

Governor Murphy Signs Legislation Establishing Sickle Cell Disease Pilot Program

01/8/2024

Appropriates \$10,200,000 from Fiscal Year 2024 Budget

TRENTON – Governor Phil Murphy today signed legislation (A4052) appropriating \$10,200,000 to establish a three-year sickle cell disease pilot program. Under the bill, the Department of Health (DOH), in consultation with the Department of Human Services, will establish a three-year sickle cell disease pilot program, under which DOH will select Federally Qualified Health Centers to develop and implement comprehensive sickle cell disease treatment programs and services.

“I am proud to sign legislation that will make meaningful steps toward removing barriers to care for people with sickle cell disease in New Jersey,” **said Governor Murphy**. “While sickle cell disease impacts people of all backgrounds, it disproportionately affects the Black community, which is why we must work to close health disparities across our state. This innovative and critical program has the potential to improve health outcomes for underserved populations while ensuring New Jerseyans with sickle cell disease can access the care that they deserve.”

Sickle Cell Disease (SCD) is a group of inherited red blood cell disorders. Individuals with this chronic disease may experience pain episodes and other complications. Prevention and treatment strategies may focus on lifestyle behaviors, medical screening, interventions to prevent SCD complications, and/or transplantation to cure SCD.

Under the legislation, the Department of Health will select Federally Qualified Health Centers for participation in the pilot program on a competitive basis based on criteria to be established by the Commissioner of Health. Priority will be given to Federally Qualified Health Centers located in Jersey City, Newark, Paterson, Plainfield, Trenton, Camden, and, subject to the availability of funds, to Federally Qualified Health Centers in other municipalities which demonstrate a patient population in that geographic area that is in need of sickle cell disease care. The Federally Qualified Health Centers selected for participation in the pilot program will be eligible for financial support from the funds appropriated to the Department of Health.

“This program will build on our collaboration with Federally Qualified Health Centers to better connect specialty sickle cell care with affected individuals in key communities in our state,” **said Acting Health Commissioner Dr. Kaitlan Baston**. “This funding will help increase access to comprehensive and equitable health services for those who need it and help boost awareness and education about this chronic disease.”

“Providing coordinated care to individuals with sickle cell disease through Federally Qualified Health Centers is an investment in access, equity, and wellness for these New Jerseyans,” **said Sarah Adelman, Commissioner of Human Services**. “NJ FamilyCare covers more than 2,700 members who sought care for sickle cell disease, which can be a stigmatizing condition. Preventing hospital stays and acute crisis for sickle cell patients through this pilot will improve health outcomes and quality of life.”

The pilot program aims to:

- (1) Link outpatient sickle cell disease care to sickle cell disease care in inpatient health care settings and other health care settings, which may include, if permitted by law, telehealth services;
- (2) Provide coordinated, comprehensive, team-based medical, behavioral health, mental health, social support, and other services under the supervision of health care professionals who have expertise in treating individuals with sickle cell disease;
- (3) Foster outreach to individuals and families with sickle cell disease and providers of medical, nursing, and social services who serve and treat persons with sickle cell disease;
- (4) Promote sickle cell disease education and awareness;

(5) Develop initiatives to build a State medical workforce of clinicians who are knowledgeable about the diagnosis and treatment of sickle cell disease; and

(6) Establish practices for the collection of in-state data on sickle cell disease to monitor incidence, prevalence, demographics, morbidity, health care utilization, and costs.

This builds upon universal newborn screening for Sickle Cell Disease in New Jersey, where newborns identified with SCD are referred to Sickle Cell Treatment Centers at select acute care hospital facilities.

Primary sponsors of the legislation include Senators Shirley Turner and Assemblywoman Verlina Reynolds-Jackson, as well as Senator Andrew Zwicker and Assemblymembers Herb Conaway, Jr., Raj Mukherji, and Linda S. Carter.

"Despite medical advances, sickle cell patients continue to have difficulty accessing specialty care, which in turn disproportionately affects Black and Latino communities, who are more likely to be born with the disease," **said Senator Turner**. "The lack of a robust and well-resourced sickle cell specialty network limits patient access to new and potentially better treatment options. This legislation is a good first step towards eliminating discriminatory treatment practices, improving the quality of life of sickle cell patients, and getting patients the care they need and deserve."

