## GENERAL ASSEMBLY OF NORTH CAROLINA SESSION 2023

S SENATE BILL 466

Short Title:	Help Medically Complex Children.	(Public)
Sponsors:	Senators Perry and Lee (Primary Sponsors).	
Referred to:	Rules and Operations of the Senate	

## April 4, 2023

A BILL TO BE ENTITLED

AN ACT TO PROVIDE COVERAGE OF COMPREHENSIVE GENOMIC TESTING TO MEDICAID BENEFICIARIES TWENTY-ONE YEARS OLD OR YOUNGER EXPERIENCING CERTAIN ACUTE OR COMPLEX ILLNESSES.

Whereas, children with medical complexity have at least one chronic condition, technology dependence, multiple subspecialist involvement, and substantial healthcare use; and

Whereas, although these children with medical complexity compose less than one percent (1%) of the pediatric population, they account for thirty-three percent (33%) of all pediatric health care spending; and

Whereas, a genetic cause is suspected in a large proportion of children with medical complexity, but most remain undiagnosed with conventional genetic testing; and

Whereas, for many families, the diagnostic process is time intensive, resource intensive, and emotionally intensive; Now, therefore,

The General Assembly of North Carolina enacts:

 **SECTION 1.** The Department of Health and Human Services, Division of Health Benefits (DHB), shall seek the necessary approval from the Centers for Medicare and Medicaid Services (CMS) to draw down a federal Medicaid match for coverage of comprehensive genomic testing, including rapid whole genome sequencing, for Medicaid beneficiaries 21 years old or younger. For the purposes of this coverage, all of the following shall apply:

- (1) The beneficiary is experiencing an acute or complex illness of unknown etiology that has not been confirmed to be caused by an environmental exposure, ingestion of a toxic substance, an infection with normal response to therapy, or trauma.
- (2) The beneficiary is receiving inpatient hospital services in an intensive care unit or a high acuity pediatric care unit.
- Rapid whole genome sequencing shall be included. Rapid whole genome sequencing is the investigation of the entire human genome, including coding and non-coding regions and mitochondrial deoxyribonucleic acid, to identify disease-causing genetic changes and that returns (i) preliminary positive results within five days of the sample being taken and (ii) final results within 14 days of the sample being taken.
- (4) Coverage includes beneficiary-only whole genome sequencing and duo and trio whole genome sequencing of the beneficiary experiencing the acute or complex illness and any biological parent of that beneficiary, whether the parent is a Medicaid beneficiary or not.



- (5) Coverage shall begin on the effective date approved by CMS and shall be implemented to the extent approved by CMS.
- (6) Genetic data generated as a result of the covered testing shall have the primary use of assisting the beneficiary's healthcare providers in the diagnosis and treatment of the beneficiary. The federal Health Information Portability and Accountability Act (HIPAA) shall apply to all data collected. This genetic data may be used in scientific research if consent for that use has been expressly given by the beneficiary or the beneficiary's legal guardian, as applicable.
- (7) Access to the results of the comprehensive genomic testing shall be made available upon request to the beneficiary, any biological parent of the beneficiary, or the beneficiary's legal guardian.
- (8) Coverage shall begin on the date approved by CMS but shall begin no sooner than July 1, 2023.

**SECTION 2.** Effective July 1, 2023, there is appropriated from the General Fund to the Department of Health and Human Services, Division of Health Benefits, the sum of five hundred thousand dollars (\$500,000) in recurring funds for the 2023-2024 fiscal year and the sum of five hundred thousand dollars (\$500,000) in recurring funds for the 2024-2025 fiscal year to implement the Medicaid coverage described under Section 1 of this act. These funds shall provide a State match for nine hundred sixty-seven thousand dollars (\$967,000) in recurring federal funds for the 2023-2024 fiscal year and nine hundred sixty-seven thousand dollars (\$967,000) in recurring federal funds for the 2024-2025 fiscal year. Those federal funds are appropriated to the Division of Health Benefits to pay for costs associated with the Medicaid coverage described under Section 1 of this act.

**SECTION 3.** This act is effective when it becomes law.