



## RADY CHILDREN'S LAUNCHES "PROJECT BABY BEAR"

\$2 million Medi-Cal pilot funded by the State of California to provide genomic testing to acutely ill newborns in select cities across California

San Diego – Sept. 26, 2018—Rady Children's Hospital-San Diego is launching Project Baby Bear, the first California State funded program to offer rapid whole genome sequencing (WGS) for critically-ill newborns.

The \$2-million Medi-Cal pilot program will provide genome testing for babies hospitalized in intensive care. Project Baby Bear will leverage rapid WGS as a first-line diagnostic test done by Rady Children's Institute for Genomic Medicine for babies at four participating hospitals statewide.

"We are honored to be selected as the first California children's hospital to use the Medi-Cal platform to deliver access to this life-changing test to children who need it, regardless of their family's ability to pay," said Donald Kearns, MD, MMM, President and CEO of Rady Children's. "California is once again leading the way in improving the lives of children and families with Project Baby Bear."

Whole genome sequencing has been used at Rady Children's to diagnose babies and children hospitalized in intensive care with rare diseases since July 2016, but only as part of clinical trials. As of Sept. 20, the Institute has sequenced nearly 1,200 children. More than one-third (34 percent) received a genomic diagnosis enabling physicians to make life-changing adjustments in care for 70 percent of those diagnosed.

Until the initiation of Project Baby Bear, whole genome sequencing has not been covered by insurance or Medi-Cal and was available only through clinical trials paid for by research grants or philanthropic donations.

At the launch announcement held today (Sept. 26) at Rady Children's, Stephen Kingsmore, MD, DSc, President and CEO of Rady Children's Institute for Genomic Medicine, introduced a mother whose newborn received a life-saving diagnosis through genomic sequencing.

Kara Coltrin shared the story of how her son suffered unrelenting seizures that took him to the brink of death before WGS pinpointed the cause of his illness and led doctors to change his treatment. "Genomic testing saved his life," she said. "We're blessed to be able to share his story so that we can help other children have access and give their parents hope."

The Rady Children's Institute for Genomic Medicine team led by Kingsmore holds the world record for fastest diagnosis through genomic sequencing at 19.5 hours. "Here at Rady Children's, we've seen that using whole genome sequencing to diagnose and guide the care of





babies hospitalized with rare diseases is reducing suffering and infant mortality, decreasing hospital stays and healthcare costs,” Kingsmore said.

“We are enormously grateful to the leadership of our elected officials in California for their willingness to support this important demonstration project,” Kingsmore added. “It’s our belief that rapid whole genome sequencing should become a first-line diagnostic test and standard of care in neonatal intensive care units everywhere.”

The program was championed by the California Legislative Rare Disease Caucus co-chaired by Assemblyman Brian Maienschein. He was among the lawmakers on hand for the program launch at Rady Children’s Hospital. Also attending was State Senate President Pro Tem Toni Atkins, Assemblyman Todd Gloria and State Secretary of the California Health and Human Services Agency Michael Wilkening.

