

PEN



## inside

- 3 **As I See It:** Health Database Built on Partnerships
- 4 **Inhibitor Insights:** Guarding Your Personal Info
- 5 **Richard's Review:** Guitarist with Hemophilia Inspires Novelist
- 6 **Project SHARE:** \$6.5 Million Program
- 7 **Pulse on the Road:** 2011 Travel Wrap-up



# Private Parts:

## Is Your Personal Health Information Exposed?

*Laureen A. Kelley*

“Information is power,” declares J. Edgar Hoover, as played by Leonardo DiCaprio in Clint Eastwood’s 2011 movie *J. Edgar*. The founder of the FBI obsessively collected personal information about Hollywood celebrities, political activists, criminals, and even average citizens in his quest to root out crime bosses, Nazi sympathizers, and communists—and later, to find out who opposed him in government. Hoover’s ambition, plus his massive collection of personal files, gave him unchecked power over political events in America for almost 50 years. Both feared and admired, Hoover stirred controversy by using any means, including illegal ones like wiretapping, to gather personal information—especially sordid information to blackmail his opponents.

The movie raises privacy issues that are particularly relevant today, especially for patients with chronic disorders such as hemophilia or von Willebrand disease (VWD). In a bleeding disorder marketplace facing increased competition and more federal scrutiny, gathering detailed information about patients truly can create power—and can increase revenues. Who is collecting your personal health information, and what are they doing with it? When is this data collection practice unethical or illegal, and when is it actually beneficial?

»» page 8

# welcome

Laurie Kelley

So it's Christmas and I am shopping online, for Transformers toys for my 21-year-old daughter Tara (a story for another time). Unsuccessful, I decide to take a break and check out the CNN.com headlines, and *voila!* Pop-ups and sidebars appear like magic on my computer screen—can you guess?—Optimus Prime, Shockwave, and Megatron. Scary. Not the Transformer creatures, but the swiftness with which the cyberspace sales force hunts me down and cattle-prods me with flashy ads.

Is privacy truly dead? Is it a quaint, old-fashioned idea whose time is passed? We're getting so used to invasions of our privacy that they hardly surprise us anymore. What do the Google-Facebook Powers-That-Be out there know about us? Plenty. More than we can possibly imagine.

Forget about strange cyber-shopping action figure experiences, and think instead: what does a lack of privacy mean for bleeding disorder families? Naïvely trusting factor providers and market researchers, what information do we willingly hand over on a golden platter, unaware of how it will be used?

This issue of PEN is dedicated to helping you get sharper and smarter about protecting your personal health information. You need to know who wants it and why. Learn the ways that the marketplace tries to woo it from you. And think twice about what you post on Facebook.

And if you happen to find a 12-inch Megatron somewhere online, please let me know? But email me privately. ☺



## inbox

THANK YOU VERY MUCH FOR YOUR EFFORT IN HELPING MY son Denniel by providing medicine. We are hoping for his fast recovery. More power to Project SHARE, and may God continue to provide you more donations and blessings so that you can help more patients with hemophilia like our son.

*Dennis Abena and family  
The Philippines*

I WOULD JUST LIKE TO SAY THANKS TO PROJECT SHARE again for always helping us. My son will be two years old soon, and I feel I'm still in denial of the fact that he has hemophilia.

*Ian Anderson  
The Philippines*

»» page 19

## PARENT EMPOWERMENT NEWSLETTER FEBRUARY 2012

EDITOR-IN-CHIEF Laureen A. Kelley | SCIENCE EDITOR Paul Clement

CONTRIBUTING WRITERS | Richard J. Atwood • Jo Schaffel

MANAGING EDITOR Sara P. Evangelos | LAYOUT DESIGNER Tracy Brody

DIRECTOR, MARKETING Kathryn Ondek

DIRECTOR, PROJECT SHARE Zoraida Rosado

PEN is a newsletter for families and patients affected by bleeding disorders. PEN is published by LA Kelley Communications, Inc., a worldwide provider of groundbreaking educational resources for the bleeding disorder community since 1990.

