DNA sequencing saves newborns' lives, but what happens to personal genetic information?

By two months of age, the boy was near death. He had spent his entire short life in the neonatal intensive care unit (NICU) at Children's Mercy Hospital in Kansas City, Missouri, while physicians tried to work out the cause of his abnormalities. When his liver failed in April 2013, the medical staff warned his parents that the outlook was grim.

Then geneticist Stephen Kingsmore and his team at Children's Mercy took on the case. Within three days, they had sequenced the genomes of the baby and his parents, and identified a rare mutation that was common to the child and both of his parents. The mutation turned out to be linked to a disease in which an overactive immune system damages the liver and spleen. Armed with a diagnosis, the baby's physicians put him on drugs to lower his immune response. The boy is now at home and healthy. Had physicians sent his DNA off for a conventional genomic test, the diagnosis could have taken more than a month — by which time he would probably have died.

Misha Angrist, a genomic-policy expert at Duke University in Durham, North Carolina, says that although the 24-hour genome process is impressive, it is not clear whether genomic sequencing of newborns will soon become standard practice. Many questions remain about who will pay for sequencing, who should have access to the data and how far clinicians should go in extracting genome information that is unrelated to the disease at hand. Then there is the question of how informative the process is.

Read full, original article: Fast genetic sequencing saves newborn lives