

## Department of Planning and Budget 2024 Session Fiscal Impact Statement

**1. Bill Number:** HB252

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

**2. Patron:** Cole

**3. Committee:** Passed both Houses.

**4. Title:** Sickle cell disease; statewide registry; collection of sickle cell disease case information.

**5. Summary:** Creates a statewide registry of sickle cell disease patients to be maintained by the State Health Commissioner. The bill establishes: (i) standards and selection criteria for the collection of sickle cell disease information; (ii) penalties for unauthorized use of data from such registry; and (iii) notice requirements for patients whose personal identifying information has been submitted to such registry. The bill allows patients diagnosed with sickle cell disease to self-report information to the sickle cell disease registry. Under the bill, a patient has the right to opt out of having his information reported to the statewide sickle cell disease registry. The bill also directs the Commissioner to submit an annual report of the information obtained from the sickle cell disease registry to the Governor and the General Assembly by December 1 of each year.

**6. Budget Amendment Necessary:** Yes, item 277.

**7. Fiscal Impact Estimates:**

**7a. Expenditure Impact:**

<i>Fiscal Year</i>	<i>Dollars</i>	<i>Positions</i>	<i>Fund</i>
2024			
2025	\$405,260	3	01000
2026	\$405,260	3	01000
2027	\$286,077	2	01000
2028	\$286,077	2	01000
2029	\$286,077	2	01000
2030	\$286,077	2	01000

**8. Fiscal Implications:** The provisions of this legislation would have a fiscal impact on the Virginia Department of Health (VDH) to create a statewide registry for sickle cell disease that is maintained by the State Health Commissioner. The bill would require hospitals, clinics, and independent pathology laboratories to report information about patients living

with sickle cell disease to the Commissioner to create the registry. The bill states that the purpose of the registry shall include:

1. Determining means of improving the diagnosis and treatment of sickle cell disease patients.
2. Determining the need for and means of providing better long-term, follow-up care to sickle cell disease patients.
3. Conducting epidemiological analyses of the incidence, prevalence, survival, and risk factors associated with occurrence of sickle cell disease in Virginia.
4. Improving rehabilitative programs for sickle cell disease patients.
5. Assisting in the training of hospital personnel.
6. Determining other needs of sickle cell disease patients and health personnel.

VDH does not have a system to maintain all patient data that is reported by hospitals, clinics, and independent pathology laboratories. VDH's Office of Information Management estimated it would take approximately two years to develop the system and promulgate necessary regulations. There would be ongoing costs to maintain the system and to meet the provisions of the legislation. VDH would need two developers in the Office of Information Management to develop the system estimated at a total cost of \$250,000. Servers for the registry would cost \$14,688 annually, and database disaster recovery costs are \$19,488 annually. VDH would also need a program coordinator (\$103,492 salary and fringe) and partial support of an existing Blood Disorders Coordinator (\$7,600 annually). These positions would be responsible for managing the system properly, monitoring project progression, producing relevant data reports, assuring data quality, and conducting site visits as required by the bill. VDH would also need \$10,000 for travel, printing, media campaigns and awareness efforts.

Beginning in FY2027 after the development of the database is complete, the two developer positions will no longer be needed. However, a senior epidemiologist would be needed once it is up and running to manage of the data related responsibilities outlines in the legislation. The cost of this position is \$130,809 including salary and fringe benefits.

Any costs to promulgate regulations can be handled within existing resources.

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

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

**11. Other Comments:** None.