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Above:
(Left to Right): Matt Flanders, Congressman Pete Stauber (R-MN), Twila Brase

Wrapping Up a Productive Year in Washington, D.C.

By Matt Flanders, State Legislative & Policy Director

We were heavily engaged at the federal level in 2019. On the ninth and final trip to Washington, D.C., Twila Brase (President and Co-founder) and Matt Flanders (State Legislative and Policy Director) spent December 9-12 in meetings on Capitol Hill and with the Trump administration.

In the midst of federal budget negotiations, CCHF was able to schedule meetings with eight Senate offices — Republican and Democrat — and Minnesota Republican **Congressman Pete Stauber**.

We were particularly pleased to get eight Senate meetings with top staffers of members of the Senate Committee on Appropriations — the committee charged with deciding the details of the final budget package, including whether to include the controversial Unique Patient Identifier (UPI).

Stopping the UPI was our primary objective. We asked the Senators to maintain the funding prohibition that for 20 years had stopped development of a Unique Patient Identifier (UPI)— the national patient-tracking number first proposed in HillaryCare (1993), which became law as part of HIPAA (1996). We had strategically forged a coalition with 23 other organizations nationwide whose leaders signed our letter urging Appropriations Committee Chairman **Senator Richard Shelby** (R-AL) to prohibit development funding for the UPI.

We know a national patient ID would give America’s patients no place to hide. Medical records for a person’s entire life could be connected and used to create comprehensive dossiers. Throughout 2019, we worked with **Senator Rand Paul’s** (R-KY) office to try to stop the UPI from being

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Health Freedom Watch

Health Freedom Watch is published quarterly by Citizens' Council for Health Freedom (CCHF), a 501(c)(3) tax-exempt health care policy research and education organization.

CCHF's mission is to protect health care choices, individualized patient care and medical and genetic privacy rights.

CCHF's does not endorse any health care treatment, provider, or product. Nothing in Health Freedom Watch should be construed as medical advice or legal counsel.

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funded, developed and imposed.

We won this battle! About a week after our meetings in D.C., we learned that the language *prohibiting* funding for a UPI was included in the final federal funding package.

We were also on Capitol Hill to discuss a very hot issue—the shocking “Big Data” contracts between health care systems and “Big Tech” companies, as revealed by *The Wall Street Journal* in November.

Although the WSJ only reported that the **Ascension** healthcare system shared patient-identifiable medical records of 50 million people with **Google**, we brought information about **Cerner** sharing millions of records with **Amazon**, **Mayo Clinic** signing a 10-year data-sharing agreement with **Google**, and **Microsoft** analyzing patient data from **Humana** and

Providence St. Joseph Health. IBM is also getting patient data.

As Senate offices had just discovered, these contracts are legally permitted by HIPAA. CCHF has long known that HIPAA does not protect patient privacy, but we saw the WSJ news as an opportunity to push for real patient privacy rights.

To advance privacy rights, we told staffers about the protective **Minnesota Health Records Act**, which requires patient consent before information can be shared. Some asked us to send them the language of our nation-leading privacy law.

We also shared our advice and opinion on pending federal legislation to protect individual health data not regulated by HIPAA, such as personal data from fitness tracking apps, the Apple Watch, Fitbit, and more.

Thus far, the Republican proposal is unfortunately filled with loopholes that undermine privacy rights, while the Democrat bill lets individuals sue for violations, permits stronger state laws to pre-empt federal law, and lets individuals provide or refuse consent and demand their data be corrected or destroyed. Of utmost importance, we want to make sure this “non-treatment” health data is not put under HIPAA, where it would have no privacy protection and could be broadly shared without patient consent.

There is much to be done in 2020. Thanks to your support, CCHF will continue to work with our connections in Congress, at HHS and in the Trump administration to build free markets and protect patient access to personalized care, individual control over medical records, and patient consent rights for all.

