

## Department of Planning and Budget 2021 Fiscal Impact Statement

**1. Bill Number:** HB1995ER

**House of Origin**    ☐ Introduced    ☐ Substitute    ☐ Engrossed  
**Second House**    ☐ In Committee    ☐ Substitute    ☒ Enrolled

**2. Patron:** Murphy

**3. Committee:** Health, Welfare and Institutions

**4. Title:** Rare Disease Advisory Council; report.

**5. Summary:** Creates the Rare Disease Advisory Council in the executive branch of state government for the purpose of (i) advising the Governor and the General Assembly on the needs of individuals with rare diseases in the Commonwealth; (ii) identifying challenges that such individuals face, including delays in obtaining a diagnosis or the receipt of a misdiagnosis, shortages of medical specialists who can provide treatment, and lack of access to therapies and medication used to treat rare diseases; (iii) funding research related to rare diseases and the development of new treatments for rare diseases; and (iv) funding for supports for persons with rare diseases in the Commonwealth.

**6. Budget Amendment Necessary:** Yes, Item 301.

**7. Fiscal Impact Estimates:**

**7a. Expenditure Impact:**

<i>Fiscal Year</i>	<i>Dollars</i>	<i>Positions</i>	<i>Fund</i>
2021			
2022	\$42,716		General
2023	\$42,716		General
2024	\$42,716		General
2025	\$42,716		General
2026	\$42,716		General
2027	\$42,716		General

**8. Fiscal Implications:** This bill, as amended, would have a fiscal impact on the Commonwealth. The provisions of the bill create the Rare Disease Advisory Council (the Council), which within the first year must convene public hearings, make inquiries, and solicit comments from the general public to assist the Council in understanding rare diseases in Virginia. The Council is also required to research and consult with experts on rare disease to develop policy recommendations, publish a list of accessible resources regarding diagnosis and treatment, and submit an annual report to the Governor and the General Assembly. Furthermore, the bill states that staff to the Council shall be provided by the Virginia Department of Health (VDH), and that all other agencies shall provide assistance upon request. To meet the provisions of the bill, VDH would need a part-time contracted staff

person to lead, organize, implement, and staff the Advisory Council as well as to draft and submit the annual report. VDH has estimated that the cost of the part-time contractor would be \$42,716. The provisions of the bill state that the members of the Council shall serve without compensation or reimbursement, therefore no travel costs were included.

**9. Specific Agency or Political Subdivisions Affected:** The Virginia Department of Health.

**10. Technical Amendment Necessary:** No.

**11. Other Comments:** None.