General Assembly

Raised Bill No. 5367

February Session, 2024

LCO No. **1896**

Referred to Committee on HUMAN SERVICES

Introduced by:
(HS)

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:

Section 1. (NEW) (*Effective July 1, 2024*) (a) As used in this section "rapid whole genome sequencing" means a test designed to diagnose genetic disorders in time to inform or change acute medical or surgical management of a critically ill infant. The Commissioner of Social Services shall provide medically necessary Medicaid coverage for rapid whole genome sequencing of critically ill infants enrolled in the Medicaid program who are being treated in a neonatal intensive care unit.

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

(c) The commissioner shall, if necessary under federal law, amend the Medicaid state plan or seek a waiver from federal Medicaid law, in accordance with the provisions of section 17b-8 of the general statutes, to implement the provisions of this section. The commissioner shall establish evidence-based medical necessity criteria for such rapid whole genome sequencing coverage that shall include, but need not be limited to: (1) The infant having symptoms that suggest a diagnosis that would require an evaluation utilizing multiple genetic tests if rapid whole genome sequencing is not performed, (2) the infant's treating health care provider having provided a written determination that rapid whole genome sequencing is necessary to guide clinical decision making, and (3) the infant having a complex or acute illness of unknown etiology.

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

Statement of Purpose:

To provide Medicaid coverage for rapid whole genome sequencing of critically ill infants.

[Proposed deletions are enclosed in brackets. Proposed additions are indicated by underline, except that when the entire text of a bill or resolution or a section of a bill or resolution is new, it is not underlined.]