hall, Department for Aging and Independent Living, Cabinet for Health and Family Services; Janet Luttrell, Department for Public Health, Cabinet for Health and Family Services; Amy Womack, Tami Delimpo, Elizabeth and David Turner; Thalia Peters, Kentucky Association of Sexual Assault Programs; Carol Steckel, Commissioner, David Gray, Director for Provider Relations, and Stephanie Bates, Department for Medicaid Services, Cabinet for Health and Family Services; and Terri Thomas, Harbor House.

LRC Staff: DeeAnn Wenk, Ben Payne, Dana Simmons, Gina Rigsby, and Becky Lancaster.

Approval of Minutes

A motion to approve the minutes of the August 15, 2018 minutes was made by Senator Buford, seconded by Senator Alvarado, and approved by voice vote.

Kentucky Pediatric Cancer Research Trust Fund

Jamie Ennis Bloyd, MPA, President, Kentucky Pediatric Cancer Research Trust Fund, thanked the General Assembly for the $5 million appropriation to the trust fund in the 2018-2020 biennial budget. Scientific peer reviewers have looked at proposals and decided how the appropriation would be spent. September is Childhood Cancer Month. A private donor has given a $6 million donation for other projects to run concurrently with the projects at the University of Kentucky and the University of Louisville.

Eric B. Durbin, DrPH, MS, Director of Cancer Informatics, Kentucky Cancer Registry, stated that Kentucky Cancer Registry data from 2007 to 2016 showed that over 2,000 children have been diagnosed with cancer in Kentucky. Cancer occurs 54 percent in males and 46 percent in females. The most frequently occurring types of cancer are leukemia, brain and central nervous system (CNS), lymphomas, and other epithelial neoplasms. Incidences of cancer among males and females has risen approximately 18.6 percent. The increase in cases has risen in Kentucky and throughout the United States. Childhood cancer occurs more frequently in Eastern Appalachian regions of Kentucky, however there are no statistically significant differences across Kentucky's 15 area development districts (ADDs) or comparing Appalachian to non-Appalachian Kentucky. The rates for brain and CNS tumors is higher in the Appalachian area than in the United States. From 2005 to 2014, Kentucky was ranked 22nd nationally for cancer rates and is ranked 4th in brain and CNS tumors. The data for 2009 to 2013 show that survival rates for children with leukemia and brain and CNS tumors was significantly lower. The data also shows that brain and CNS tumors were the leading cause of death among all children in the United States.

John D'Orazio, MD, PhD, Pediatric Hematology/Oncology, University of Kentucky, Kentucky Children's Hospital, stated that data from the Kentucky Cancer Registry show that cancer is the major cause of death from disease in young people.

Approximately 2,500 children and teenagers in the United States die from cancer annually. Over 220 Kentucky children are diagnosed with cancer each year. From 2011 to 2015, over 1,091 Kentucky children were diagnosed with cancer. Children are diagnosed with leukemia, brain tumors, lymphomas, neuroblastoma, muscle, kidney, bone, eye, liver, and other types of cancer. One of the challenges of children that have leukemia is to understand who will relapse with or after completion of therapy. The Pediatric Cancer Research Trust Fund projects awarded to the University of Kentucky are to develop circulating tumor DNA as a prognostic biomarker in acute lymphoblastic leukemia (ALL), collect blood and spinal fluid from children with ALL before and after chemotherapy, to identify factors associated with high incidence of pediatric brain tumors in Kentucky, and to develop mithramycin derivatives as new drugs for the treatment of Ewing sarcoma, cancer of the bone with a now survival rate because of the lack of new therapies. The University of Kentucky has partnered with the Children's Hospital of Philadelphia to help leverage $1.25 million for the DNA sequencing.

