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Coalition Supports Parental Consent for Use of Newborn DNA in Research

Thirty-four Organizations Send Coalition Letter to U.S. Senator Lamar Alexander, Chairman of the U.S. Senate HELP Committee

ST. PAUL, Minn. — Citizens’ Council for Health Freedom (CCHF) formed a nationwide coalition in support of Senator Lamar Alexander, Chairman of the U.S. Senate Committee on Health, Education, Labor and Pensions (HELP), and his decision to protect the genetic privacy rights of newborns.

CCHF, along with 33 other organizations, penned a May 14, 2020 letter to Chairman Alexander thanking him for adding parental consent requirements to the Newborn Screening Saves Lives Reauthorization Act of 2019.

“Thank you for your consideration of the privacy issues concerning newborn screening and the issues surrounding state government storage, use and sharing of the newborn’s dried blood spots (DBS). We greatly appreciate that you have added language to the Newborn Screening Saves Lives Reauthorization Act of 2019 that will require parent consent for the use of DBS—newborn DNA—in federally funded research,” states the coalition letter.

“We are pleased that Senator Lamar Alexander is moving to protect children from becoming the unwitting and unwilling subjects of genetic analysis and exploitation in federally-funded research,” said Twila Brase, president and co-founder of CCHF.

Newborn genetic screening is conducted on almost every newborn within 48 hours of birth. After delivery, the baby’s heel is pricked and drops of blood are squeezed onto a piece of special filter
paper. These blood spots are then dried, sent to the state’s public health laboratory and tested for all or most of the 35 genetic conditions recommended by a national panel. Some states test for additional conditions.

“Many parents have no idea that newborn screening happened. Even for those who do know, most don’t realize that this is a government genetic testing program,” Brase added. “They don’t know that the government keeps the results of the tests and may store, use, and share the information and the newborn’s DNA for purposes unrelated to the newborn screening program. Much of this is done in secret, without consent from the child’s parents.”

In some states, the DNA-rich blood spots are sold. As CBS San Francisco reported in 2018, California gives newborn DNA to researchers for $20 to $40 per blood spot, without parent knowledge or consent. Mothers interviewed for the story were surprised and upset.

“What is being done to newborn citizens without their consent or the consent of their parents could not be done to adult citizens,” Brase said. “The government cannot take the DNA of adults, or store, use, analyze or share it without specific and informed consent, unless the adult is a criminal or suspected criminal. Babies are not criminals, but too many state governments, and those who want the child’s DNA for research, have laid an improper claim on the genetic information of America’s children.”

CCHF maintains a patient-centered, privacy-focused, free-market perspective. CCHF has worked in its home state of Minnesota and at the national level for more than 20 years to protect health care choices, individualized patient care, and medical and genetic privacy rights. In 2016, CCHF launched The Wedge of Health Freedom, an online directory of direct-pay practices (JointheWedge.com)

Twila Brase, RN, PHN has been named by Modern Healthcare as one of the “100 Most Powerful People in Health Care.” She is the host of the daily Health Freedom Minute radio program heard by over 5 million weekly listeners on more than 800 radio stations nationwide, and the author of the four-time award-winning book, “Big Brother in the Exam Room: The Dangerous Truth About Electronic Health Records.

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