‘Really tough decision’: What should doctors do when genetic testing reveals that dad isn’t the child’s biological father?

The child was critically ill. The treating team at Children’s National Hospital in Washington, DC, was stumped and worried that time was running out. Every test was coming back negative.

Genetics was called in to look for chromosomal mutations that might suggest the source of the problems. The geneticist recommended whole-exome sequencing, which tells a story based not only on all of the child’s genes, but on two additional sources as well: the mother’s and the father’s genes.

They found something they weren’t looking for. The father, the worried man in the waiting room who raised this child, wasn’t the biological father. In genomics it’s called an “incidental finding,” and it raises huge ethical questions: Do you reveal this to the parents? Only to the mother? Or, if the results don’t affect the child’s care, do you even tell anyone?

In this case, the team called on the hospital’s ethics committee for help.

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“I think withholding information can feel paternalistic,” [genetic counselor Monisha Samanta] Kisling says. “We don’t want to say, ‘Hey, I don’t think you can handle this information.’ That’s not necessarily our judgment call to make. Overall, it’s just a really, really tough decision.”

Read full, original post: ‘You’re Not the Father’: A Moral Dilemma in Genetic Testing