

# BIG BROTHER KIDNAPPING YOUR BABIES' DNA?

Because I was diagnosed with breast cancer at a really young age, doctors routinely ask if I want to undergo genetic testing. I've always responded that I'd be happy to give researchers DNA material, and even to arrange for other family members who might be of interest to donate their DNA, too (there's a small chance there's a fairly funky genetic issue in question). But they always push, instead, to have me to do the paid genetic testing counseling following by the even more highly paid genetic testing targeted for the patented BCRA genes (for which I'm a less likely candidate). The explanation is at least partly the hospital wants me to undergo the counseling so I can give informed consent to what genetic testing might mean.

Apparently, newborn babies in a number of states are having the opposite problem: doctors submitting their DNA for research without either notice or consent.

Newborn babies in the United States are routinely screened for a panel of genetic diseases. Since the testing is mandated by the government, it's often done without the parents' consent, according to Brad Therrell, director of the National Newborn Screening & Genetics Resource Center. In many states, such as Florida, where Isabel was born, babies' DNA is stored indefinitely, according to the resource center.

[snip]

Genetic testing for newborns started in the 1960s with testing for diseases and conditions that, if undetected, could kill a child or cause severe problems, such as mental retardation. Since then,

the screening has helped save countless newborns.

Over the years, many other tests were added to the list. Now, states mandate that newborns be tested for anywhere between 28 and 54 different conditions, and the DNA samples are stored in state labs for anywhere from three months to indefinitely, depending on the state. (To find out how long your baby's DNA is stored, see [this state-by-state list](#).)

Brad Therrell, who runs the federally funded genetic resource consortium, says parents don't need to worry about the privacy of their babies' DNA.

"The states have in place very rigid controls on those specimens," Therrell says.

Now, there may be really good public health reasons for this. But considering increasing efforts to collect DNA databases for criminal reasons, not to mention the efforts to profit off of this, it seems like hospitals ought to be far more transparent about this process.