
THE GENERAL ASSEMBLY OF PENNSYLVANIA

HOUSE RESOLUTION

No. 186 Session of
2023

INTRODUCED BY KINSEY AND BULLOCK, AUGUST 29, 2023

REFERRED TO COMMITTEE ON HEALTH, AUGUST 29, 2023

A RESOLUTION

1 Ensuring greater access to sickle cell disease treatments and
2 designating the Department of Health to conduct a
3 comprehensive and coordinated data collection effort to
4 better understand and quantify the scope and impact of sickle
5 cell disease on patients, communities and states throughout
6 the United States.

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

10 WHEREAS, Sickle cell disease is a disease in which a person's
11 body produces abnormally shaped red blood cells that resemble a
12 crescent or sickle; and

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

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

18 WHEREAS, According to the Department of Health, an estimated
19 3,870 Pennsylvanians were reported living with sickle cell
20 disease in 2019-2020; and

1 WHEREAS, The exact number of people with sickle cell disease
2 nationwide is still unknown, though the Centers for Disease
3 Control and Prevention estimates that sickle cell disease
4 affects more than 100,000 Americans; and

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

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

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

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

19 WHEREAS, Further, there is a need for states to provide open
20 access to therapies that treat sickle cell disease, particularly
21 innovative therapies that have been approved in recent years to
22 treat the underlying cause of 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 universal access to innovative 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; and

1 WHEREAS, Involving other potential stakeholders, such as
2 organizations and other national and international health-
3 related agencies, would significantly contribute to efforts
4 relating to advocacy, technology transfer and capacity building;
5 therefore be it

6 RESOLVED, That the House of Representatives ensure greater
7 access to sickle cell disease treatments and designate the
8 Department of Health to conduct a comprehensive and coordinated
9 data collection effort to better understand and quantify the
10 scope and impact of sickle cell disease on patients, communities
11 and states throughout the United States; and be it further

12 RESOLVED, That the House of Representatives and members of
13 the Legislative Black Caucus urge Federal policymakers to ensure
14 that individuals with sickle cell disease have access to all
15 medications and forms of treatment for the disease, including
16 services for enrollees who are diagnosed with the disease and
17 who are eligible for covered services under Medicare and
18 Medicaid programs, and to ensure that new and effective
19 treatments are developed for sickle cell disease.