Human Services Committee
JOINT FAVORABLE REPORT

Bill No.: HB-5367
Title: AN ACT CONCERNING MEDICAID COVERAGE OF RAPID WHOLE GENOME SEQUENCING FOR CRITICALLY ILL INFANTS.
Vote Date: 3/19/2024
Vote Action: Joint Favorable Substitute
PH Date: 3/7/2024
File No.:

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SPONSORS OF BILL:

Human Services Committee

REASONS FOR BILL:

For newborn parents and families, having a critically ill infant can be an emotional and difficult time. Not knowing what is happening to their child or waiting weeks for a diagnosis can prevent time-sensitive care. When a disease or condition is not treated in time, it can lead to irreparable damage. Rapid whole genome sequencing is an essential tool that gives medical professionals important diagnostic information in five days or less. This information can be imperative for critically ill infants and their families. This bill looks to expand Medicaid coverage of rapid whole genome sequencing for critically ill infants. By providing life-changing diagnoses and changes in care, rapid whole genome sequencing can improve outcomes for children through effective treatments and can be cost-saving for the healthcare system.

SUBSTITUTE LANGUAGE:

The substitute language adds treatment in the pediatric intensive care unit. It includes the age of 0-12 months for qualifying infants, substitutes a longer waiver, creates a State Plan Amendment directive, and expands the DSS medical criteria charge.

RESPONSE FROM ADMINISTRATION/AGENCY:

Department of Social Services (DSS), Commissioner, Andrea Barton Reeves; opposes this bill stating having this sort of mandated coverage would unbundle the existing All Patient Refined, Diagnosis Related Group (APR-DRG) hospital payment methodology. It is stated that this would create a precedent for further unbundling of services which could then lead to an increase in costs for the administration of Medicaid payments. Additionally, it is stated

having mandated coverage for rapid whole genome sequencing is an additional expense that is not included in the Governor's recommended budget.

NATURE AND SOURCES OF SUPPORT:

BioCT, President & CEO, Jodie Gillon; supports this bill starting rapid whole genome sequencing is the most powerful tool available and will shorten the time to diagnose patients from years to days. It is stated that genetic testing is underutilized and having education and building awareness will increase utilization. It is also stated that the technology has advanced and is now available at a faster and cheaper rate.

CT Bioscience Growth Council, Senior Counsel & Executive Director, Paul Pescatello; supports this bill stating rapid whole genome sequencing decreases the diagnosis time and is a targeted solution when it is medically necessary. It is stated that this legislation is cost-effective and cost-saving for our healthcare system and will greatly help rare disease patients.

CT Chapter of the American Academy of Pediatrics, Chair of Advocacy Committee, Molly Markowitz; supports this bill stating there has been an increase in rapid whole genome sequencing in clinical settings. It is stated the use of this in intensive care settings allows medical professionals to diagnose and treat critically ill children more efficiently and effectively.

Connecticut Children's, Physician in Chief, Juan Salazar; supports this bill stating that in 2021 Connecticut Children's started a research institution, and through this, they have been able to work with the Jackson Laboratory for Genomic Medicine to put them on the cutting edge of genetics and genomics. It is stated that rapid whole genome sequencing is a tool that will allow pediatric experts to have better care for their patients by tailoring their needs to each patient. It is stated that despite insurance coverage, all critically ill children should have equitable access to various treatments and medications, including rapid whole genome sequencing.

CT Rare Disease Advisory Council, Member, Lesley Bennet; supports this bill stating that she has been advocating for medically fragile patients for over 30 years. It is stated that this legislation is important to her family since her daughter, Kelly, was born with an acute illness. It is stated that her doctors believed Kelly would have benefited from rapid whole genome sequencing. It is stated that rapid whole genome sequencing can help children who do not have a diagnosis avoid several hospitalizations, tests, and procedures.

CT Rare Disease Advisory Council, Advocate, Colleen Brunetti; supports this bill stating rapid whole genome sequencing there are about 100-150 children born in Connecticut each year with a rare disorder that is not detected by the state's newborns screening program. It is stated that the Centers for Medicare & Medicaid has sponsored pilot programs in many states to see if rapid whole genome sequencing will improve the quality of care and lower costs. It is also stated that these pilot programs resulted in improved care and cost savings for the state Medicaid program.

Jackson Laboratory, Clinical Research Project Manager, Alexandra McClellan; supports this bill stating rapid whole genome sequencing bill provides faster access to diagnostic

information as results can be received in five days or less. It is stated that having equitable coverage of rapid whole genome sequencing for critically ill children can address equity issues for those who face health care barriers.

Physician/Scientist, Joanna Gell, M.D.; supports this bill stating she has seen firsthand the difficulties families and patients go through when it comes to diagnosing and treating rare diseases. It is stated that policy needs to keep up with technology and expanding coverage of rapid whole genome sequencing can help critically ill newborns.

Olivia's Dad, Benjamin King; supports this bill sharing his family's story about his daughter, Olivia, and her diagnosis. It is stated that because of rapid whole genome sequencing, although it did not change Olivia's diagnosis, it changed the way they cared for her and interacted with her providers. It is stated that rapid whole genome sequencing should be more readily accessible and should be a standard of care for complex babies in the NICU.

Connecticut Resident, Guilford, Rennie Negron; supports this bill sharing that their child has a rare illness that took months to diagnose. It is stated that with these types of illnesses, having a timely diagnosis can ensure children are getting the care they need.

The following individuals have submitted written testimony in support of this bill.

Laura Rinaldi
Ray Rinaldi

NATURE AND SOURCES OF OPPOSITION:

None expressed.

Reported by: Chandra Persaud **Date: March 22, 2024**