

## \*\*\*NEWS RELEASE\*\*\*

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# Whose DNA Is It, Anyway?

## *Citizens' Council for Health Freedom Attending National Conference in D.C. That Will Address Pressing Privacy Issues*

**ST. PAUL, Minn.**—Twila Brase, president and co-founder of *Citizens' Council for Health Freedom (CCHF, [www.cchffreeedom.org](http://www.cchffreeedom.org))*, will be attending a conference in Washington, D.C., today and tomorrow, hosted by the Association of Public Health Laboratories, that will look at newborn screening research and programs.

Brase will attend as a representative of patient freedoms and privacy protections, as the event will consider the impact of newly implemented requirements mandating parental consent before federally funded research can be conducted on newborn bloodspots.

Last year, *CCHF* was instrumental in advocating a parental consent requirement as part of the Newborn Screening Saves Lives Reauthorization Act of 2014, which passed both houses of Congress and was signed into law on December 18.

*“CCHF has long fought for the inclusion of informed consent requirements before newborn bloodspots can be stored and used for research,” Brase said, as she prepared to depart for the nation’s capital. “But now, lawmakers, researchers and others are looking for ways to get around the built-in consents that protect parents, their newborn babies, and these infants as they grow into toddlers, children, teens and adults. We look forward to listening to this interesting conversation and to continuing to serve as advocates for patient rights and protections before a person’s private genetic blueprint becomes the subject of government research.”*

*CCHF*, a Minnesota-based national organization dedicated to preserving patient-centered health care and protecting patient and privacy rights, has been a major player in many of the issues being discussed today and tomorrow at the event, titled “A National Conversation on Newborn Screening Research and Informed Consent.”

Interested media may interview Brase while she is participating at the conference, in order to hear about the most up-to-date issues being discussed in the sessions. Namely, Brase will pay close attention to three key issues:

1. **What is research?** One session today will focus on “What Constitutes Newborn Screening Research: An evaluation of essential program activities for screening and new conditions.” Brase says if the generally accepted meaning of “research” is redefined, some informed consent requirements may not apply to the tests.
2. **Broad Consent Packages:** Some attendees at the conference, Brase says, will be looking for ways around these relatively new informed consent requirements. For instance, a session tomorrow titled, “Informed Consent for Newborn Screening Research: Examples of a Broad Consent Package,” will examine how states approach informed consent, how informed consent is funded and a model of “broad consent.” Brase is concerned that the push will be for hospitals and clinics to ask parents to sign one sheet of paper, in the midst of the stress of welcoming a newborn, that will allow researchers and the government to have access to their baby’s health information in one fell swoop.
3. **Newborn screening and Electronic Health Records (EHR):** As the federal government pushes newborn screening to include genome sequences, a person’s medical records may soon contain their genetic code, accessible for many to see without the express consent of the parents or the individual.

For more information about **CCHF**, visit its web site at [www.cchfreedom.org](http://www.cchfreedom.org), its Facebook page at [www.facebook.com/cchfreedom](http://www.facebook.com/cchfreedom) or its Twitter feed, @CCHFreedom.

*Citizens’ Council for Health Freedom is a patient-centered national health freedom organization based in St. Paul, Minn., that exists to protect health care choices and patient privacy. CCHF sponsors the daily, 60-second radio feature, Health Freedom Minute, which airs on approximately 350 stations nationwide, including 200 on the American Family Radio Network and 100 on the Bott Radio Network. Listeners can learn more about the agenda behind health care initiatives and steps they can take to protect their health care choices, rights and privacy.*

*CCHF president and co-founder Twila Brase, R.N., has been called one of the “100 Most Powerful People in Health Care” and one of “Minnesota’s 100 Most Influential Health Care Leaders.” A public health nurse, Brase has been interviewed by CNN, Fox News, Minnesota Public Radio, NBC Nightly News, NBC’s Today Show, NPR, New York Public Radio, the Associated Press, Modern Healthcare, TIME, The Wall Street Journal, The Washington Post and The Washington Times, among others. She is at the forefront of informing the public of crucial health issues, such as intrusive wellness and prevention initiatives in Obamacare, patient privacy, informed consent, the dangers of “evidence-based medicine” and the implications of state and federal health care reform.*

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**For more information or to interview Twila Brase, president and co-founder of Citizens’ Council for Health Freedom, contact Deborah Hamilton at 215-815-7716 or 610-584-1096, ext. 102, or Beth Harrison at 610-584-1096, [Media@HamiltonStrategies.com](mailto:Media@HamiltonStrategies.com).**