Your gift is very much appreciated and fully deductible as a charitable contribution. A copy of our latest financial report may be obtained by writing to Citizens' Council for Health Freedom, 161 St. Anthony Ave., Ste 923, St. Paul, MN 55103, 651-646-8935. If you are a resident of one of these states, you may obtain financial information directly from the state agency: CALIFORNIA – As of August 2016, CCHF no longer solicits donations from California residents. A FLORIDA – A COPY OF THE OFFICIAL REGISTRATION AND FINANCIAL INFORMATION MAY BE OBTAINED FROM THE DIVISION OF CONSUMER SERVICES BY CALLING TOLL-FREE, 1-800-435-7352 (800-HELP-FLA) WITHIN THE STATE OR BY VISITING www.800helpfla.com. REGISTRATION DOES NOT IMPLY ENDORSEMENT, APPROVAL, OR RECOMMENDATION BY THE STATE. Florida Registration (CH35276). GEORGIA - A full and fair description of the programs of Citizens' Council for Health Freedom and our financial statement summary is available upon request at the office and phone number indicated above. MARYLAND – For the cost of copies and postage, Office of the Secretary of State, State House, Annapolis, MD 21401. MISSISSIPPI – The organization's official registration and financial information may be obtained from the Mississippi Secretary of State's office by calling 1-888-236-6167. Registration by the Secretary of State does not imply endorsement. NEW JERSEY – INFORMATION FILED WITH THE ATTORNEY GENERAL CONCERNING THIS CHARITABLE SOLICITATION AND THE PERCENTAGE OF CONTRIBUTIONS RECEIVED BY THE CHARITY DURING THE LAST REPORTING PERIOD THAT WERE DEDICATED TO THE CHARITABLE PURPOSE MAY BE OBTAINED FROM THE ATTORNEY GENERAL OF THE STATE OF NEW JERSEY BY CALLING (973) 504-6215 AND IS AVAILABLE ON THE INTERNET AT <http://www.state.nj.us/lps/ca/charfrm.htm>. REGISTRATION WITH THE ATTORNEY GENERAL DOES NOT IMPLY ENDORSEMENT. NEW YORK – Office of the Attorney General, Department of Law, Charities Bureau, 120 Broadway, New York, NY 10271. NORTH CAROLINA – FINANCIAL INFORMATION ABOUT THIS ORGANIZATION AND A COPY OF ITS LICENSE ARE AVAILABLE FROM THE STATE SOLICITATION LICENSING BRANCH AT 1-888-830-4989. THE LICENSE IS NOT AN ENDORSEMENT BY THE STATE. PENNSYLVANIA – The official registration and financial information of Citizens' Council for Health Freedom may be obtained from the Pennsylvania Department of State by calling toll-free, within Pennsylvania, 1-800-732-0999. Registration does not imply endorsement. VIRGINIA – Virginia State Office of Consumer Affairs, Department of Agricultural and Consumer Services, PO Box 1163, Richmond, VA 23218. WASHINGTON – Charities Division, Office of the Secretary of State, State of Washington, Olympia, WA 98504-0422, 1-800-332-4483. WEST VIRGINIA – Residents may obtain a summary of the registration and financial documents from the Secretary of State, State Capitol, Charleston, WV 25305. Registration with any of these state agencies does not imply endorsement, approval or recommendation by any state.



Twila Brase, RN, PHN, President & Co-founder, CCHFreedom.org

A Letter From The President

The deadline is near. President Trump's October 3, 2019 executive order requires the Dept. of Health and Human Services (HHS) and the Social Security Administration to decouple Social Security benefits from Medicare enrollment by **March 31**. This means senior citizens will no longer be forced to forfeit retirement benefits if they choose to opt out of Medicare. We achieved this success through:

- **Relationships** – Over the years, we have built relationships with individuals who are now leaders in the Trump administration.
- **Persistence** – For nearly three years we used these relationships to push this initiative up the chain of command and into the White House.
- **Examples** – We provided the White House with a list of individuals and groups who would benefit. We also had a ready-made example of a group who would benefit immediately (Samaritan Ministries does not require health-sharing members to ever enroll in Medicare).

