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ASSEMBLYMEMBER, SEVENTY-SEVENTH DISTRICT

Assembly Bill 114

Rapid Whole Genome Sequencing

As Introduced 12/17/20

Summary

AB 114 aims to close disparities in access to life saving opportunities for critically ill babies on Medi-Cal by establishing rapid whole genome sequencing as a covered Medi-Cal benefit.

Background

In 2018 the State of California funded a $2 million pilot project which was later dubbed Project Baby Bear. The project sought to demonstrate that a rapid precision medicine program for critically ill Medi-Cal babies improves clinical outcomes, improves the experience of care, and reduces net healthcare expenditures.

When critically ill babies are admitted to the hospital, the underlying causes of their illness are likely genetic but the exact cause is not always clear. This can lead to a lengthy diagnostic process that may involve painful and risky procedures. Achieving a diagnosis often involves genetic testing which can take up to several weeks to produce results- precious time that critically ill infants often do not have

Project Baby Bear employed rapid Whole Genome Sequencing for infants at five clinical sites across the State who were critically ill with undetermined causes. Rapid Whole Genome Sequencing was used to quicken the diagnosis of rare, genetic diseases and transition patients from generic treatments to treatments that target specific conditions with known causes, thus preventing further irreversible harm.

During the course of Project Baby Bear, Rapid Whole Genome Sequencing was performed on 178 babies and families and diagnoses were provided for 76 babies. For 55 babies, the results of genome sequencing led to changes in the management of the patient's condition which resulted in fewer hospital days and fewer procedures or new therapies and 35 rare conditions were diagnosed that occur in less than one in one million babies. For families, these results meant quicker answers, less unnecessary invasive procedures, and the ability to make

informed decisions about their child's care whether that be additional treatments or palliative care.

Project Baby Bear also demonstrated $2.5 million in cost savings to the healthcare system largely due to enabling doctors to discharge babies sooner and reduce the number of procedures. Quantitatively, these informed changes in patient care led to 513 fewer days in the hospital, 11 fewer major surgeries and 16 fewer invasive and diagnostic tests.

Currently, access to rapid whole genome sequencing is limited and patients with the ability to pay have greater access than those who cannot. Private health insurance companies have begun covering sequencing, however that is not the case for families on Medi-Cal creating a disparity in access to information that could alter the course of care or even save a child's life.

This Bill

Assembly Bill 114 seeks to provide Medi-Cal patients with access to raapid whole genome sequencing by making it a covered Medi-Cal benefit for critically ill babies.

Support

Rady Children's Hospital - San Diego (Sponsor)

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