



# Citizens' Council on Health Care

*A free-market resource for designing the future of health care*

## **CCHC Testimony Informed Consent for Newborn Genetic Testing SF 3344 – Senator Linda Scheid March 30, 2006**

In 2003:

- The Minnesota Department of Health asked for and was allowed to expand from 5 genetic tests to a number determined at their own discretion. No public comment or legislative notification is required. More than 50 are being done now.
- The legislature required that parents be told they can refuse testing—or allow the full roster of tests to be done by the State of Minnesota but require the results and the blood samples to be destroyed.
- There was no requirement for informed consent; no requirement that the testing be discussed; no requirement that parents be told that the testing is genetic testing or offered options for private testing.

**We began hearing from parents.** The opt-out was not being offered.

**Six reasons why opt-in parent consent should be required by law:**

- 1) **Opt-out is not Informed Consent.** Opt-out (current law) means that genetic testing takes place unless tired, overwhelmed, frazzled new parents get the information, read the information, and say no before the testing occurs.
- 2) **This is an all or nothing testing program.** To get the PKU – the test most parents care about – parents must allow their children to be tested for the full roster of tests. All test results, even those they don't want done, or those that could some day negatively impact insurance or employment, end up in the child's permanent medical record.
- 3) **Little attention to the downsides of blood spot retention.** Only benefits of specimen retention must be discussed. But what does it mean to have your DNA-rich blood spot in a state repository and available to others? Some want to use them to build a citizen DNA database.
- 4) **Linking of government databases.** The Minnesota Department of Health has started to electronically link various child health databases to the child's birth certificate. Are we building citizen profiles from birth?
- 5) **Government List of Parents.** Opt-out requires parents to sign a form that gets sent to the government. What should be a private medical decision thus creates a government record on the parent, and a roster of all parents who opt out.
- 6) **Unconsented Genetic Research.** The Health Department is making the blood spots available for medical and genetic research without parent consent.