



General Assembly

**Substitute Bill No. 5367**

February Session, 2024



**AN ACT CONCERNING MEDICAID COVERAGE OF RAPID WHOLE GENOME SEQUENCING FOR CRITICALLY ILL INFANTS.**

Be it enacted by the Senate and House of Representatives in General Assembly convened:

1 Section 1. (NEW) (*Effective July 1, 2024*) (a) As used in this section, (1)  
2 "rapid whole genome sequencing" means a test designed to diagnose  
3 genetic disorders in time to inform or change acute medical or surgical  
4 management of a critically ill infant, and (2) "infant" means a child from  
5 birth to age twelve months. The Commissioner of Social Services shall  
6 provide medically necessary Medicaid coverage for rapid whole  
7 genome sequencing of a critically ill infant enrolled in the Medicaid  
8 program who is being treated in a neonatal intensive care or pediatric  
9 intensive care unit.

10 (b) The commissioner shall require that any health care provider  
11 receiving reimbursement for such test certify, in writing, that any  
12 genetic data resulting from such test is (1) used only to assist in  
13 diagnosing and treating the infant, (2) protected in accordance with the  
14 federal Health Insurance Portability and Accountability Act of 1996, P.L.  
15 104-191, as amended from time to time, and (3) not used in scientific  
16 research unless a parent or legal guardian of the infant expressly  
17 consents to such use.

18 (c) The commissioner shall take actions necessary to implement the

19 provisions of this section, including, but not limited to, (1) promulgating  
20 regulations in accordance with chapter 54 of the general statutes to  
21 provide payment for such rapid whole genome sequencing, and (2)  
22 submitting to the Centers for Medicare and Medicaid Services any new  
23 waiver application, amendment to an existing waiver or Medicaid state  
24 plan amendment necessary to ensure federal financial participation for  
25 Medicaid coverage of such rapid whole genome sequencing.

26 (d) In developing regulations pursuant to subsection (c) of this  
27 section, the commissioner shall establish evidence-based medical  
28 necessity criteria for such rapid whole genome sequencing coverage that  
29 shall include, but need not be limited to: (1) The infant has symptoms  
30 that suggest a broad differential diagnosis that would require an  
31 evaluation by multiple genetic tests if rapid whole genome sequencing  
32 is not performed, (2) the infant's treating health care provider has  
33 provided a written determination that rapid whole genome sequencing  
34 is necessary to guide clinical decision making, and (3) the infant has  
35 complex or acute illness of unknown etiology, which may include (A)  
36 congenital anomalies involving at least two organ systems or complex  
37 or multiple congenital anomalies in one organ system, (B) specific organ  
38 malformations highly suggestive of a genetic etiology, or (C) abnormal  
39 laboratory tests or abnormal chemistry profiles suggesting the presence  
40 of a genetic disease.

This act shall take effect as follows and shall amend the following sections:		
Section 1	July 1, 2024	New section

**Statement of Legislative Commissioners:**

In Subsecs. (c) and (d), references to "rules" were deleted for statutory consistency in accordance with the provisions of chapter 54 of the general statutes.

**HS**            *Joint Favorable Subst.*