- **On the Right Side** – We insisted that forcing senior citizens into Medicare to obtain their rightful Social Security retirement benefits was unlawful, never approved by Congress, and just plain wrong.
- **Your Financial Support** – We know that we do not work alone. Thank you.

As a reminder, Section 11 of the *Executive Order on Protecting and Improving Medicare for Our Nation's Seniors* states:

“Maximizing Freedom for Medicare Patients and Providers. (a) Within 180 days of the date of this order, the Secretary, in coordination with the Commissioner of Social Security,

shall revise current rules or policies to preserve the Social Security retirement insurance benefits of seniors who choose not to receive benefits under Medicare Part A . . .”

Individuals interested in exercising this option continue to contact us. Some have given up their Social Security benefits for years to keep their preferred coverage and avoid Medicare restrictions. They want their dollars and freedom restored.

This freedom cannot come soon enough. Interested Americans must begin exercising their right to opt out of Medicare as soon as possible. If there is a change in the presidency in November, this freedom could vanish in a heartbeat. Especially if no one has yet taken advantage of it. Already, our contacts in the Trump administration have told us that officials in the established bureaucracy are pushing back. But we have underscored the need to get opt-outs on the record.

Therefore, I have a request. Would you take a few minutes to contact President Trump by letter, tweet or the online form on the White House contact page (<https://www.whitehouse.gov/contact/>)?

First, thank the president for his executive order. **Second**, ask him to allow no obstacles and no obstructive behaviors to deter his plan to restore to Americans the freedom they rightfully have to opt out of Medicare and keep their Social Security benefits. **Third**, ask him to make it happen by March 31. For more information, find our **Six Reasons** to consider opting out at MedicareOptOut.com.

Twila Brase, RN, PHN
President and Co-founder

IN THE NEWS



December

“Appeals Court Rules ACA’s Individual Mandate Is Unconstitutional” - Alicia Ault, *Medscape*, 12/18/19

“A Win for Patient Data Privacy” - Jordan Roberts, *John Locke Institute*, 12/18/19

“Google May Now Have Your Private Medical Records (Podcast guest: Twila Brase)” - AnneMarie Schnieber, *The Heartland Institute*, 12/24/19

January

“Health Freedom Update: Wins, Concerns, and Continuing Struggles” - Hon. Sam Rohrer, *Stand in the Gap Today*, 1/15/20

“State Diminishes ‘mission creep’ prescription monitoring” - Chris Woodward, *One News Now*, 1/20/20

“Privacy Advocate Tackles Issue of Patient Consent Rights” - Marianne Kolbasuk McGee, *Healthcare Info Security*, 1/31/20

February

“Will Minnesota Legislators Let Google Into Your Medical Records?” (commentary) - Twila Brase, Richard Larkin McLay, *Alpha News*, 2/1/20

“The Schilling Show: Hour 1 with Twila Brase” - Rob Schilling, *The Schilling Show*, AM 1070 WINA (VA), 2/13/20



🔍 why does Google have my medical records?



Google Search

I'm Feeling Lucky

DOES GOOGLE HAVE YOUR MEDICAL RECORDS?

By Twila Brase, RN, PHN, President and Co-founder

The Ascension healthcare system is sharing the medical records of **50 million Americans** with Google. This includes patient names, test results, hospitalizations, medications, diagnoses, and more. Google plans to use the data to design new artificial intelligence (AI) and machine learning (ML) software that can be used to suggest changes to an individual patient's care at Ascension's 2,600 hospitals and facilities. **Patient consent is not required.**

Although Google is not charging for its services and cannot sell any patient data, having free access to patient data is the payment. Google hopes this arrangement will lead to new software it can then sell to other health systems for a price.

Code-named "**Project Nightingale**," this data-sharing agreement is legal under HIPAA. Google's website states:

"All of Google's work with Ascension adheres to industry-wide regulations

(including HIPAA) regarding patient data, and come with strict guidance on data privacy, security and usage. We have a Business Associate Agreement (BAA) with Ascension, which governs access to Protected Health Information (PHI) for the purpose of helping providers support patient care."