PEN respects the privacy of all subscribers and registered patients and families with bleeding disorders. Personal information (PI), including but not limited to names, addresses, phone numbers, and email addresses, is kept confidential and secure by the LA Kelley Communications editorial staff in accordance with our privacy policies, which can be viewed in entirety on our website. PEN publishes information with written consent only. Full names are used unless otherwise specified.

PEN is funded by corporate grants or advertisements. Sponsors and advertisers have no rights to production, content, or distribution, and no access to files. The views of our guest writers are their own and do not necessarily reflect the views of LA Kelley Communications, Inc., or its sponsors.

PEN is in no way a substitute for medical care or personal insurance responsibility. Parents or patients who question a particular symptom or treatment should contact a qualified medical specialist. Parents or patients with personal insurance questions should contact their employer's human resource department, Medicaid or Medicare caseworker, payer representative, or HTC social worker.

Articles may be reprinted from PEN only with express written permission from the editor, and with proper citation. PEN and/or its articles may not be published, copied, placed on websites, or in any way distributed without express written permission.



65 Central Street

Georgetown MA 01833 USA

978-352-7657 • fax: 978-352-6254

info@kelleycom.com • www.kelleycom.com

Credit for the photos in this issue, unless otherwise noted: Copyright © 2011 LA Kelley Communications, Inc. and its licensors. All rights reserved.

as i see it



*Diane Aschman*

## A National Health Database Built on Partnerships

Doctors, scientists, policymakers, and other healthcare providers need a large pool of patient data to answer scientific, public health, and policy questions about the safest and most cost-effective ways to treat bleeding and clotting disorders.

To help answer these questions, the American Thrombosis and Hemostasis Network (ATHN), a nonprofit founded in 2006, has partnered with over 130 hemophilia treatment centers (HTCs) to establish a safe, secure national database, and to create the ATHNdataset.

Having your health information in the ATHNdataset will ensure that the

dataset represents all Americans with bleeding and clotting disorders, not just a select few.

### What Privacy Concerns Do Patients Have?

ATHN understands that people with bleeding and clotting disorders share a concern for data privacy protections related to how their health information is collected, managed, and used.

Patients may be concerned that their sensitive data is collected without their knowledge or authorization. Or they may worry that those collecting the data may be careless in handling the information, leaving patient identifying information exposed, and breaching confidentiality of health data. They may worry that data will be passed on to others and used for unintended purposes that may harm them. They may fear that the data is incorrect, and that they may have no opportunity to correct it.

These are all legitimate concerns, but they are concerns that ATHN has gone to great lengths to appropriately handle. To protect patient confidentiality, we have ensured that we comply with all requirements, including federal and state privacy rules and laws.

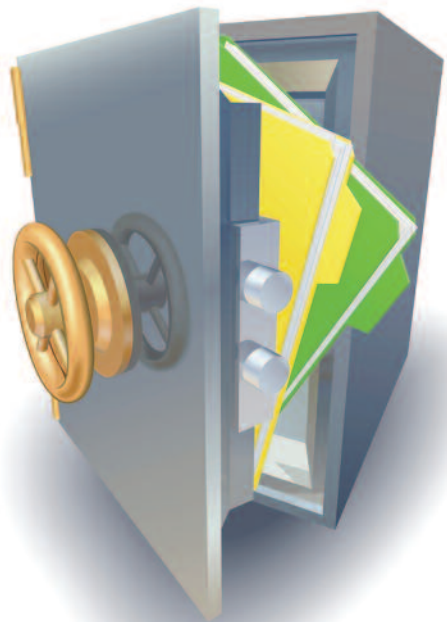


### Why is ATHN Collecting Patient Data?

ATHN's purpose is to help the community use the ATHNdataset to accomplish these goals:

- Gain a better understanding of the issues affecting patients and families.
- Increase knowledge of the genetics and natural history of blood disorders.
- Study treatment and develop standards of care.
- Keep a close watch on FDA-approved therapies.
- Increase community support and education.

