

**\*\*\*Statement\*\*\***

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***Government ‘Common Rule’ for Research Strips  
Nation’s Newborn Citizens of Privacy Protections***

***Citizens’ Council for Health Freedom Will Urge Congress to  
Consider Changes to Final Common Rule During Review Process***

**ST. PAUL, Minn.**—The U.S. Department of Health and Human Services and 15 other federal agencies today issued the final rule on “Federal Policy for the Protection of Human Subjects,” typically called “The Common Rule.”

According to an HHS news release, the rule updates “regulations that safeguard individuals who participate in research,” but ***Citizens’ Council for Health Freedom (CCHF, [www.cchffreedom.org](http://www.cchffreedom.org))***, a national health freedom and patient advocacy organization, says the rule leaves the country’s youngest citizens out in the cold when it comes to patient privacy.

Twila Brase, president and co-founder of ***CCHF*** released the following statement today about the rule.

***“Special protections for the genetic privacy of children and newborn citizens were originally set forth in the Newborn Screening Saves Lives Reauthorization Act of 2014, but it appears those protections have been lost,” Brase said. “Now, we will urge Congress to use the Congressional Review Act to reconsider this rule due to the absence of those 2014 protections in the final Common Rule.”***

Brase added that today’s new Common Rule, for which most provisions will go into effect in 2018, states that the Newborn Screening Saves Lives Reauthorization Act of 2014 “made a number of changes relevant to the HHS regulations for protecting research subjects, including asserting that research with newborn dried blood spots (DBS) that is federally funded pursuant to the Public Health Service Act is to be considered research with human subjects, and that the provisions allowing IRBs to waive consent would not apply. By statute, the changes made by this law applied only until changes to the Common Rule are promulgated. **Thus, the changes made by this statute will no longer apply after the effective date of this rule, January 19, 2018.**” [emphasis added]

***CCHF*** has been instrumental in securing the protection of newborn bloodspots (“Baby DNA”) and in requiring consent from parents before federal agencies can study the bloodspots of newborns.

Earlier this year, ***CCHF*** launched ***The Wedge of Health Freedom ([www.JointheWedge.com](http://www.JointheWedge.com))***, an initiative to transform and simplify health care in America, starting with direct payment between

patients and doctors. Once the hundreds of third-party-free doctors practicing today nationwide join **The Wedge** and are a part of the “Map of Freedom,” patients will be able to easily find them and embark on a journey back to freedom, affordability and simplicity. These [Wedge practices](#), where patients can find affordable, confidential, patient-centered care, are located in 42 states and can be found online.

**CCHF** is a national patient-centered health freedom organization existing to protect health care choices, individualized patient care, and medical and genetic privacy rights. For more information about **CCHF**, visit its web site at [www.cchffreedom.org](http://www.cchffreedom.org), its [Facebook](#) page or its Twitter feed @CCHFFreedom. For more about **The Wedge of Health Freedom**, visit [www.JointheWedge.com](http://www.JointheWedge.com), **The Wedge** [Facebook](#) page or follow **The Wedge** on Twitter @wedgeoffreedom.

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*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*

**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, or Beth Harrison at 610-584-1096, [Media@HamiltonStrategies.com](mailto:Media@HamiltonStrategies.com).**