Ashok Raj, MD, Chief of Pediatric Hematology/Oncology, Bone Marrow Transplant Unit, University of Louisville Norton Children's Hospital, stated that the most common childhood cancer in the United States is acute lymphoblastic leukemia with a 90 percent survival rate. More than two-thirds of children have more than one organ system affected. On March 29, 2018, the Food and Drug Administration (FDA) granted accelerated approval to blinatumomab (Blincyto, Amgen Inc.) for the treatment of adult and pediatric patients with B-cell precursor acute lymphoblastic leukemia (ALL) in first or second complete remission with minimal residual disease (MRD) greater than or equal to 0.1%. A chimeric antigen receptor (CAR) engineered T-cell is a patient's T-cell (a component of the immune system) that has been genetically modified to express a protein on its surface with the capability to bind to a target protein on another cell. Upon binding the target protein, the CAR protein will send a signal across the cell membrane to the interior of the T-cell to set in motion mechanisms to selectively kill the targeted cancer cell. Compound CAR T cells simultaneously target two leukemia markers and will eliminate highly resistant leukemia disease. Supercharged CAR T cells have a decoy protein that will prevent tumor cells from escaping elimination and will kill childhood neuroblastoma and brain tumors.

Senator Alvarado stated that patients who use CAR T therapy have an 83 percent complete resolution from their cancers.

External Child Fatality and Near Fatality Review Panel

Representative Wuchner stated that in 2012, the Governor issued an executive order to establish the External Child Fatality and Near Fatality Review Panel to help to determine why children were dying while in the care of the Commonwealth or in their own home. The panel was codified in statute in 2013.

Jaime Pittenger, MD, FAAP, Pediatric Hospitalist, Program Director, Pediatrics, Associate Clinical Professor, UK HealthCare, Department of Pediatrics, stated that the panel consists of physicians, Department for Community Based Services (DCBS) staff, Department for Public Health (DPH), medical examiners, court appointed special advocates (CASAs), and the Kentucky State Police. The panel's goal was to look at the issue in a multifaceted approach to improve the welfare for children. The panel reviews cases referred from the DCBS and DPH. If cases are referred from DCBS, the panel has access to the department's data collection system, SharePoint. If the cases are referred to the panel from DPH, staff from the Justice and Public Safety Cabinet uploads the information for the panel. The panel gets information from DCBS reports, legal reports, medical records, and any information pertaining to a case. The cases are divided between the panel's analysts and groups for panel discussion. The analyst summarizes each case and creates a timeline. Each group reviews a certain amount of cases and reports back to the full panel for in-depth, comprehensive discussions of each case to see how Kentucky can do better. Data is collected on family characteristics to see who the most vulnerable children are and then focus on preventative measures. The panel will make a determination in the case on what caused the fatality or near fatality of the child.

Child abuse happens in every county in Kentucky with children under the age of four years being the most vulnerable. In 2017, the panel findings include: 85 percent of the cases reviewed had a prior history with child protective services, 75 percent of all cases are potentially preventable, 41 percent of all cases of abusive head trauma (AHT) were found to be in the care of a substitute caregiver at the time of the incident, 39 percent of the fatalities reviewed wee cases of sudden unexplained death in infancy (SUDI), and 65 percent of the SUDI cases involved an impaired caregiver who shared a sleep surface with their baby and the baby died from suffocation or asphyxiation. Focus areas of prevention of the panel include safe sleep practice, plan of safe care at birth, drug testing caregivers at the time of an unexpected death, additional law enforcement training regarding child death scenes, education and standardization of reporting child deaths to the appropriate authorities by coroners, implementing hospital-based prevention education to the parents of all newborns, and encourage reporting by family members, neighbors, and professionals. Bruising in babies is not normal.

Honorable Paul Sherlock, Retired Chief Judge of Jefferson County Family Courts, stated that in 2009, Kentucky lead the nation in child-related deaths. The panel tries to identify and fix problems within the medical profession, the cabinet, the courts, and law enforcement that hinder the protection of Kentucky's children. The panel makes recommendations for system and process improvements to help prevent child fatalities and near fatalities that are due to abuse and neglect. An annual report is sent to the Governor, the Cabinet for Health and Family Services (CHFS), the Chief Justice of the Supreme Court, the Attorney General, and the Legislative Research Commission (LRC) to be distributed to the Interim Joint Committees on Health and Welfare and Family Services and Judiciary.