One of the greatest benefits of the ATHNdataset is its power to begin addressing questions that haven't been answered before about bleeding and clotting disorders, inhibitors, and treatment. The more patients contribute their information, the more certain we can be that the ATHNdataset represents the whole community. The ATHNdataset opens the door to new possibilities for this community, now and for future generations.



» page 17

## The Valuable Inhibitor Community: Guarding Your Personal Health Info

“Win a free Wii!” screams the headline on a postcard in the morning’s mail. It’s from a company selling factor. All you have to do is fill in your name, address, phone number, child’s name and factor deficiency. But think before you return that postcard: do you want your personal data in the hands of a company you may know nothing about?

Most people with a bleeding disorder walk a fine line between privacy and community. This is especially true for those with inhibitors. People with inhibitors represent a small subset of a rare condition, yet they often use large amounts of factor or very expensive bypassing agents—and they are very profitable clients for a home care company or hemophilia treatment center (HTC) that sells factor. In the past, there was intense competition among home care companies to “land” an inhibitor account. Although the wooing of potential inhibitor clients with lavish gifts is largely a thing of the past, competition for these patients among home care companies can still be fierce.

The small number of inhibitor patients makes it especially easy for personal health information to be “mined” from online forums, newsletters, camps, community functions, or just casual contact. Naturally, you want to stay connected with others for help and support, which means sharing some health information. But you also want to have some control over who has this info and how they can use it. Once a company has your contact info, you (or your children) may be besieged by annoying phone calls, sales pitches, or worse.

### Giveaways? Or take-aways?

National Hemophilia Foundation (NHF) annual meetings and other community events are exciting and valuable. You can mingle with other families, learn about new therapies or discoveries, and have a chance to meet with experts. You can also sign up for lots of “stuff.” But remember that most raffles and drawings are designed specifically by home care companies or marketing researchers to collect health information. Why? So they can try to sell you on their company’s services or products, or sell your health info and contact info to another company.



“After we attended our very first NHF annual meeting, we were inundated with phone calls and mailers from home care and pharmaceutical companies,” recalls one mother. “We had probably signed up for every giveaway possible...not noticing that the fine print on the entry cards said that by completing the form, we were giving the company permission to send marketing materials and contact us regarding services.” She tried to be polite to the cheerful rep who called weekly, but finally told him “flat out” to stop calling.

Another mom described a company that probably got her health info through a giveaway contest. “They took us to dinner. Gifts for the kids would just show up in the mail with a note from the company representative.” She started hearing negative stories about this company from other consumers and told the company directly that she was not looking to switch factor suppliers. The gifts and offers stopped.

The many brochures you receive in the mail after signing up for giveaways might just be marketing “fluff” that you can recycle, or they could contain valuable information about new products. But be warned: some unscrupulous representatives or companies may invade your privacy.

Richard J. Atwood



## Getting to Know a Character with Hemophilia

*The Night Train (2011)*  
by Clyde Edgerton

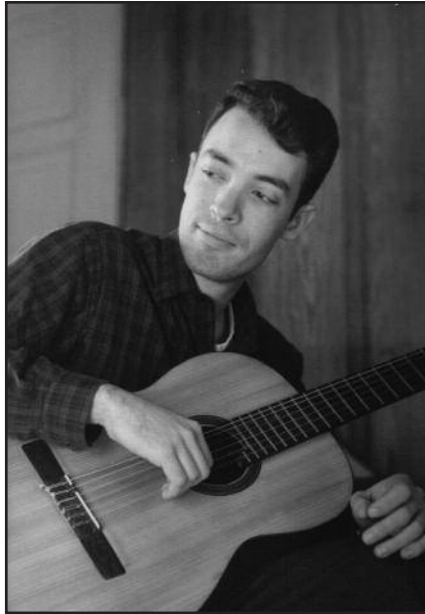
**H**ow does an author create a fictional character with hemophilia?

