

LIMITED-SCOPE AUDIT PROPOSAL

Kansas Department of Health and Environment: Evaluating Issues Related to Department Services for Individuals with Phenylketonuria (PKU)

SOURCE

This audit proposal was requested by Representative Kyle Hoffman.

BACKGROUND

K.S.A. 65-180 requires the Kansas Department of Health and Environment (KDHE) to provide newborn screening services intended to detect certain genetic diseases including Phenylketonuria (PKU). For individuals with PKU, treatment is lifelong and involves nutritional supplements intended to help mitigate increasing damage from the disease. The nutritional supplements can be very costly and range anywhere from between \$5,000 a year for an infant to \$20,000 a year for an adult.

State law requires KDHE to help provide, within the limits of appropriated funds, the necessary treatment for diagnosed PKU cases when the nutritional supplements are not available through other state sources. KDHE regulations specify how much financial assistance will be provided to individuals needing the treatment based on family income levels. At least two medical centers provide necessary treatments for individuals with PKU eligible for state assistance: Children's Mercy Hospital in Kansas City, Missouri and KU Wichita Pediatrics in Wichita.

AUDIT OBJECTIVES AND TENTATIVE METHODOLOGY

The audit objectives listed below represent the questions that we would answer through our audit work. The proposed steps for each objective are intended to convey the type of work we would do, but are subject to change as we learn more about the audit issues and are able to refine our methodology.

Objective 1: Are individuals who are eligible for state assistance receiving the PKU nutritional treatments they need? Our tentative methodology would include the following:

- Interview officials from the two medical providers in Kansas that provide PKU treatments to determine whether they have had difficulties providing eligible individuals with treatments they need and if so, why.
- Interview a small sample of individuals with PKU who are eligible for state assistance to determine whether they, or someone they know, has had difficulty getting the nutritional treatments they need and if so, why.
- Interview KDHE officials to identify their proposed solutions for any problems identified in our previous interviews.

ESTIMATED RESOURCES

We estimate this audit would require **100 staff hours** to complete.