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**Rady Children's Shows Genomic Sequencing for Infants in Intensive Care
Yields Life-Changing Benefits and Medical Cost Savings**

State funded Medi-Cal pilot completed at 5 Children's Hospitals Statewide

San Diego – June 18, 2020 – In a pilot program funded by the State of California, Rady Children's Hospital-San Diego demonstrated that a rapid precision medicine program for critically ill babies enrolled in Medi-Cal produced better health outcomes and reduced suffering for the infants while decreasing the cost of their care.

Using the most comprehensive genomic test available—rapid Whole Genome Sequencing (rWGS)—the program called Project Baby Bear analyzed the genetic code of 178 infants to provide doctors and families with vital diagnostic information that empowered them to make life-altering medical decisions resulting in shorter hospital stays, fewer invasive procedures and targeted personalized care.

"Among high-risk infants with rare, genetically determined diseases, time-to-treatment is crucial," said Stephen Kingsmore, MD, DSc, President and CEO of Rady Children's Institute for Genome Medicine (RCIGM). "Project Baby Bear significantly shortened the time needed to accurately diagnose and optimally treat these critically ill children."

Project Baby Bear helped doctors identify the exact cause of rare, genetic diseases in an average of three days, instead of the four to six weeks standard genetic testing offers. This allowed physicians to deliver timely treatment tailored to the baby's specific condition.

Through the program, Rady Children's Institute for Genomic Medicine provided rapid Whole Genome Sequencing for 178 babies eligible for Medi-Cal, resulting in a diagnosis for 43% that explained the reason for the infant's admission to the hospital; 31% had changes in their medical care as a result of rWGS.

In addition, substantial reductions in healthcare spending—\$2.5 million—accrued largely because rWGS permitted doctors to discharge babies sooner (513 fewer hospital days) and reduce the number of procedures that may have been performed in the absence of a precise diagnosis. Avoided procedures included 11 major surgeries and 16 fewer diagnostic tests including open muscle, liver and other biopsies that are performed under general anesthesia.

"The economic data from Project Baby Bear showed that in addition to life-changing health benefits there are cost savings in getting a quick diagnosis from a single comprehensive test," said David Dimmock, MD, RCIGM Senior Medical Director. "Doctors were able to avoid additional testing,

ineffective treatments and lengthy hospitalizations that would have resulted in greater pain and medical spending.”

Project Baby Bear was funded by the State of California as a \$2-million Medi-Cal pilot aimed at examining the benefits of using rWGS to help improve outcomes for infants hospitalized in intensive care with undiagnosed illness and whether the use of this technology would be cost effective.

Patient blood samples were sent to RCIGM for sequencing and interpretation from the California Children’s Services accredited regional neonatal and pediatric intensive care units at the following participating hospitals:

- UC San Francisco Benioff Children’s Hospital Oakland
- UC Davis Children’s Hospital (Sacramento)
- Valley Children’s Hospital (Madera)
- CHOC Children’s Hospital (Orange County)
- Rady Children’s Hospital–San Diego

The program was championed by Assemblymember Todd Gloria (San Diego) in partnership with the California Legislative Rare Disease Caucus led by Assemblymembers Brian Maienschein (San Diego) and Rob Bonta (Oakland). Strong support also came from State Senate President Pro Tem Toni Atkins (San Diego); and Assemblymembers Joaquin Arambula, MD (Fresno); and Marie Waldron (San Diego).

Until the initiation of Project Baby Bear, Whole Genome Sequencing had not been covered by private insurance nor public health programs and was available only through clinical trials paid for by research grants or philanthropic donations.

“Project Baby Bear has shown that California is once again leading the way in improving the lives of children and families faced with unexplained rare diseases,” said Patrick Frias, President and CEO of Rady Children’s Hospital-San Diego. “Based on the results of this demonstration program, California is now in a position to be the first state to make this life-changing diagnostic solution available to every child who needs it.”

Encouraged by the early success of Project Baby Bear, the State of Florida and State of Michigan have since initiated their own publicly-funded rWGS demonstration projects. In addition, San Diego Congressman Scott Peters introduced “Ending the Diagnostic Odyssey Act of 2019” that would provide rapid Whole Genome Sequencing to diagnose children with critical unexplained conditions. That bill, HR 4144, as well as is a counterpart bill in the U.S. Senate, are now pending.

Project Baby Bear Final State Report

https://radygenomics.org/wp-content/uploads/2020/06/PBB-Final-Report_06.16.20.pdf

About Rady Children’s Institute for Genomic Medicine:

The Institute is leading the way in advancing precision healthcare for infants and children through genomic and systems medicine research. Discoveries at the Institute are enabling rapid diagnosis and targeted treatment of critically ill newborns and pediatric patients at Rady Children’s Hospital-San Diego and collaborating hospitals. The vision is to expand delivery of this life-saving technology to enable the practice of precision pediatric medicine at children’s hospitals across California, the nation and the world. RCIGM is a subsidiary of Rady Children’s Hospital and Health Center. Learn more at www.RadyGenomics.org. Follow us on [Twitter](#) and [LinkedIn](#).

About Rady Children's Hospital-San Diego:

[Rady Children's Hospital-San Diego](#) is a 505-bed pediatric care facility providing the largest source of comprehensive pediatric medical services in San Diego, southern Riverside and Imperial counties. Rady Children's is the only hospital in the San Diego area dedicated exclusively to pediatric healthcare and is the region's only designated pediatric trauma center. In June 2020, U.S. News & World Report ranked Rady Children's among the best children's hospitals in the nation in all ten pediatric specialties the magazine surveyed. Rady Children's is a nonprofit organization that relies on donations to support its mission. For more information, visit www.rchsd.org and find us on [Facebook](#), [Twitter](#) and [Vimeo](#).

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