
THE GENERAL ASSEMBLY OF PENNSYLVANIA

SENATE RESOLUTION

No. 237 Session of
2024

INTRODUCED BY HAYWOOD, STREET, HUGHES, FONTANA, KANE AND
SANTARSIERO, FEBRUARY 12, 2024

REFERRED TO HEALTH AND HUMAN SERVICES, FEBRUARY 12, 2024

A RESOLUTION

1 Directing the Joint State Government Commission to conduct a
2 study to better understand and quantify the scope and impact
3 of sickle cell disease on patients and communities throughout
4 this Commonwealth.

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

8 WHEREAS, Sickle cell disease is a disease in which an
9 individual's body produces abnormally shaped red blood cells
10 that resemble a crescent or sickle; and

11 WHEREAS, Sickle cell disease typically first appears in
12 children around six months of age; and

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

16 WHEREAS, According to the Department of Health, an estimated
17 3,870 Pennsylvanians were reported living with sickle cell
18 disease; and

19 WHEREAS, The exact number of individuals with sickle cell

1 disease nationwide is still unknown, though the Centers for
2 Disease Control and Prevention estimates that sickle cell
3 disease affects more than 100,000 Americans; and

4 WHEREAS, Sickle cell disease occurs in approximately 1 out of
5 every 365 Black or African-American births nationwide; and

6 WHEREAS, Individuals living with sickle cell disease
7 encounter barriers to obtaining quality care, such as limited
8 geographic access, financial and socioeconomic barriers,
9 specialist availability, transportation needs, translation
10 services and social factors, such as stigma, bias and lack of
11 public awareness; and

12 WHEREAS, Due to new treatments, individuals with sickle cell
13 disease now have a longer life expectancy, improved quality of
14 life and survival rates past 50 years of age; and

15 WHEREAS, However, there is a need for more comprehensive and
16 coordinated data collection efforts to better understand and
17 quantify the scope and impact of sickle cell disease; and

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

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

27 WHEREAS, Efforts should focus on the identification and the
28 promotion of affordable interventions, including community
29 education, training of health professionals and newborn
30 screening for early diagnosis of sickle cell disease; therefore

1 be it

2 RESOLVED, That the Senate direct the Joint State Government
3 Commission to conduct a study to better understand and quantify
4 the scope and impact of sickle cell disease on patients and
5 communities throughout this Commonwealth; and be it further

6 RESOLVED, That the Joint State Government Commission study
7 include, at a minimum, the following:

8 (1) availability of health care and support services for
9 individuals with a diagnosis of sickle cell disease,
10 including the availability of health care practitioners
11 specializing in the treatment of sickle cell disease and
12 whether there are health care workforce or support service
13 gaps that exist;

14 (2) review of current data available on individuals
15 diagnosed with sickle cell disease, and whether additional
16 reporting is needed to ensure comprehensive data collection;

17 (3) review of current sickle cell disease educational
18 efforts and materials available to health care providers and
19 Pennsylvanians;

20 (4) review of current State funding and programs focused
21 on sickle cell disease;

22 (5) considerations of ancillary and co-occurring health
23 challenges as a result of sickle cell disease and its
24 treatments, including, but not limited to, reproductive
25 health and iatrogenic infertility; and

26 (6) recommendations for improvements in the delivery of
27 and access to health care services and treatments for
28 individuals with a diagnosis of sickle cell disease;

29 and be it further

30 RESOLVED, That the Joint State Government Commission seek

1 input and information as appropriate from at least the
2 following:

- 3 (1) the Department of Health;
 - 4 (2) the Department of Human Services;
 - 5 (3) individuals with a diagnosis of sickle cell disease
6 and caregivers of individuals with a diagnosis of sickle cell
7 disease;
 - 8 (4) community-based sickle cell disease organizations;
 - 9 (5) health care providers who specialize in the
10 treatment of individuals diagnosed with sickle cell disease;
11 and
 - 12 (6) comprehensive adult and pediatric sickle cell
13 disease treatment centers and transplant institutions;
- 14 and be it further

15 RESOLVED, That the Joint State Government Commission be
16 authorized to request information from the Department of Health
17 and the Department of Human Services for the study on behalf of
18 the Senate; and be it further

19 RESOLVED, That the Joint State Government Commission report
20 its findings and recommendations to the Senate no later than one
21 year after the adoption of this resolution.