In response to questions by Senator Danny Carroll, Dr. Pittenger stated that the adolescent population is a difficult population to take care of, and if they think they are going to be reported for drug use, the likelihood of that person telling anyone lessens. Judge Sherlock stated that few of the cases of fatalities and near fatalities reviewed by the panel were ever heard in court. Jefferson County will begin a Family Drug Court in October. Parents who suffer from drug addiction need quick and efficient intervention and affordable treatment.

In response to questions by Representative Gibbons Prunty, Elizabeth Caywood, Deputy Commissioner, Department for Community Based Services, Cabinet for Health and Family Services, stated that she would send the committee the department's policy and practice guidelines for acceptance criteria for investigation of a report of abuse or neglect. The department has conducted extensive work in regard to safe plans of care for children born with neonatal exposure to substances. There has to be a risk for the child before the department accepts a report. If the mother is compliant to treatment, a plan of safe care is implemented.

In response to questions by Representative Moser, Dr. Pittenger stated that availability of services in the Kentucky Sobriety Treatment and Recovery Team (START) or Health Access Nurturing Development Services (HANDS) programs depends on where someone lives in Kentucky. The more difficult and challenging something is for new parents, the less likely they are to take advantage of the available resources. Judge Sherlock stated that START is an intensive, hands-on and accountable program. All research shows that parents who can keep a connection with their child while they are in drug treatment are more likely to be successful.

In response to questions by Senator Givens, Dr. Pittenger stated that one of the most important things that new parents need to hear at the hospital is about safe sleep practice. The panel has analytics on household characteristics and a history of criminal activity, substance abuse, domestic violence, or mental illness. Most of the cases reviewed by the panel have one or more high risk traits. Judge Sherlock stated that everyone needs to be aware that bruising in non-mobile infants is not normal. Do not leave a child with a non-biologically related person if that person has a history of violence or domestic violence. Senator Givens challenged everyone to start a conversation with a pregnant woman or new parents about safe sleep practices and quality caregivers and offer to help them find available resources that could make a difference in the life or death of a child.

Senator Thomas stated that the HANDS program is very successful and should be available across Kentucky.

In response to a question by Representative Bentley, Dr. Pittenger stated that the Kentucky All Schedule Prescription Electronic Reporting (KASPER) system is used in a

hospital before prescribing a patient medications. She was unsure if a parent's medical record that shows a drug abuse problem is linked to a child's record.

Panel members Scott Lengle, Lieutenant, Kentucky State Police, and Steve Shannon, Executive Director, Kentucky Association of Regional Mental Health-Mental Retardation Programs were available to answer questions.

Consideration of Referred Administrative Regulations

The following administrative regulations were on the agenda for consideration: **201 KAR 2:015** – establishes requirements for the continuing pharmacy education of registered pharmacists and requires all registered pharmacists holding a license issued by the board to participate in continuing pharmacy education as a means of renewal of their licenses; **910 KAR 1:090** – establishes the Personal Care Attendant Program; **910 KAR 2:030** – establishes accounting provisions for adult guardianship; **910 KAR 2:052** – repeals 910 KAR 2:050, which unnecessarily restricts the cabinet from collecting fees for services pursuant to KRS 387.760(2); **921 KAR 1:380** – specifies the process by which an individual may apply for child support services, the scope of services available, and the process for an intergovernmental case; and **921 KAR 3:030** – establishes the application and the voter registration processes used by the cabinet in the administration of the Supplemental Nutrition Assistance Program (SNAP). A motion to accept the administrative regulations was made by Senator Buford, seconded by Representative Elliott, and accepted by voice vote.

Introduction of New Cabinet for Health and Family Services Staff

Brandon J. Smith, Executive Director, Office of Legislative and Regulatory Affairs, Cabinet for Health and Family Services, introduced Carol Steckel the new Commissioner of the Department for Medicaid Services, and David Gray, the new Director of Provider Relations, Department for Medicaid Services.