In the 1960s, Clyde Edgerton—a young, aspiring writer and part-time musician—frequented jazz clubs in his hometown of Durham, North Carolina. There he crossed paths with Harrison Register, a young jazz guitarist who happened to have hemophilia. Forty years later, Edgerton is now teaching at the University of North Carolina–Wilmington (UNC), and is also an award-winning, best-selling author. In *The Night Train*, Edgerton has included a minor character named “the Bleeder”—a jazz musician with hemophilia. Harrison Register was the inspiration for this fictional character.

*The Night Train* is a coming-of-age novel, set in the summer of 1963 in eastern North Carolina, in which the passion for music dissolves the racial divide for two teenagers, Larry and Dwayne. Larry, age 16, discovers jazz after learning gospel music on the piano and playing drums in his high school marching band. Dwayne, age 17, organizes a garage band and is influenced by the soul music and showmanship of James Brown. At a time of racial tension, sit-ins, and school consolidation, Larry lives on the west side of the railroad tracks with the other black families, while Dwayne lives in the white community on the east side of the tracks. For these two friends, it's easy to share music, go fishing, and hang out together. Yet adults still impose their own rules of behavior for racial interaction.

Larry has a mentor, an African American musician named Josh, who has hemophilia. Josh plays guitar and piano with four white men at a bar called “The Frog.” Before Josh teaches Larry how to listen to musical notes by seeing their colors and feeling their shapes, he introduces himself: “I’m the Bleeder. That’s what they call me.”

Charles Register



Harrison Register, circa 1960

A night train rumbles through the community, symbolically separating the town along racial lines. Yet Larry and Dwayne share the simple agenda of discovering music that will continually influence their lives, and their interactions ring true. The seriousness of their quest, aided by the recent technological advances of vinyl records,

transistor radios, and reel-to-reel tape recorders, is balanced by their comical exploits. Edgerton, as in all of his novels, inserts unexpected and humorous interludes.

After the novel’s release, Harrison’s brother, Charles Register, contacted Edgerton. Charles also has hemophilia, and is webmaster for the organization Hemophilia of North Carolina. He wanted to confirm that Harrison was the model for the Bleeder. Edgerton could not remember Harrison’s name, but he told Charles about the 25-year-old guitarist with hemophilia he’d heard playing around 1960. The time and place matched up. And according to Charles, “It was common knowledge that Harrison was a ‘bleeder.’ He certainly never made any attempt to hide the fact—limps and bruises are hard to hide.” An accomplished guitarist, Harrison was approached to play with famed guitarist Chet Atkins in Nashville, but he didn’t want to stray too far from Durham and his medical care at Duke and UNC hemophilia treatment centers. Unfortunately, Harrison died in 1973 from complications of his hemophilia and an inhibitor.

Fortunately for the bleeding disorder population, Charles Register and his wife Kathy have contributed immensely to Hemophilia of North Carolina since its inception over 35 years ago. In so many ways, so many members of the bleeding disorder community are inspirations for us all. ☺

# a project share story

Kathryn Ondek

## The \$6.5 Million Program

**M**erlin, 17, from the Philippines with a severe GI bleed. Mohammad, 31, from Bangladesh with a limb-threatening thigh bleed needing emergency surgery. Samuel, 7, from Nigeria with a life-threatening head bleed. These are just a few of the patients that Project SHARE helped in 2011, saving their lives and the lives of many others.

Project SHARE donated over \$6.5 million worth of factor in 2011 to 37 developing countries. Since its inception in 2002, Project SHARE has donated \$45 million worth of factor to 62 countries.

There are approximately 400,000 people with hemophilia worldwide, yet 75% have little or no access to factor. That's because they live in developing countries with inadequate care. Project SHARE receives unwanted or unused factor from treatment centers, specialty pharmacies, patients, and pharmaceutical companies, and then donates millions of dollars' worth of this factor to dozens of developing countries annually. Donations are used to treat life- and limb-threatening bleeds, and to enable surgeries and rehabilitation. Project SHARE also offers educational materials and expertise to guide patients, hemophilia nonprofits, physicians, and clinics toward self-sufficiency.