The words, "support patient care," mean whatever the partnership says they mean. Ascension still owns the data, but WSJ says, "Neither Google nor Ascension would give details on who at Google can access data."

Before HIPAA, patient data could not be shared without patient consent. Consent requirements indicate ownership. HIPAA ended patient consent. In fact, its "health care operations" (HCO) definition—a nearly 400-word list of at least 65 non-clinical, business activities—permits Ascension to give Google the data.

Tim Holtzman at CynergisTec told

HealthITSecurity.com that HHS is making it "easier for the industry to access and disclose treatment information for purposes not directly tied to the treatment or health care of that individual and to expand the definition of health care operations and remove the minimum necessary standards."

CCHF has been in D.C. pushing to restore consent requirements. This legalized breach of patient rights is a hot issue in Congress. One concerned staffer told us, "We KNOW this is legal." One staffer suggested patient notification requirements, but we said that would not protect patient rights and insisted patient consent be restored.

But we actually don't need Congress to act. The 1996 HIPAA law does not require the elimination of patient consent. As I wrote in my book, *Big Brother in the Exam Room*, when Congress failed to pass a privacy law, the Clinton administration

wrote the HIPAA rule and unilaterally decided to eliminate patient consent requirements. Thus, the Trump administration has the power to restore patient consent by simply rewriting the HIPAA rule.

In fact, the Clinton administration restored consent requirements for treatment, payment and health care operations after a public outcry over the proposed HIPAA rule. But the Bush administration, pressured by health plans, rescinded consent requirements, leaving all Americans vulnerable to access by “Big Tech.”

In December, we sent a letter to Roger Severino, director of the HHS Office for Civil Rights (OCR), which is investigating the Ascension-Google agreement. We asked him to use his authority to restore consent requirements. Read the letter here: bit.ly/CCHFletterOCR

In February, I met with Joe Grogan, director of the White House Domestic Policy Council (DPC), and his team. I had six items to discuss, and among other things, they wanted to discuss the pending HHS “interoperability of health data” rule. I said Epic, the world’s largest electronic health record (EHR) vendor, and tech companies like Google and Amazon are in a “**turf war.**” Epic wants the White House to keep Big Tech out, falsely claiming it will protect privacy, and Big Tech wants access to all EHR data for their own business purposes. Neither wants patients to control their own data.

I asked the White House to restore patient consent eliminated by HIPAA. I asked them to give patients the right to decide what health data to share when, with whom, and for what purposes. The rule is expected soon. **Thank you for your financial support. It lets us fight for patient rights at the highest level!**



“CCHF is pushing to restore consent requirements. This legalized breach of patient rights is a hot issue in Congress.”

The U.S. Dept. of Health and Human Services where the Office for Civil Rights is located



Twila Brase meets with Joe Grogan, Director of the White House Domestic Policy Council (DPC)



Read more about how HIPAA eliminates patient privacy: BigBrotherInTheExamRoom.com

RADIO: HEALTH FREEDOM MINUTE

CCHF's Minute is heard on more than **840 stations** around the nation. Find our station list at cchffreedom.org and tune in every weekday wherever you live!

(To listen: www.healthfreedomminute.net)



SCOTUS Tells Dems "No" on Obamacare Request

January 30, 2020

In December, the 5th Circuit Court of Appeals struck down the Obamacare individual mandate, calling it unconstitutional. It sent the case back to the district court asking it to review the entire Affordable Care Act and see if other provisions are unconstitutional. This action upset the Democratic states and the U.S. House who are defending the law.

With the 2020 election in mind, they asked the Supreme Court to take the case out of the hands of the lower courts and to rule on it before July. President Trump's Department of Justice told the court there's no reason to expedite a review of the lawsuit. On January 21st, the Supreme Court agreed, likely taking the law out of 2020 election politics. That said, health care remains a very hot topic for 2020.

