The ACLU of Minnesota is a nonpartisan, nonprofit organization dedicated to protecting the civil liberties of all Minnesotans under the United States and Minnesota constitutions. We have 8,500 members throughout Minnesota, and promote our mission through litigation, public education and lobbying efforts.

The ACLU of Minnesota opposes HF 2526. This bill represents a dangerous effort to enable unlimited retention and minimize parental consent, allowing newborn blood samples to be used at the whim of the government and researchers, rather than through the consent of the newborn and their family.

To be clear, the ACLU of Minnesota supports screening for identifiable conditions which could result in substantial harm to the child if not immediately detected and treated. However, outside of this narrow use of the samples, informed parental consent is necessary, including the retention of samples after completion of the screen and research use of the samples by states and third parties.

This bill is problematic for numerous reasons. It represents a radical departure from traditional practice. It implicates important privacy and self-determination interests. The information is not anonymous. Finally, obtaining informed consent for the retention and later use after newborn screening for all purposes is not only possible but practical.

HF 2526 represents a radical departure from the traditional use of newborn blood samples. The program was originally developed for the benefit of the health of the child whose blood is taken. HF 2526 transforms this program into one geared towards benefitting medical research at the expense of individual rights. The bill is also troubling because it takes a blood sample originally used for a clear and finite use and extends this to an indefinite array of possible uses.

This bill unnecessarily implicates important privacy and self-determination interests, ignoring them in favor of a policy of unlimited retention and unknown future use of an individual’s genetic material for research without informed consent. Some parents, even those who agree with the blood sampling in general, do not wish to give up control over the future uses of the sample. Their legitimate reasons include religious beliefs, fear of discrimination because of genetic profiles showing a predisposition to certain diseases, a desire not to know what diseases their children are predisposed to such as Alzheimer’s, the belief that genetic info is their own business, not the government’s, and concerns about future potential for law enforcement uses of
samples. Even parents who would gladly consent to some types of research object to others. HF 2526 would rob them of the ability to make this determination.

The argument that these problems are solved by making the blood sample anonymous is meritless. The samples contain DNA which makes anonymity impossible. Individual identification is currently possible where a reference sample is available. The ability to identify individuals using DNA is only advancing. These advances, along with the relative ease of disseminating the information, make it more important than ever to obtain consent for use of the samples.

There is a simple solution to the difficulties caused by HF 2526. The bill should require informed consent through an opt-in provision for all collection, storage, use and dissemination of newborn blood samples other than for screening for identifiable conditions which could result in substantial harm to the child if not immediately detected and treated. Past this narrow exception, the government interest is inadequate to support nonconsensual use of samples.

A parent who consents to secondary uses of infant’s blood must know: (1) what tissue is being collected and what information can be extracted from that tissue; (2) period of time over which the sample and any derivative information will be stored; (3) any and all purposes for which the sample and derivative information will be used; and (4) to whom and under what circumstances the sample or any data drawn from it may be released to third parties. In addition, the parents must be provided with appropriate privacy notifications sufficiently in advance of the collection in order to deliberate and make a decision. Every parent must be informed of their right to learn later whether and to whom the sample and associated info has been disclosed, and how they may later withdraw their consent.

Informed consent through an opt-in provision is absolutely necessary to protect the rights of each party involved. It is also unlikely to have a great effect on the interest of the government: to obtain a satisfactorily broad pool of samples for research. A consent requirement enables the parents with these concerns to opt-out of certain uses of their children's blood samples, while allowing the others to donate their children's blood samples to public health research.

Minnesota should pass legislation to aid public health research, however, not at the cost of individual rights over genetic material. An opt-in informed consent requirement would be simple, uncostly, and would allow the government to reach its research goals without violating the rights of parents and children. Accordingly, we respectfully urge this Committee to oppose HF 2526.