

Prepared Testimony – Twila Brase, President and Co-founder
SF 2047, Newborn Screening modifications (Marty)
Thursday, March 20, 2014, 6:00 p.m. Hearing
Senate Judiciary Committee

Mr. Chair and Members of the Committee,

As a starting point, let me reiterate that newborn screening is the “largest single application of genetic testing in medicine,” according to Dr. Jeffrey Botkin, MD, MPH, at the university of Utah’s Department of Pediatrics and Medical Ethics. Also, I’d like to draw to your attention the written testimony submitted by the Council for Responsible Genetics, and Minnesota ACLU which both oppose this bill. The Council notes that that language is in opposition to recommendations by national committees and research studies.

Second, to be clear, this bill is not about the newborn screening program. Babies are being tested today like they were before and after the lawsuit against the Department’s violation of the genetic privacy law. Instead, this bill is focused on what happens after the newborn screening is over. It’s focused on who gets primary control of the DNA of every newborn and who gets secondary control. This bill shifts power from parents to government. SF 2047 gives government first dibs to the genetic code of all newborns.

I’d like to draw to your attention to several concerning changes proposed in the bill. On line 1.24, the Department is required to only disclose information on a form parents may never actually see regarding the benefits of storage, not risks such as government ownership of the DNA and genetic code of the child. On line 4.8, the requirement to also disclose risks is being deleted. On line 3.31, the requirement to disclose identification and use of the child’s DNA for genetic research or “test development” is repealed. The switch from consent to dissent is found on lines 2.1, 2.17 and 2.31. On line 3.16, genetic research without consent is being added to newborn screening program operations. On line 4.26 genetic research is being deleted from the section requiring consent. And finally, the repealer on line 5.16 repeals the 71 day and 24 month standard retention times, making the storage of the child’s genetic information forever – unless the parents discover what happened and sign a dissent form and send it to the Department.

This bill is a dissent bill. It eliminates consent. Consent is an affirmative action taken by an individual; a signature on a paper that permits the government to go ahead after the parent has been fully informed of the purpose of the government’s request for genetic data. In other words: No signature. No storage. No signature. No use. No signature. No analysis. No signature. No research. No signature. No sharing.

Today in Minnesota, the newborn screening law has a consent requirement for storage, use and dissemination. This bill only allows dissent. The health department told Minnesota Public Radio (MPR) that the consent process is too burdensome for them and that only 200 people consented to government storage and use. Perhaps the rest valued their privacy. So now, the Departments wants to take and use what isn’t theirs to take and use – the genetic code of a child – and place the burden on *parents* to stop the government from the

infringement. The Department knows most people will not opt out because of the burden or because they have no idea it ever happened. Some describe being in a “fog.” And if parents do opt out – if they dissent – the government will also keep a record of anyone who refused the intrusion.

The federal government already has a model consent form for genetic research (“MODEL CONSENT LANGUAGE” from the eMERGE Networks, Dec. 5, 2009). I’ll submit it for the record. And genome.gov discusses special concerns about studying children and getting parental consent (“Special Informed Consent Considerations,” National Human Genome Research Institute, <http://www.genome.gov/27026636>, Last updated Feb 19, 2014, and accessed March 20, 2014). I’ll submit that for the record as well.

Minnesota is one of the only states to truly protect genetic privacy. Oklahoma is another. Their law says, all laboratories, medical facilities, hospitals and birthing places are “prohibited from the unauthorized storage, transferring, use or databasing of DNA from any newborn child without express parental consent.”

In a study called “Not Without My Permission,” Dr. Beth Tarini, MD, at the University of Michigan discovered that only 28.2 percent of parents were very or somewhat willing to have their newborns participate in research if they were not asked for their consent. That means 71.8% would refuse if not asked for permission.

SF 2047 ignores the 71.8%. It says the state doesn’t have to ask for permission. It keeps parents in the dark at a vulnerable time in their life – the delivery of a new child. It eliminates government transparency, moving the state’s genetic storage and use research program from sunshine to secrecy. It eliminates parent and individual consent requirements. It creates a large government genetic research program with access to the genetic code of every citizen and non-citizen born from now into the future. It violates Article 1, Section 10 of the Minnesota Bill of Rights within the Minnesota Constitution, a right that aligns with the Fourth Amendment against unreasonable search and without a warrant and probable cause.

For six years while the state was taking baby DNA we had a campaign to inform people about the government’s storage, use and sharing program to encourage them to consider private screening. But for the last two years Minnesota has had consent requirements.

But if this bill is passed, you should expect more parents to refuse newborn screening, putting their children at risk. Before the MN Supreme Court ruling gave parents consent rights, our organization was the only one informing parents about the department’s secret genetic storage and use program. In 2003, two families refused newborn screening. In 2008, 89 families refused.

This bill puts children at risk and repeals the state genetic privacy Act without actually repealing the statute. It’s a repeal of genetic privacy. It’s also a coercive abuse of trust. The government is taking advantage of the parents when they are in a trusted institution and

distracted by the birth of a child and definitely not thinking about the long arm of government reaching into the bassinet to take their child's DNA.

We ask you to vote No SF 2047.