Frequently Asked Questions

What is Project Baby Bear?
This is a demonstration project funded by the State of California to examine and demonstrate the benefits of rapid Whole Genome Sequencing (rWGS). Requested and strongly supported by Assemblymembers Brian Maienschein (R-San Diego) and Rob Bonta (D-Oakland), co-chairs of the California Legislative Rare Disease Caucus, the project aims to show that using rWGS will help improve the treatment of infants and children with undiagnosed illnesses under the care of Medi-Cal, while decreasing the cost associated with the program

What patients were served by the program?
Project Baby Bear was funded to serve a minimum of 100 Medi-Cal neonatal and pediatric patients with undiagnosed diseases that have either remained undiagnosed or had multiple incorrect diagnoses. Ultimately, 178 babies were sequenced through the project.

What hospitals are participating?
Five hospitals were selected to participate in referring patients for sequencing via Project Baby Bear. The participating hospitals are: UC Davis Medical Center (Sacramento), Valley Children's Hospital (Madera, CA), UCSF Benioff Children's Hospital Oakland, Children's Hospital Orange County (CHOC) and Rady Children's Hospital-San Diego.

What is Whole Genome Sequencing?
The purpose of whole genome sequencing is to find genetic variations that are associated with a child's health condition. DNA, which makes up our genetic code, is found in most cells of a person's body. Whole genome sequencing is a genetic test that reads through most of an individual's DNA sequence to look for changes in the 'spelling' of genes. Genes provide the specific instructions needed to tell our bodies how to grow and develop. When a gene contains a spelling error or variant, it may not work properly and can lead to a genetic disorder.

What are the benefits of Whole Genome Sequencing?
Knowing the genetic cause of a disorder can:

1) Provide a name for a condition and confirm a diagnosis
2) Help doctors more precisely manage care of a child
3) Let family members know if they are at risk to have the same genetic condition or if there is a chance of having another child with the same genetic condition.

What is the process for arriving at a diagnosis through Whole Genome Sequencing?
It begins with a blood sample from the patient. The DNA is extracted from the blood and processed through an advanced instrument (sequencer) that "reads" the entire DNA code. That data is uploaded and sorted through advanced bioinformatic computer programs that extract the parts of the data most relevant to the patient's condition. A certified medical geneticist then analyzes and interprets the data to determine if there is a genetic variant responsible for the patient's condition.

Has whole genome sequencing been previously covered Medi-Cal or private insurance?
Until now, whole genome sequencing has not been covered by any state or federal government healthcare program in the U.S. Most medical insurance providers have also not made it a covered benefit. Project Baby Bear is an important first. The State of California will closely monitor the program to determine If whole genome sequencing actually improves health outcomes and reduces healthcare costs.

AT A GLANCE

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.

President & CEO: Patrick Frias, MD
Service area: San Diego, Imperial and Riverside counties
The largest children's hospital in California (based on admissions)

NOTE: The State of California provided the funding directly to Rady Children's Hospital to administer Project Baby Bear.

About Rady Children's Institute for Genomic Medicine:
We are transforming pediatric critical care by advancing disease-specific healthcare for infants and children with rare disease. 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 a growing network of more than 60 children's hospitals nationwide. The vision is to expand delivery of this life-changing technology to enable the practice of Rapid Precision Medicine™ at children's hospitals across the nation and the world. RCIGM is a non-profit, research institute of Rady Children's Hospital and Health Center. Learn more at www.RadyGenomics.org. Follow us on Twitter and LinkedIn

President & CEO: Stephen Kingsmore, MD, DSc
Established 2014 with $120 million gift from Ernest and Evelyn Rady.
Non-profit, medical research organization

Embedded within Rady Children's Hospital, the Institute is one of the few places in the U.S. where genomic sequencing is being implemented in a hospital setting.

In February 2018, the team achieved the world speed record for fastest diagnosis via whole genome sequencing in 19.5 hours.

NOTE: Rady Children's Hospital contracted the Institute for Genomic Medicine to carry out the work of rapid whole genome sequencing as well as provide the analysis and interpretation leading to a molecular diagnosis.