Prevent Child Abuse Kentucky

Jill Seyfred, Executive Director, and Joel Griffith, Director of Programs and Prevention Services, Prevent Child Abuse Kentucky (PCAK), stated that organization's vision is to engage partners to utilize PCAK to end child maltreatment. PCAK's mission is to prevent the abuse and neglect of Kentucky's children. According to the 2018 annual report by the United States Department of Health and Human Services, Kentucky was ranked third in the nation per capita rate of child maltreatment. In 2017, 23,827 children were confirmed victims of child maltreatment with substance abuse and family violence the top risk factors. The average lifetime cost for each confirmed victim in Kentucky is $210,012. PCAK and its partners have services available in all 120 counties in Kentucky. PCAK hosts an annual Kids Are Worth It!® statewide multidisciplinary conference that focuses on child abuse and neglect prevention and intervention.

PCAK has served as the sole source provider of parent education, self-help, and support services offered throughout the state for more than 20 years. There is at least one provider in ever DCBS region. From 2014 to 2016, funded providers served approximately 41,000 participants. Referrals from DCBS account for more than 60 percent of the referrals to parenting education classes across the state. Referrals are made to assist families in the prevention of child abuse and neglect or because of safety concerns identified by the various referral sources. These families may be at risk of having children removed from the home or have already had their children placed outside the home. Most parents want to be able to take care of their child even though some have problems.

All providers are required to screen participants for substance abuse issues. In addition to teaching the nurturing parenting curriculum, providers make referrals to outside agencies to meet the needs of their clients. Service providers are trained to assure services are delivered in a respectful and supportive manner. The Adult-Adolescent Parenting Inventory (AAPI) measures a parent's skill level and strengths. The AAPI measures expectations, empathy, use of corporal punishment, parent-child roles, and supportiveness of a child's independence associated with child abuse and neglect. PCAK currently offers 17 different trainings that can be altered to meet the needs of a specific agency.

In 2010, the General Assembly enacted HB 285 that addressed prevention of pediatric abusive head trauma (PAHT). Since the legislation was enacted, PACK has trained over 4,000 social workers, child care staff, and other professionals in face-to-face trainings. Other professionals have received on-line training. PCAK's goal and the intent of HB 285 is to help professionals recognize the signs of PAHT, to help parents understand the dangers of shaking a child, and given parents alternatives to lashing out in response to an inconsolable crying child. PCAK has partnered with the Kentucky Hospital Association, Norton Children's Hospital Prevention and Wellness program, and others to assure that resources and information is provided consistently to the parents of newborns at every Kentucky hospital.

In response to a question by Representative George Brown, Mr. Griffith stated that parenting discipline styles range from permissive to overly harsh. PCAK teaches parents that not all kids respond the same to the same type of discipline. Children thrive in structured environments with expectations and discipline. The goal is to teach parents the difference between discipline and abuse. Representative Brown stated that children need to be taught respect.

In response to a question by Representative Jenkins, Director Seyfred stated that PCAK was aware of the baby box program that some states and some other countries send home with a new mom that gives a safe sleeping alternative for the newborn, but did not know if Kentucky was close to implementing this program. Representative Jenkins said that parents are required to have a car seat to take their newborns home from the hospital, and said that a safe place to sleep should be required for every child.

Decubitus Ulcers

Representative John Blanton, House District 92, stated that in the United States, approximately 2.5 million patients a year will be diagnosed with pressure ulcers with almost 60,000 deaths and an estimated cost of almost $11 billion. Anyone across the medical spectrum is susceptible to pressure sores with some being fatal. It is vital to bring awareness to the issue and as a legislative body to explore every avenue available to find ways to prevent as many individuals as possible from developing bedsores.

Tommy Howard, stated that his 32-year old paraplegic daughter, Bridgette, was admitted to the hospital for a pancreatic attack and died nine days later on October 12, 2013 from complications of three bedsores, one stage 4. Having a bedsore is a horrible way for someone to die. If a facility knows it can be charged with a serious offense, it would follow protocol closer. The hospital where his daughter was staying was negligent with her care. When a patient cannot turn themselves, it only takes a few minutes for a bedsore to develop. His daughter Bridgette was paralyzed from her waist down and taken care of by her mother and never developed a bedsore until she went into the hospital. Stiffer laws and penalties are needed to help people who cannot help themselves.

