

MINUTES OF THE HOUSE SOCIAL SERVICES BUDGET COMMITTEE

The meeting was called to order by Chairman Bob Bethell at 3:30 P.M. on March 13, 2007 in Room 514-S of the Capitol.

All members were present.

Committee staff present:

Susan Kannarr, Kansas Legislative Research Department
Amy VanHouse, Kansas Legislative Research Department
Kay Dick, Committee Assistant

Conferees appearing before the committee:

Dr. Howard Rodenberg, KDHE
Suzanne Wikle, Director of Health Policy, Kansas Action for Children
Dr. Dennis Cooley, KS Chapter of the American Academy of Pediatrics
Tonia & Michael Kroll
Kris Smith
Chad Austin, Vice Pres., Government Relation, Kansas Hospital Assoc.
Michelle Leeker
Cynthia Smith, Sisters of Charity of Leavenworth Health System
Candy Shively, Deputy Sec. For Integrated Service Delivery, SRS
Casey Spencer, Intern, TFI Family Service

Others attending:

See attached list.

Chairman Bethell introduced Guest Speaker, Stephen Moses, President of the Center for Long-Term Care Reform, Inc. Seattle Washington.

Hearing opened on HB 2224 - Department of health and environment, certain genetic diseases and disorders, education and screening, assistance.

Amy VanHouse, Kansas Legislative Research Department give briefing on **HB 2224** to the Committee. Explaining that this bills amends the law for newborn program, this would allow KDHE to adopt new rule and regulations no later than July 1, 2008. To require newborn screening test for various disorders.

Dr. Howard Rodenberg, KDHE, gave testimony in support of **HB 2224** stating that the Kansas program falls far short of the recommended national core panel. Only Arkansas and West Virginia screen for as few conditions as Kansas and Arkansas has just adopted legislation to advance their effort to meet the national norm. KDHE's goal is to insure that Kansas does not once again fall behind in screening it's newborns for time-critical conditions that, if promptly treated, can result in children leading normal, happy and healthy lives. (Attachment 1)

Chair recognized Suzanne Wikle, Director of Health Policy for Kansas Action for Children. Ms. Wikle gave testimony as a proponent on **HB 2224**. She stated that Kansas babies are currently screened for only 7 treatable conditions. National organizations, including the March of Dimes and the American College of Medical Genetics, recommend that states screen for the 29 treatable conditions that are now proposed in Kansas. (Attachment 2)

Dr Dennis Cooley. American Academy of Pediatrics spoke in support of **HB 2224**. He explains that identifying these relatively rare diseases are cost effective as evidenced of states with expanded programs. The conditions screened for are ones in which early intervention and treatment result in significant

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reduction of morbidity, mortality and associated disabilities. In other words, better medical outcomes which will result in cost savings. ([Attachment 3](#))

Tonia and Michael Kroll, parents of a child who nearly died shortly after birth, submitted testimony in support of **HB 2224**. They professed that passing this bill will save families from unimaginable trauma. They also emphasized that with the expansion, it would save babies from a completely unnecessary risk of death and disabilities. ([Attachment 4](#))

Shawn and Michelle Black testified as a proponent for **HB 2224**, in favor of expanding newborn screening. Mrs. Black talked of how it made such an impact on her when Dr. Hillman, a genetic specialist from the University of Columbia, MO, told them that if their son, Connor, had been born in Missouri, where they have expanded newborn testing, Connor could have avoided the brain damage with medical intervention. She stated that they were never given the option to complete the expanded testing at birth. Mrs. Black went on to say that the additional cost of expanded newborn screening is \$30 to \$50 per baby at birth compared to \$400,000 for one child later in childhood. ([Attachment 5](#))

Kris Smith provided testimony in support of **HB 2224**. She talked about her granddaughter, Alexis, who died at age 8 from a disease, that had she been test as a newborn, would be alive today. Mrs. Smith tells that it is at least 55 known disorders that can be detected through expanded screening. It is estimated that one child is born every 4 hours with one of the disorders. In some cities, like Kansas City, which side of the state line a child is born on can literally make a difference between life and death. ([Attachment 7](#))

Chad Austin, Vice President, Government Relations for Kansas Hospital Association, gave testimony as a proponent for **HB 2224**. KHA and its members believe that expanding the newborn screening program to the recommended 29 treatable conditions is an important public health issue. ([Attachment 8](#))

Chairman Bethell recognized Michelle Leeker, a parent who lost her child because he was not identified with a disorder that could have been treated with expanded newborn screening, rendered testimony in support of **HB 2224**. Ms. Leeker, as others, points out that bordering states have the expanded newborn screening and how many Kansas babies lives are at risk and may potentially be destroyed because they are born here in Kansas and not in a bordering state. ([Attachment 9](#))

Cynthia Smith , Sisters of Charity of Leavenworth Health System, spoke in support of **HB 2224**. ([Attachment 10](#))

The Chairman pointed out written only testimony in support of **HB 2224** from:

Kelly Peters, mother of Alexis Knapton ([Attachment 11](#))

Elizabeth Overman, mother, CARES Foundation ([Attachment 12](#))

Jennifer Arverson, RN, mother, CARES Foundation ([Attachment 13](#))

University of Kansas Hospital ([Attachment 14](#))

Kelly Leight, Exe. Director, CARES Foundation ([Attachment 15](#))

Greg Alejos, State Director, March of Dimes Greater Kansas Chapter ([Attachment 16](#))

The hearing on HB 2224 was closed.

Opened hearing on HB 2546 - Repealing sunset on Kansas foster child educational assistance act

Susan Kannarr briefed the Committee on **HB 2546**.

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Candy Shively, Deputy Secretary for Integrated Service Delivery for SRS, gave testimony in support of **HB 2546**. (Attachment 17)

Casey Spencer, Intern for TFI Family Service, under Dr. Steve Solomon, Director of Public Policy, provided testimony in support of **HB 2546**. She told that this bill not only would repeal the expiration date of the Educational Assistance Act, but it sends a message to these youth in foster care stating that they deserve a good education and a better life. (Attachment 18) Ms. Spencer brought attention to the Committee of the written testimony of Matthew Hudson. (Attachment 19)

Bruce Linho, Exe. Director of Children's Alliance of Kansas provided supportive written only testimony. (Attachment 20)

Diane Duffy, Vice-President, Finance & Administration for Kansas Board of Regents submitted written only testimony in support of **HB 2546**. (Attachment 21)

Chairman Bethell closed the hearing on HB 2546

Meeting was adjourned.