SENATE BILL REPORT
SHB 1079

As Reported by Senate Committee On:
Health & Long Term Care, March 21, 2023

Title: An act relating to rapid whole genome sequencing.

Brief Description: Concerning rapid whole genome sequencing.

Sponsors: House Committee on Health Care & Wellness (originally sponsored by Representatives Thai, Slatter and Ryu).

Brief History: Passed House: 2/27/23, 95-0.
Committee Activity: Health & Long Term Care: 3/16/23, 3/21/23 [DP, w/oRec].

Brief Summary of Bill

- Requires that medical assistance programs provide coverage for rapid whole genome sequencing for enrollees who are up to age 1 in accordance with the medical necessity criteria to be adopted by the Health Care Authority.

SENATE COMMITTEE ON HEALTH & LONG TERM CARE

Majority Report: Do pass.
Signed by Senators Cleveland, Chair; Robinson, Vice Chair; Rivers, Ranking Member; Muzzall, Assistant Ranking Member; Conway, Dhingra, Holy, Randall and Van De Wege.

Minority Report: That it be referred without recommendation.
Signed by Senator Padden.

Staff: Julie Tran (786-7283)

Background: A genome is a human's or other organism's complete set of genetic information. The genome of a human contains between 20,000 and 25,000 genes. Each

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gene carries information that determines a different trait, which is a feature or characteristic that may be inherited from the parents and passed down to the offspring. The molecules that make up the genome and its genes are called deoxyribonucleic acid (DNA). The genetic information in DNA is stored as a code made up of four building blocks, or bases. A gene variant is a heritable change to the DNA sequence that makes up a gene. Most gene variants have no impact on a person's health or development, but some gene variants result in genetic diseases.

Using a method or technology called DNA sequencing, it is possible to determine whether a person has one or more variants in a single gene, multiple genes, or in the whole genome. When testing for single gene variants and an analysis of one or more gene sequences does not provide a diagnosis of disease, whole genome sequencing may be used to locate rare gene variants that may be the genetic cause of the condition.

The Health Care Authority (HCA) does not have an official policy on Medicaid reimbursement for payment codes related to whole genome sequencing.

Summary of Bill: Beginning January 1, 2024, medical assistance programs administered by HCA must require provider payment for rapid whole genome sequencing for enrollees who are up to age 1. HCA must adopt medical necessity criteria for the coverage upon consideration of standards developed by the American College of Medical Genetics and Genomics and hospitals in Washington that predominantly serve children.

"Rapid whole genome sequencing" means the unbiased sequencing of all DNA bases in the genome of a patient for the purpose of determining whether one or more potentially disease-causing genetic variants are present in the genome of the patient or biological parent. It also includes any analysis, interpretation, and data report derived from the sequencing.

HCA must submit a brief summary of the process used to adopt the medical necessity criteria for rapid whole genome sequencing and the final medical necessity criteria to certain committees of the Legislature by January 1, 2024.

Appropriation: None.

Fiscal Note: Available.

Creates Committee/Commission/Task Force that includes Legislative members: No.

Effective Date: Ninety days after adjournment of session in which bill is passed.

Staff Summary of Public Testimony: PRO: One in eight Americans are affected by a rare disease and 80% of rare diseases have a genetic cause. This bill asks for Medicaid to cover rapid whole genome sequencing for those under the age of one to identify rare diseases. Early diagnosis saves lives, reduces economic impact, and prevents patients from having

interventions that are not beneficial. Genome sequencing has revolutionized overall health assessment and advances the ability to diagnose and treat cancer. Until recently, health care providers had to conduct one test at a time to diagnose genetic conditions which is time consuming, costly, and not always successful in diagnosing. Rapid whole genome sequencing combines many tests into one. This bill offers access to ending the diagnostic odyssey for patients and their families.

Persons Testifying: PRO: Representative My-Linh Thai, Prime Sponsor; Carolina Sommer, Born a Hero, Research Foundation and NW Rare Disease Coalition; Lindsey Topping-Schuetz, NW Rare Disease Coalition; Sarah Tompkins, NW Rare Disease Coalition; Jessie Conta.

Persons Signed In To Testify But Not Testifying: No one.