Steve Davis, Inspector General, Office of Inspector General, Cabinet for Health and Family Services, stated that upon review of Bridgette's case, the OIG's surveyor found wound care and infection control deficiencies against the hospital. Surveyors spend three to four days on the road conducting inspections. They are not advocates for facilities or clients of facilities, and try to be fair and ethical. When a complaint is investigated, the surveyor looks at what type of protocol, and policies and procedures of the facility are in place, and apply federal and state licensure laws to the case. Healthcare is the most heavily regulated industry in the United States. State licensure laws regulate the facility standards. The cabinet has a contract with the Centers for Medicare and Medicaid Services (CMS) that designates the OIG as the state agency for conditions of participation. CMS has specific references in regulation for care and prevention of pressure ulcers. Avoidable pressure ulcers should not happen in a long-term care facility. With the state licensure process, the OIG has the ability to issue a Type A, imminent danger or substantial risk of death or serious mental or physical harm, or Type B, direct or immediate relationship that does not present a direct harm, citations. An administrative regulation was filed by the cabinet in September 2018 that recognizes that if a facility receives a pressure ulcer violation, either under state or federal law, it is now designated as a specific act that would warrant issuance of a Type A or Type B violation depending on how it is classified. CMS recently added language to the existing pressure ulcer laws that a facility has an obligation not just to prevent and treat pressure ulcers but to apply professional standards.

The OIG has developed a quality program that exists separate and apart from the enforcement program funded by the $32 million federal civil money penalty (CMP) imposed against skilled nursing facilities (SNFs), nursing facilities (NFs), and dually-

certified SNF/NF for either the number of days or for each instance a facility is not in substantial compliance with one or more Medicare and Medicaid participation requirements for long-term care facilities. The CMP funds will also fund an incentive program to help attract and retain staff in healthcare facilities. The OIG has partnered with the New Jersey Hospital Association and will use CMP funds to distribute a pocket guide on pressure ulcers to all healthcare providers who treat clients at risk of developing a pressure ulcer and every regional office. Surveyors will be trained on the information provided in the pocket guide.

The OIG is collecting data on all deficiencies to measure the quality of a surveyor. A telecommute model has been implemented, because the surveyors are conducting surveys in the field a large portion of the time.

Beth Gamble, PhD, MSN, RN, CNE, Education Consultant, Kentucky Board of Nursing, stated that any force of pressure to the skin compromises blood flow to the area, cuts off oxygen and nutrients causing cells to die. The risk factors of developing a bedsore are immobility or limited movement, numbness, elderly, children and premature babies, previously had pressure ulcers, medical conditions, cognitive deficiency, and poor nutrition. Pressure ulcers can develop anywhere, but tend to develop more in areas that have very thin skin that is not able to provide a cushion. A patient's clinical condition needs to be evaluated and the more risk factors a patient has, the more prone a patient is to develop a pressure ulcer. An evidence-based prevention program needs to be implemented. A patient needs to be evaluated when entering the facility, followed by thorough, comprehensive daily assessments of the skin. Turning and repositioning a patient is critical as are the use of pressure redistribution surface devices such as alternating mattresses, gels, and foams. An avoidable pressure ulcer is when a facility does not follow protocols. Not every pressure ulcer is unavoidable because of some acute illnesses that redistribute the blood flow to major organs of the body for survival. The end of life process makes a patient more susceptible to pressure ulcers because of physiological changes in the body.

Stephanie Brammer-Barnes, Regulation Coordinator, Office of Inspector General, Cabinet for Health and Family Services, was available for questions.

In response to a question by Senator Meredith, Inspector General Davis stated that he would talk to the commissioner for the Department for Medicaid Services to provide an answer to the committee as to why the state cannot increase the reimbursement rate to nursing homes by increasing the provider tax that the nursing home industry is willing to do.

There being no further business, the meeting was adjourned at 12:35 p.m.