

Real-Life Stories

Taking Baby DNA

Citizens' Council on Health Care has received email and phone calls from parents and others concerned about the Baby DNA bill that is set to eliminate current genetic privacy rights and informed written parent consent requirements for the collection, storage, use of, and research on newborn blood, baby DNA, and newborn genetic testing results (HF 1341/SF1478). Here are two short stories we've received:

Parent: We have four children. We had no idea that this was being done. The nurses may have brought us some forms for us to sign. If they did, I am sure my wife and I signed them thinking that they were just routine papers when a child is born. Really though, we have no idea if they even had us sign anything. I do know that we were not explained anything about the collection of our children's blood or DNA. I find this very disturbing and outrageous. I want my children's private information back. They are not the state's guinea pigs. They are my wife's and my children, and their blood and DNA is their private genetic information – Taconite, MN

Parent: Our nurses didn't even know we could opt out, or that any collection was going to the government. We kept being redirected as to who to go to to get the right paperwork. Postpartum nurses, nursery nurses, HUCs, no one knew where to find it. Eventually the head nurse got the proper form for us...Everyone was shocked when we told them that the collection was going on...When we got the letter from the government saying that they had destroyed the sample, they didn't spell our child's name correctly. It makes us wonder if they even destroyed our child's sample. – Woodbury, MN