2025 SESSION

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HB2500

25102996D **HOUSE BILL NO. 2500** Offered January 13, 2025 Prefiled January 8, 2025 A BILL to amend the Code of Virginia by adding in Chapter 5.3 of Title 32.1 a section numbered 32.1-162.31:1, relating to Florence Neal Cooper Smith Sickle Cell Research Endowment Fund established. Patrons-McQuinn, Anthony, Askew, Carr, Clark, Cousins, Coyner, Gardner, Glass, Henson, Herring, Hope, Keys-Gamarra, LeVere Bolling, Maldonado, McClure, Price, Rasoul, Sewell, Sullivan, Thomas and Ward Referred to Committee on Appropriations Whereas, the Florence Neal Cooper Smith Professorship was established at the Virginia Commonwealth University School of Medicine to foster aggressive, cutting-edge research that will lead to discovering a cure for sickle cell disease: and Whereas, Florence Neal Cooper Smith is a pioneer of sickle cell disease awareness, both regionally and nationally; she is a graduate of Virginia Union University and completed graduate studies in pathology at the VCU School of Medicine, formerly known as the Medical College of Virginia; and Whereas, in 1969, Florence Neal Cooper Smith organized Richmond's first city-wide survey with the help of local civic, social, and community organizations to determine the extent of sickle cell awareness in the surrounding localities; and Whereas, in 1972, with the allotment of federal dollars for sickle cell programs, Florence Neal Cooper Smith and colleague Dr. Robert B. Scott Sr. founded the innovative Sickle Cell Awareness Program at the Medical College of Virginia/Virginia Commonwealth University to educate and inform the general public about sickle cell anemia; and Whereas, the efforts of Florence Neal Cooper Smith supported the policy of screening all newborns in Virginia for sickle cell disease; and Whereas, in May 2014, Dr. Wally R. Smith was appointed as the inaugural holder of the Florence Neal Cooper Smith Professorship in the Division of General Internal Medicine, earned from being a nationally recognized expert on sickle cell disease and leading the fight in Virginia to develop methods of treatment, assist in care management, and promote continuous research; and Whereas, sickle cell disease causes red blood cells to function abnormally, becoming rigid and curving into a sickle-like shape that makes it difficult for the cells to pass through tiny blood vessels, resulting in painful blockages that prevent oxygen and vital nutrients in the blood from reaching organs and tissues resulting in tissue damage, severe recurring pain, strokes, organ damage, and other serious medical complications; and Whereas, sickle cell disease primarily affects those of African descent, but also is found in people who trace their ancestry to South and Central America, the Middle East, India, Italy, Greece, and Turkey, and thus affects Virginians; now, therefore, Be it enacted by the General Assembly of Virginia: 1. That the Code of Virginia is amended by adding in Chapter 5.3 of Title 32.1 a section numbered 32.1-162.31:1 as follows: § 32.1-162.31:1. Florence Neal Cooper Smith Sickle Cell Research Endowment Fund. A. From such funds as may be appropriated by the General Assembly and any gifts, grants, or donations from public or private sources, there is created in the state treasury a special, nonreverting, revolving, and permanent fund to be known as the Florence Neal Cooper Smith Sickle Cell Research Endowment Fund. The Fund shall be established on the books of the Comptroller and shall be administered and implemented by the Board in accordance with the provisions of this section. All funds appropriated for the Fund and any grants, donations, or other assistance provided shall be paid into the state treasury and credited to the Fund. Interest earned on moneys in the Fund shall remain in the Fund and be credited to it. Any moneys remaining in the Fund, including interest thereon, at the end of each fiscal year shall not revert to the general fund but shall remain in the Fund. Moneys in the Fund shall be used solely for the purpose of making grant payments pursuant to this section. Expenditures and disbursements from the Fund shall be made by the State Treasurer on warrants issued by the Comptroller upon written request signed by the chairman or vice-chairman of the Board B. Moneys in the Fund shall be used solely to support medical and biomedical sickle cell disease research conducted in institutions of higher education in the Commonwealth that relates to the causes and cures of

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58 C. Any appropriations, grants, donations, or other assistance provided pursuant to this section shall be 59 awarded in accordance with the Board's specific criteria and procedures, requirements for submission of research proposals, and evaluation mechanisms established pursuant to this chapter. However, no 60 requirement for matching funds shall apply to the appropriations, grants, donations, or other assistance 61 awarded to the Fund, and the leveraging of funds is incidental to the support provided under this section. The 62 appropriations, grants, donations, or other assistance provided pursuant to this section may, upon 63 demonstrating a reasonable justification to the Board's satisfaction, be awarded to support sickle cell disease 64 research that is not eligible for federal research funds through the National Institutes of Health. No moneys 65 from the Fund may be provided to any entity that conducts human sickle cell disease research from stem cells 66 obtained from human embryos or for conducting such research; however, research conducted using stem 67 68 cells other than embryonic stem cells may be funded.