



NEWS RELEASE

For Immediate Release
February 25, 2014

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Citizens' Council for Health Freedom **Celebrates 20 Years of Progress**

For 20th Anniversary, CCHF Looks Back on Four Major Accomplishments That Changed the Face of Health Care

ST. PAUL, Minn.—Over the past two decades, there has been a tireless force in the crusade to preserve patient-centered health care and protect patients' rights. The organization is the Minnesota-based *Citizens' Council for Health Freedom*, co-founded in 1994 by Twila Brase.

Twenty years ago, *Twila Brase and Martin Kellogg co-founded a* free-market resource for designing the future of health care. In 2010 the organization changed its name to *Citizens' Council for Health Freedom* to better incorporate its initiatives to protect private patient data and secure citizens' health care rights. With the slogan, "Securing Health Freedom for All," *CCHF's* mission is to "protect health care choices and patient privacy."

Through radio programming, media appearances, patient newsletters, press releases and publications, and by testifying at government hearings and speaking at events, Brase educates on topics related to *CCHF's* goals, which include: working toward individual patient and practitioner freedom; protecting patient autonomy and dignity through medical record privacy and patient consent provisions; reducing dependency on government health care programs; creating a free and open health care market and non-managed care health insurance options, as well as market competition at the patient and consumer level; fighting for equal tax treatment for purchase of health care insurance; supporting privately owned insurance independent from employment; advocating life-long insurance policies; securing a charitable safety net strengthened through tax incentives; and eliminating taxes on health care services.

Over the past 20 years, *CCHF* has made major breakthroughs in the world of health care and patient rights. Notably, four recent accomplishments have changed the face of health care and given patients new freedoms and protections.

Health Freedom Minute

Brase's daily 60-second Health Freedom Minute radio feature is heard on stations around the country. The program has experienced exponential growth and is now available on nearly 400 radio stations nationwide—150 within the American Family Radio Network and more than 90 on the Bott Radio Network.

Brase addresses hard-hitting, timely topics on Health Freedom Minute, including the Affordable Care Act or Obamacare, HIPAA, protecting patient data, Baby DNA, health information technology, medical ethics and the sharing of medical records, among many others.

Baby DNA Victory

Last month, *CCHF* and residents of Minnesota scored a victory for patient freedom and the protection of private medical data with the settlement of a Minnesota Supreme Court case that pitted 21 Minnesota families against the Minnesota Department of Health. The multi-year case argued the illegal and improper use of blood samples obtained under the Newborn Screening Program by the state health department. The ruling was in favor of the plaintiffs, and now those samples and test results obtained without consent must be destroyed.

The Minnesota Department of Health secretly established a bio-bank of blood samples and test results from blood left over after newborn screenings. More than 50,000 blood samples and test results were used for research for drug companies and equipment manufacturers—without parental knowledge or consent.

The Minnesota Supreme Court ruled in November 2011 that written, informed consent is required for storage, use or dissemination of any remaining blood samples or test results after completion of newborn screening, then remanded the case for determination of remedies. The decision last month called for the health department to destroy more than a million blood samples and 900,000 test results. As part of the settlement, the department agreed to comply with newborn screening and genetic privacy laws.

The lawsuit settlement also resulted in a change in the law. The legislature specifically mandates written, informed consent before blood samples left over after testing under the newborn screening program can be used for any research, public health study or the development of new screening tests—a significant protection for newborn children and their families now.

CCHF's efforts have led to lawsuits in Texas, as well as changes in law and regulations in various other states, such as Oklahoma, California and New York.

Refuse to Enroll

As the Obama Administration pushed Americans to sign up for the flawed government health care plan, *CCHF* embarked on an aggressive campaign to inform Americans that they could “Refuse to

Enroll” and opt for another type of health care that would not subject them to the problems of Obamacare, mainly: no private insurance, no privacy, limited choice among doctors and hospitals, and high premiums. Today, Americans have signed the “Refuse to Enroll” pledge in all 50 states.

The campaign began on October 1, 2013, when the health insurance exchange was open for business. But CCHF declared October 1 as “independence day” the first day people could choose to opt-out of the doomed program.

