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HOUSE JOINT RESOLUTION NO. 60

Offered January 10, 2024

Prefiled January 10, 2024

Directing the Joint Commission on Health Care to study sickle cell disease in the Commonwealth. Report.

 Patron—Hayes

 Referred to Committee on Rules

WHEREAS, sickle cell disease is a severe, life-shortening, and inherited blood disorder that predominantly impacts people of color, particularly African Americans; and

WHEREAS, sickle cell disease is a disease in which a person's body can produce abnormally shaped red blood cells that resemble a crescent or sickle; and

WHEREAS, sickle cell disease typically first appears in children around the age of six months; and

WHEREAS, symptoms of sickle cell disease may include anemia, pain, swelling of hands and feet, frequent infections, delayed growth or puberty, and vision problems; and

WHEREAS, according to the Virginia Department of Health, it is estimated that between 2,500 and 4,500 African American Virginians are living with sickle cell disease; and

WHEREAS, sickle cell disease occurs in approximately one out of every 365 Black or African American births nationwide; and

WHEREAS, individuals living with sickle cell disease encounter barriers to obtaining quality care, such as limited geographic access, financial and socioeconomic barriers, specialist availability, transportation needs, translation service needs, and social factors, such as stigma, bias, and lack of public awareness; and

WHEREAS, due to new treatments, individuals with sickle cell disease now have a longer life expectancy, improved quality of life, and survival rates past the age of 50; and

WHEREAS, despite improvements in treatment, there is a need for more comprehensive and coordinated data collection efforts to better understand and quantify the scope and impact of sickle cell disease; and

WHEREAS, there is a need for states to ensure access to social and health care services and therapies that treat sickle cell disease, and particularly to ensure access to innovative therapies that have been approved in recent years to treat the underlying cause of the disease; and

WHEREAS, scientific and medical research advances need to be coupled with health care delivery and payment policies to ensure timely access to innovative pipeline products, particularly for Medicaid beneficiaries; and

WHEREAS, efforts should focus on the identification and the promotion of affordable interventions, including community education and training of health professionals; now, therefore, be it

RESOLVED by the House of Delegates, the Senate concurring, That the Joint Commission on Health Care be directed to study sickle cell disease in the Commonwealth.

In conducting its study, the Joint Commission on Health Care shall review the (i) availability of health care and support services for individuals with a diagnosis of sickle cell disease; (ii) medications, forms of treatment, and existing reimbursement frameworks and methodologies for sickle cell disease; (iii) current data available on individuals diagnosed with sickle cell disease, and whether additional reporting is needed to ensure comprehensive data collection; (iv) sickle cell disease educational efforts and materials available to health care providers and Virginians; (v) current state funding and programs focused on sickle cell disease; (vi) considerations of ancillary and co-occurring health challenges as result of sickle cell disease and its treatments, including reproductive health issues and iatrogenic infertility; and (vii) recommendations for improvements in the delivery of and access to health care services and treatment of individuals with diagnosis of sickle cell disease.

Technical assistance shall be provided to the Joint Commission on Health Care by the Department of Health and the Department of Medical Assistance Services; individuals with a diagnosis of sickle cell disease and caregivers for individuals with a diagnosis of sickle cell disease; community-based sickle cell disease organizations; health care providers who specialize in the treatment of individuals diagnosed with sickle cell disease; and comprehensive adult and pediatric sickle cell disease treatment centers and transplant institutions. All agencies of the Commonwealth shall provide assistance to the Joint Commission on Health Care for this study, upon request.

The Joint Commission on Health Care shall complete its meetings by November 30, 2024, and the chairman shall submit to the Division of Legislative Automated Systems an executive summary of its

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59 findings and recommendations no later than the first day of the 2025 Regular Session of the General
60 Assembly. The executive summary shall state whether the Joint Commission on Health Care intends to
61 submit to the General Assembly and the Governor a report of its findings and recommendations for
62 publication as a House or Senate document. The executive summary and report shall be submitted as
63 provided in the procedures of the Division of Legislative Automated Systems for the processing of
64 legislative documents and reports and shall be posted on the General Assembly's website.