"Sadly, New Jersey is among the top ten states in the nation in terms of the prevalence of sickle cell disease. There is a shortage of specialists, and patients have difficulty finding integrated, comprehensive teams to provide coordinated medical, social, educational, and behavioral health services," **said Senator Andrew Zwicker**. "As a result, affected individuals are forced to obtain care in hospital emergency departments and other non-sickle cell specialty settings. Signing this legislation into law will help us begin to more aggressively address this issue by increasing patient access to centralized sickle cell specialty care."

"At its core, this program serves as a testament to our commitment in establishing comprehensive care and research that will help the countless individuals whose lives have been impacted by Sickle Cell Disease," **said Assemblywoman Linda Carter**. This legislation paves the way for a future where SCD ceases to lurk silently in within bodies, leaving those impacted to endure in isolation. Instead it allows us herald a path towards a healthier tomorrow by educating, treating, and providing supporting for those afflicted."

"We know that Sickle Cell disease disproportionately affects our Black and brown communities - one in 13 African Americans carry the sickle cell trait and one in 365 are born with the disease," **said Assemblyman Herb Conaway**. "The legislation being signed into law today is an important step, not only in connecting patients to the care they need, but also in breaking down the racial disparities that are too often present in our health care systems."

"Despite significant medical advances in the treatment of the condition, patients with sickle cell disease confront obstacles that impede access to care and knowledgeable providers," **said Assemblyman Raj Mukherji**. "Creating regional treatment centers will help alleviate the burden faced by many sickle cell disease patients in accessing the specialized care that they need."

There have been medical advances in healthcare for people with Sickle Cell Disease. However, many patients continue to have difficulty accessing care and providers who specialize in SCD," **said Assemblywoman Verlina Reynolds-Jackson**. "In fact, individuals with SCD are more likely to have less access to care than those with genetic disorders such as hemophilia and cystic fibrosis. The Sickle Cell center pilot program will create a robust and well-sourced regional system of specialty care units linked through our urban centers. It will also position New Jersey to participate in scientific advances and new therapies for patients."

"It makes a huge difference when you have a medical provider who knows how to treat sickle cell disease," **said Mary Bentley LaMar, founder and Executive Director of The Sickle Cell Association of New Jersey**. "With this pilot program, a strong network of appropriate care will be more accessible to individuals living with this devastating blood disorder. We are thrilled with the support of the Governor and State Legislators in bringing this improvement to New Jersey."

"It is vital that we do all we can to improve the resources and care available to patients with Sickle Cell Anemia so that they can live full, healthy lives," **said Brandon McKoy**. "Similar programs currently exist in states like North Carolina and Virginia, and it's great to see New Jersey making these investments."

"Living with sickle cell disease in New Jersey has come with many challenges," **said Mariah Jacqueline Scott, MS, MPH; sickle cell warrior and researcher**. "The ability to access quality healthcare, while striving to live a normal life as a mother, researcher, and a fiancée, with a debilitating, painful disease does not come easy. To have the opportunity to witness this bill being signed into law paves the road to improving the quality of healthcare and

ultimately enhancing the lives for sickle cell warriors and their families. Thank you, Governor Murphy, our legislators, and the sickle cell community, for this proud moment that will forever change and make a difference for New Jersey's community of warriors who fight each day."

Governor Phil Murphy

Statewide

[Home \(/governor/\)](/governor/)

Administration

Governor Phil Murphy
[\(/governor/admin/about\)](/governor/admin/about)
 Lt. Governor Tahesha Way
[\(/governor/admin/lt\)](/governor/admin/lt)
 In memoriam of Lt. Governor Sheila Y. Oliver
[\(/governor/admin/lt-sheila-y-oliver\)](/governor/admin/lt-sheila-y-oliver)
 Senior Staff
[\(/governor/admin/staff\)](/governor/admin/staff)
 Cabinet
[\(/governor/admin/cabinet\)](/governor/admin/cabinet)
 Office of Climate Action and the Green Economy
[\(/governor/climateaction/\)](/governor/climateaction/)
 Office of Equity
[\(/governor/admin/equity/\)](/governor/admin/equity/)
 Office of Health Care Affordability and Transparency
[\(/governor/admin/affordablehealthcare/index.shtml\)](/governor/admin/affordablehealthcare/index.shtml)
 Boards, Commissions & Authorities
[\(/governor/admin/bca\)](/governor/admin/bca)
 New Jersey Puerto Rico Commission
[\(https://www.nj.gov/puertoricocommission/\)](https://www.nj.gov/puertoricocommission/)
 Internship Opportunities
[\(/governor/admin/internship.shtml\)](/governor/admin/internship.shtml)
 Governor's Fellows Program

