A bill to be entitled

An act relating to the treatment and care of adult patients with sickle cell disease; creating s. 381.817, F.S.; providing definitions; creating the Sickle Cell Disease Task Force adjunct to the Department of Health; providing a purpose; providing for membership, meetings, and duties of the task force; requiring the task force to submit a report to the Governor and Legislature by a specified date; providing for future expiration; creating s. 381.819, F.S.; requiring the department, in consultation with the task force, to develop and implement comprehensive training and continuing education requirements for certain health care providers; authorizing the department to adopt rules; amending s. 381.981, F.S.; requiring the Florida Public Health Institute, Inc., in consultation with the department, to include sickle cell disease as part of its health awareness campaigns; providing an effective date.

Be It Enacted by the Legislature of the State of Florida:

Section 1. Section 381.817, Florida Statutes, is created to read:

381.817 Sickle Cell Disease Task Force.—

<u>(1) DEFINITIONS.—As used in this section, the term:</u>

<u>(a) "Department" means the Department of Health.</u>

<u>(b) "Task force" means the Sickle Cell Disease Task Force created under this section.</u>

<u>(2) CREATION AND PURPOSE.—The Sickle Cell Disease Task Force, a task force as defined in s. 20.03(8), is created adjunct to the department for the purpose of providing recommendations for improving the quality of treatment and care provided to adult patients diagnosed with sickle cell disease and for educating and training health care providers who treat, or participate in the treatment of, such patients regarding the best practices and guidelines for such treatment. The department shall provide staff and administrative support for the task force.</u>

<u>(3)(a) MEMBERSHIP.—The task force shall consist of 18 members, as follows:</u>

<u>1. The State Surgeon General or his or her designee.</u>

<u>2. The Secretary of Health Care Administration or his or her designee.</u>

<u>3. Three county health department directors, one of whom represents a county with a large minority population, one of whom represents a rural county, and one of whom represents a large county, appointed by the State Surgeon General.</u>

<u>4. One emergency room physician, one primary care physician, one hematologist, one registered nurse or advanced</u>

practice registered nurse, one physician assistant, and one pharmacist who treats, or participates in the treatment of, adult patients with sickle cell disease, appointed by the State Surgeon General.

5. One representative from each of the following organizations, appointed by the Governor:

a. Florida Medical Association.

b. Sickle Cell Disease Association of Florida, Inc.

c. Florida Association of County Health Officers, Inc.

d. University of South Florida College of Public Health.

e. Florida Agricultural and Mechanical University Institute of Public Health.

6. Two adult patients who have been diagnosed with sickle cell disease, one appointed by the President of the Senate and one appointed by the Speaker of the House of Representatives.

(b) The members of the task force must be appointed by September 1, 2022. A vacancy on the task force shall be filled in the same manner as the original appointment. The task force shall elect a chair from among its members.

(c) Members of the task force shall serve without compensation but are entitled to reimbursement for per diem and travel expenses pursuant to s. 112.061.

(4) MEETINGS.—

(a) The task force shall convene its first meeting by October 1, 2022. Thereafter, the task force shall meet as often as necessary to perform its duties at the call of the chair.

(b) Meetings may be conducted in person or by teleconference or other electronic means.

(5) DUTIES.—The task force shall:

(a) Develop recommendations and identify strategies for improving the continuum of care for adult patients with sickle cell disease and promoting the coordination among health care providers, including, but not limited to, delineating the elements of a comprehensive system of care and standardizing protocols for the treatment of such patients.

(b) Identify the barriers to adult patients with sickle cell disease in receiving adequate treatment and care, including, but not limited to, inconsistent and inadequate health insurance coverage, systemic racism, and a lack of coordination among health care providers within the continuum of care for such patients.

(c) Develop recommendations and identify strategies for eliminating the barriers identified under paragraph (b).

(d) Develop recommendations for and identify the services that are not covered by health insurance, but should be, for adult patients with sickle cell disease, including, but not limited to, urine screening for albuminuria, annual or biannual dilated ophthalmological examination for sickle cell retinopathy, pain specialist consultation and services, evaluation and treatment for mental illness, and diseasemodifying therapies.

(e) Develop recommendations for improving the treatment and care of adult patients with sickle cell disease for prolonged acute pain, especially in hospital emergency departments, including, but not limited to, managing pain for such patients in accordance with the National Heart, Lung, and Blood Institute's guidelines in the Evidence-Based Management of Sickle Cell Disease: Expert Panel Report, 2014.

(f) Develop recommendations for standardizing the use of individualized care plans by health care providers for each adult patient with sickle cell disease, which would be included in his or her medical records.

(g) Develop recommendations for training and educating health care providers who care for and treat, or participate in the treatment and care of, adult patients with sickle cell disease, including, but not limited to, comprehensive courses covering systemic racism and its negative impact on the accessibility of care, the management of pain in such patients, and other diseases that disproportionately affect the minority community.

(h) Develop recommendations and identify strategies for providing support to adult patients with sickle cell disease through the use of community-based organizations and case managers in health care facilities.

(6) REPORT.—By October 1, 2023, the task force shall

submit a report that includes its findings and recommendations to the Governor, the President of the Senate, and the Speaker of the House of Representatives.

(7) EXPIRATION.—This section expires October 1, 2024.

Section 2. Section 381.819, Florida Statutes, is created to read:

381.819 Training and continuing education relating to treatment and care of adults with sickle cell disease.—By September 1, 2024, the Department of Health, in consultation with the Sickle Cell Disease Task Force created under s. 381.817, shall develop and implement comprehensive training and continuing education requirements for health care providers relating to the treatment and care of adults with sickle cell disease. The department may adopt rules to implement this section.

Section 3. Paragraph (v) is added to subsection (2) of section 381.981, Florida Statutes, to read:

381.981 Health awareness campaigns.—

(2) The awareness campaigns shall include the provision of educational information about preventing, detecting, treating, and curing the following diseases or conditions. Additional diseases and conditions that impact the public health may be added by the board of directors of the Florida Public Health Institute, Inc.; however, each of the following diseases or conditions must be included in an awareness campaign during at

least 1 month in any 24-month period:

<u>(v) Sickle cell disease.</u>

Section 4. This act shall take effect July 1, 2022.