Source: West Virginia Metro News: bit.ly/2U95NXY

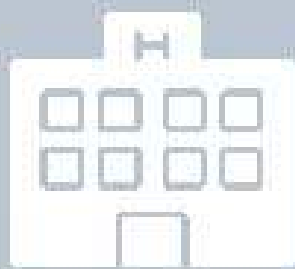
Source: The Hill: bit.ly/2ObyKP7

Protecting the Minnesota Health Records Act

Privacy rights may be under fire during the 2020 Minnesota legislative session. Since 2014, CCHF has defended the nation's strongest patient privacy law, the **Minnesota Health Records Act** (MN Statute 144.293), from large data corporations, health industry giants, and government agencies that have sought to replace the state's patient consent law with the permissive HIPAA data-sharing rule. **HIPAA permits the following:**

2.2 MILLION

The number of entities that could potentially gain access to patient data without patient consent if the MHRA is repealed (plus government agencies).

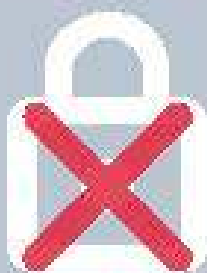


CORPORATE CONTROL OF THE EXAM ROOM

Health plans and government officials want to use patient data to develop and impose harmful one-size-fits-all standardized treatment protocols, and penalize doctors who refuse to comply.

LIFELONG REAL-TIME HEALTH SURVEILLANCE

Eliminating the MHRA would allow for tracking, recording, and linking all diagnoses, treatments, patient and physician comments, behaviors, medications, genetic codes, family structure and more.



ENDS PRIVACY PROTECTIONS

HIPAA ends privacy protections and eliminates patient control over sensitive data including addiction, mental health, HIV, and genetic information. This data could be widely shared under HIPAA-approved "health care operations," a nearly 400-word list of at least 65 non-clinical business activities.

Commentary Corner

“ I feel like we are just getting started with you. - Nooga Radio 92.7, host **David Tulis, TN** on interview with CCHF president ”

“ Thank you for all of your help, I wouldn't have known any of this without your information and education. So, much appreciated! - **D., NY** regarding Baby DNA ”

“ Twila Brase provides a valuable service to the public with detailed analysis and commentary on often complex health care policy issues. And she has proven her credibility and know-how which makes her a go-to source for policy makers and the people. - **Michele, MN** ”

“ I travel between multiple states. So while this is one of the office addresses, I am interested in USA locations. Your map was very useful. - **Jack, IL** regarding the Wedge of Health Freedom ”

YES, I WANT TO DONATE TO CCHF!

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For more information, including a sample letter for your IRA custodian, please contact us:

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**CCHF has received 501(c)3 non-profit status from the IRS. CCHF has received permission to solicit charitable donations in all states except California. In August 2016, we withdrew our registration in CA to avoid the AG's demand that we share the confidential names of certain donors. The full disclosure regarding solicitation is found on page 2 of this newsletter.*



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OVERHEARD

“Lawmakers did not anticipate that our electronic medical records (EMRs) would become so open that everyone from first-year medical students to acupuncturists could access the EMR of anyone in the system.”

– **Kevin R. Stone, MD**,
The Stone Clinic,
December 29, 2019

“For some companies, ownership of data is the entire business model. The public policy goal ... should be preventing (health) data from being used as a currency.”

– **Medical technologist**,
Discussion at GE Healthcare,
November 29, 2019

“Hospitals are massive containers of patient data. The data belongs to whoever has it.”

– **Lisa Bari**, Bari Digital
Strategies, *Daily Mail*,
January 27, 2020

“It has been our experience that lockdowns and quarantines do not help control Ebola, as they end up driving people underground and jeopardizing the trust between people and health providers.”

– **Doctors Without Borders**,
NPR, January 26, 2020

“HIPAA is an example of a good idea gone terribly wrong. It is transcendental clerical tyranny.”

– **Jim Baer**, *Concord Monitor*,
December 19, 2019



“Everyone hates the health care system.”

– **John Wilbanks**,
SageBionetworks, Medium,
January 27, 2020