Key Initiatives

Economy & Jobs
[\(/governor/initiatives/#Economy\)](/governor/initiatives/#Economy)
 Education
[\(/governor/initiatives/#Education\)](/governor/initiatives/#Education)
 Environment
[\(/governor/initiatives/#Environment\)](/governor/initiatives/#Environment)
 Health
[\(/governor/initiatives/#Health\)](/governor/initiatives/#Health)
 Law & Justice
[\(/governor/initiatives/#Justice\)](/governor/initiatives/#Justice)
 Transportation
[\(/governor/initiatives/#Transportation\)](/governor/initiatives/#Transportation)

News & Events

Press Releases
[\(/governor/news/news/562024/approved/news_archive.shtml\)](/governor/news/news/562024/approved/news_archive.shtml)
 Photos
<https://www.flickr.com/photos/govmurphy>
 Public Addresses
[\(/governor/news/addresses\)](/governor/news/addresses)
 Executive Orders
[\(/infobank/eo/056murphy/approved/eo_archive.html\)](/infobank/eo/056murphy/approved/eo_archive.html)
 Administrative Orders
[\(/governor/news/ao/approved/ao_archive.shtml\)](/governor/news/ao/approved/ao_archive.shtml)
 Direct Appointments
[\(/governor/news/appointments\)](/governor/news/appointments)
 Advice and Consent Appointments
[\(/governor/news/acappointments\)](/governor/news/acappointments)
 Statements on Legislation
[\(/governor/news/statements/approved/statements_archive.shtml\)](/governor/news/statements/approved/statements_archive.shtml)
 Administration Reports
[\(/governor/news/adminreports/approved/archive.shtml\)](/governor/news/adminreports/approved/archive.shtml)

Social

Facebook
<https://www.facebook.com/governorphilmurphy/>
 Twitter
<https://twitter.com/GovMurphy>
 Instagram
<https://www.instagram.com/govmurphy/>
 Snapchat
<https://www.snapchat.com/add/philmurphy>
 YouTube
<https://www.youtube.com/njgovernorsoffice>

Contact Us

Scheduling Requests
[\(/governor/contact/scheduling/\)](/governor/contact/scheduling/)
 Contact Us

NJ Home

[\(/www.nj.gov\)](http://www.nj.gov)
Services A to Z
[\(/www.nj.gov/njgov/alphaserv\)](http://www.nj.gov/njgov/alphaserv)

Departments/Agencies

[\(/www.nj.gov/njgov/deptserv/\)](http://www.nj.gov/njgov/deptserv/)

FAQs

[\(/www.nj.gov/faqs/\)](http://www.nj.gov/faqs/)

Contact Us

[\(/www.nj.gov/nj/feedback.html\)](http://www.nj.gov/nj/feedback.html)

Privacy Notice

[\(/www.nj.gov/nj/privacy.html\)](http://www.nj.gov/nj/privacy.html)

Legal Statement &

Disclaimers

[\(/www.nj.gov/nj/legal.html\)](http://www.nj.gov/nj/legal.html)

Accessibility Statement

[\(/www.nj.gov/nj/accessibility.html\)](http://www.nj.gov/nj/accessibility.html)

(/governor/admin/fellows) Transition Reports

Governor's Residence - (/governor/news/reports/approved/reports_archive.shtml)

Drumthwacket Press Kits

(http://drumthwacket.org/) (/governor/news/press)

(//nj.gov/opra/)

Copyright © State of New Jersey, 1996-2024
Office of Governor PO Box 001
Trenton, NJ 08625
609-292-6000

(https://my.state.nj.us/openam/UI/Login)

(https://tech.nj.gov/)