



Citizens' Council on Health Care

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OPEN LETTER TO GOVERNOR TIM PAWLENTY

May 5, 2007

Governor Tim Pawlenty
Office of the Governor
130 State Capitol
Saint Paul, MN 55155

Dear Governor Pawlenty,

Please pick up your veto pen. You have a critical decision to make.

The future of human rights, privacy rights, and the rights of human subjects in genetic research will be determined by your decision to sign or veto S.F. 3138.

S.F. 3138 eliminates **current** legal informed written parent consent protections for the Minnesota Department of Health's genetic research program.

Today, parents must give their consent *before* the health department can store, use, or share their newborn baby's DNA for the department's genetic research program.

If you do not veto S.F. 3138, the bill will take away today's informed consent requirements and make Minnesota citizens available for involuntary genetic research.

In short, if S.F. 3138 becomes law, current ethical standards, research standards, privacy standards, and human rights standards will be eliminated. If you do not veto S.F. 3138, your administration will usher in a standard supportive of involuntary research on human subjects.

Without consent, the blood and DNA of newborn citizens could be used to create genetic profiles on citizens, analyze blood for the presence of genetic defects, assess citizen for future disease potential, and conduct research, which may be objectionable to the subject of that research.

We believe that this is not the legacy you wish for the Pawlenty administration.

Please recall that an administrative law judge ruled in March 2007 that the 2006 Minnesota Genetic Privacy Law legally requires the Minnesota Department of Health to get informed parent consent before storage, use and dissemination to researchers of newborn citizen blood and DNA.

Rather than comply with the judge's decision—or state law—the Commissioner of Health brought S.F. 3138 to the legislature to specifically exempt the health department's DNA analysis and genetic research program from the informed consent requirements of the Minnesota Genetic Privacy Law.

What does this mean in real numbers? As I said in our press conference last Thursday (*YouTube video available online on our website – www.itsmydna.org*):

If this bill becomes law, it means that the **780,000 children** whose DNA has already been claimed as state property (and illegally stored in what we call the Minnesota “DNA Warehouse”) will not be protected by the Minnesota genetic privacy law. Like the **42,210 children** who have already been [involuntary] subjects of government genetic research, the DNA and genetic information of all 780,000 children can be used and given to researchers now and into the future without consent. It means that the **73,000 children born each year** whose DNA is added to the warehouse will not be protected by the informed consent requirements of the genetic privacy law.

It means that the DNA and genetic code of our youngest citizens can be profiled, probed, analyzed and experimented on *into adulthood* without consent—unless the parent in the midst of labor, delivery and mind-numbing, post-delivery exhaustion understands the sweeping research authority of the State and takes steps to object.

But, let’s be clear, the right to object is not the right to be fully informed. And the right to object is nowhere close to the legal rights of opt-in consent, which we have in law today—and SF 3138 is about to eliminate.

Two years ago the Minnesota legislature looked into the future and rightly saw the critical need to protect citizens from having their DNA and genetic information collected, stored, used, and shared by government agencies and others. The 2006 legislature took action to protect the citizens of Minnesota from involuntary genetic research. They passed the 2006 Minnesota Genetic Privacy Law (Minn. Statutes 13.386), which requires informed consent for collection, storage, use and dissemination of the genetic information of individuals.

S.F. 3138 is about to undo that law...and the legal rights of parents, families and individuals.

If you do not veto S.F. 3138, the legal right of citizens to be fully informed, the legal right of informed consent, and the legal right of citizens to protect themselves and their families from the genetic research agendas of the Minnesota Department of Health and others will be eliminated.

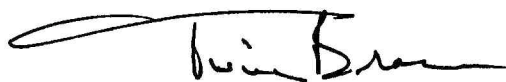
In 2006, informed consent became a legal requirement and a guaranteed right of citizens. In 2008, will citizens lose this right?

The decision rests on you. Your decision will define your administration’s legacy in protecting the rights of all Minnesota citizens. Will you veto S.F. 3138 to protect citizens, or make the bill law and leave citizens vulnerable to becoming involuntary subjects of government research?

The decision is yours alone.

We ask you to protect individuals and families by using the strong stroke of your veto pen.

Sincerely,



Twila Brase
President



Martin N. Kellogg
Chairman