To help citizens exercise their rights, **CCHF** created a special section of its web site at www.refusetoenroll.org, which provides visitors with a form they can complete to declare that they are opting out of “any and all participation in the national Obamacare Exchange system,” for four main reasons: to protect privacy, to avoid this national insurance registration system, to protest a coercive attack on free-market medical care, and to exercise their right to not participate.

Through the “Refuse to Enroll” page, Brase provides Americans with information on how they can share facts in their neighborhoods, on social media, at town hall meetings and at their workplace. She also offers three smarter, more affordable and more viable alternatives to government health care: to buy private insurance outside of the government exchanges, to pay the penalty tax in 2015 for being without coverage or to claim one of nine Obamacare exemptions.

This national campaign follows on the heels of CCHF efforts in 2007, 2008, 2011 and 2012 which stopped the Minnesota legislature from establishing a government health exchange.

The 50-State Report on Health Surveillance

In August 2013, **CCHF** released the findings of one of its most important and extensive works to date. For eight years, Brase and her team researched health departments in all 50 states to find out how they use funding from the federal government to obtain and store citizens’ private medical information—in most cases, without patients’ consent.

The report, “Patient Privacy and Public Trust: How Health Surveillance Systems Are Undermining Both,” includes details about all of the private patient data that states collect and maintain. One alarming fact that Brase uncovered is that the information is kept and identified along with the name of each individual American, not simply stored as bulk facts and figures.

For the project, Brase researched the medical data that states collect on Americans—from birth to death—on everything from birth defects to cancer diagnoses. The 50-state report contains extensive information on the types of health data collected by states, including but not limited to: hospital discharge data, stage of the disease at diagnosis, date of initial treatment, course of treatment, as well as ADHD, vaccinations, cancer, birth defects, newborn screenings, autism, diabetes, asthma, STDs, strokes and cardiovascular disease, Alzheimer’s, ER visits, obesity and body mass index. Other personal information collected and stored includes the patient’s name, address, sex, race, ethnicity, date of birth, Social Security number and occupation. To demonstrate the comprehensiveness of data collection, the report captures state statutes on data, consent, and research regarding four specific

databases operating in all 50 states.

CCHF highlighted its many findings in the report, including:

- States have created an array of government patient-tracking systems, and they are given government money to create and maintain these databases.
- As a part of the federal funding requirement, state agencies overseeing these systems share data and/or private health information with various federal agencies, including the Centers for Disease Control and Prevention, the Department of Health and Human Services and the Department of Homeland Security.
- Federal requirements for computerized medical records, and the so-called federal HIPAA privacy rule, have facilitated government access to patient data.
- Patient consent for collection and use of their data is typically not required, although dissent is sometimes permitted.
- Members of the public are not aware of the level of this state health surveillance, and most are probably not aware that they and their children could be named individually on one of the state patient-tracking systems.
- Funding for health surveillance systems comes from the federal government, state legislatures and private organizations.
- Patient trust, which is key to excellent medical care, may be harmed once patients understand their data is shared with the government for health surveillance.

“Over the past 20 years, we’ve seen so many changes in health care,” Brase said. “Especially as the government intrudes more and more on our private health care decisions, Americans need an advocate to protect their choices and their rights. We look forward to the next 20 years of working tirelessly to protect patients’ rights and including their right to access individualized patient care without government intrusion, surveillance or restriction of choices.”

Twila Brase shares health care-related news with the public in her daily, 60-second radio feature, ***Health Freedom Minute***, which airs on more than 150 stations nationwide on the American Family Radio Network and 90-plus stations on the Bott Radio Network. During the daily features, listeners can learn more about the agenda behind proposed health care initiatives and policies and what they can do to protect their health care choices, rights and privacy.

Brase, a public health nurse and health care freedom advocate, informs listeners of crucial health issues, such as the intrusive wellness and prevention initiatives in Obamacare, patient privacy and the need for informed consent requirements, the dangers of “evidence-based medicine” and the implications of state and federal health care reform.

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