

Real Life Stories

Taking Baby DNA

The MN Dept. of Health is violating the written informed consent requirements of the MN genetic privacy law for the taking, storage, and use of newborn blood, baby DNA, and newborn genetic testing results. MDH now seeks to pass legislation to eliminate these consent requirements altogether. CCHC has been contacted by parents and others concerned about the Baby DNA bill's repeal genetic privacy rights and of informed written consent (HF1760/HF1341/SF1478). Here are two stories we've received:

Never Told: The 48 hours in the hospital setting for a birth is a zoo. Everyone's coming in at all hours. My wife was hardly left alone. In fact, for our fourth child, my wife says it was such a blur that she can hardly remember choosing our son's name. I can guarantee that both she and I would remember if a 4-page document had been placed in front of us explaining why the MDH was going to store my son's DNA for its own purposes following the PKU testing. No such information was provided, not even a paragraph. Indeed, I didn't learn about the MDH's practice until about 2 months ago, a full 6 months after my son's birth. And I had to learn about it from a non-profit organization concerned about the rights of citizens in this state. That, to me, is utterly disturbing. – Father, West Metro, MN

Requested, Not Told: For our first three children, I was NEVER showed any information in the hospital, making me aware of the storage of my babies DNA samples. There was no paper in my stack that explained what was going to happen with this blood sample and there was no paper provided saying I could opt out, until our newest child was born 5 days ago, only because I REQUESTED it being I now knew about what has been illegally going on. – Mother, Cokato, MN