

**COMMONWEALTH OF KENTUCKY STATE FISCAL NOTE STATEMENT
LEGISLATIVE RESEARCH COMMISSION
2018 REGULAR SESSION**

MEASURE

2018 BR NUMBER **0949**

HOUSE BILL NUMBER **165**

RESOLUTION NUMBER _____

AMENDMENT NUMBER _____

SUBJECT/TITLE **An ACT establishing the Kentucky Rare Disease Advisory Council and making an appropriation therefor.**

SPONSOR **Representative Nelson**

NOTE SUMMARY

FISCAL ANALYSIS: IMPACT NO IMPACT INDETERMINABLE IMPACT

LEVEL(S) OF IMPACT: STATE LOCAL FEDERAL

BUDGET UNIT(S) IMPACT: **Cabinet for Health and Family Services**

FUND(S) IMPACT: GENERAL ROAD FEDERAL RESTRICTED AGENCY _____ OTHER

FISCAL SUMMARY

| FISCAL ESTIMATES | 2017-2018 | 2018-2019 | 2019-2020 | ANNUAL IMPACT AT FULL IMPLEMENTATION |
|-------------------------|------------------|------------------|------------------|---|
| REVENUES | | Indeterminable | Indeterminable | Indeterminable |
| EXPENDITURES | | Indeterminable | Indeterminable | Indeterminable |
| NET EFFECT | | Indeterminable | Indeterminable | Indeterminable |

() indicates a decrease/negative

MEASURE'S PURPOSE: HB 165 establishes the Kentucky Rare Disease Advisory Council in an effort to research and develop best practices for the treatment of individuals diagnosed with a rare disease.

PROVISIONS/MECHANICS: Section 1 creates a new section of KRS Chapter 211 establishing the council and identifying all terms and parameters of the members. There shall be no less than 15 members appointed by the Governor. Members will not be paid for serving and will not be reimbursed for any expense involved with attending a meeting. The council shall hold 3 meetings, annually, with the administrative assistance of the Cabinet for Health and Family Services (CHFS).

Section 2 creates a new section of KRS Chapter 211 to provide an outline of responsibilities and reporting requirements.

Section 3 creates a new section of KRS Chapter 211 to create the Rare Disease Trust Fund. This fund is intended to finance the operations of the council and support rare disease research and

treatment for Kentucky patients. CHFS shall administer the fund and shall submit a detailed expenditure report to the council and the General Assembly on an annual basis. Remaining funds shall carry forward into succeeding fiscal years.

Section 4 creates a new section of KRS Chapter 211 declaring that the council shall cease to exist on December 1, 2028, unless reestablished by the General Assembly.

FISCAL EXPLANATION: CHFS has indicated that administering a newly established council would increase costs to the Department of Public Health (DPH). The cost of administrative support will vary based on the plans developed from the meetings of the council. CHFS also indicated additional staff would be required to provide administrative support.

However, the cost could be offset with the acquisition of federal grant funds or other sources of revenue outlined in Section 1.

As a result of the unknown scope of projects, administrative job duties and additional income sources, the fiscal impact is indeterminable.

DATA SOURCE(S): Cabinet for Health and Family Services

PREPARER: Jake Fouts **NOTE NUMBER:** 39 **REVIEW:** JAB **DATE:** 1/18/2018