Despite these generous donations, our supply is chronically low, sometimes nonexistent. We've only scratched the surface—we need to help more of the hundreds of thousands of people in developing countries who have hemophilia and receive no treatment.

### How Can You Help?

Donate your unwanted, in-date factor legally. You must have a valid medical reason for donating, like these:

- You have changed factor brands.
- You have developed an inhibitor, or for some other medical reason you no longer respond to your current product.
- You have factor that cannot be used before it expires.

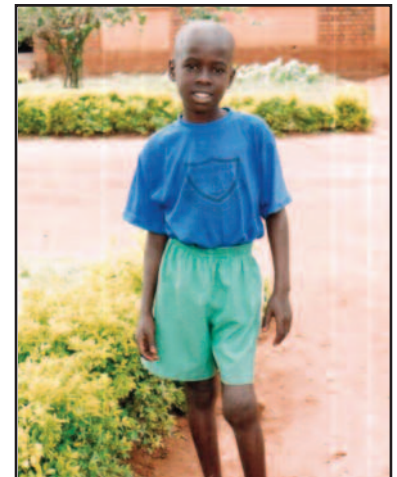
Project SHARE is funded with support from the following:

- Baxter Healthcare Corporation
- CSL Behring
- Novo Nordisk Inc.
- Octapharma USA
- ASD Healthcare
- Hemophilia Alliance

We're grateful for this continuing support. ☺



Angelo L., a patient from the Philippines



Eddie O., a patient from Uganda



Indian patients receiving factor from Project SHARE



### Project SHARE

c/o LA Kelley Communications, Inc.  
65 Central Street • Georgetown, MA 01833 USA  
978-352-7657 • fax: 978-352-6254  
share@kelleycom.com • www.kelleycom.com

Kathryn Ondek

## Five-State Road Trip in 2011

**P**ulse on the Road (POTR) is an interactive, educational symposium that addresses a variety of insurance and healthcare reform topics of urgent importance to families with bleeding disorders. Inspired by the informative newsletter *PEN's Insurance Pulse*, POTR is sponsored by Baxter Healthcare Corporation.

The three-hour POTR symposium educates people at hemophilia chapter annual meetings and retreats, and includes presentations, breakout sessions, and a community forum.

In its second year, POTR visited five chapter events in 2011: Great Lakes Hemophilia Foundation, Texas

Central Hemophilia Association/Lone Star Chapter of NHF, Oklahoma Hemophilia Foundation, Bleeding Disorder Foundation of Washington, and Hemophilia of South Carolina. (A symposium for Hemophilia of North Carolina's family retreat was cancelled because of Hurricane Irene.)

In its first year, POTR presented at two annual meeting events in 2010: Hemophilia Association of the Capital Area and Hemophilia of Indiana.

Check our website to see if POTR is coming to a chapter event near you!@

[www.kelleycom.com/events.html](http://www.kelleycom.com/events.html)



Laurie Kelley introduces panelists



Elizabeth Stoltz of Baxter leads a breakout session

Audience learns how to safeguard their healthcare dollars



## Post-9/11: Exposed New World

Privacy is a hot news topic today. From concealed programs embedded in our computers or cell phones, to airport security and healthcare, sometimes corporations and even the government go too far. Big Brother, it seems, is scanning our every purchase, email, text, browse and tweet.

Personal privacy took a nosedive following the horrifying events of September 11, 2001. Because we knew that terrorist cells wanted to repeat an attack on America, and because our fear was heightened after 9/11, we grudgingly tolerated airport pat-downs, backscatter x-ray machines, government surveillance of phone calls and emails, and constant monitoring by TV cameras in public places and offices. In time, we even got used to it all.

But privacy invasion has now gone much farther than terrorism prevention. How far? Look at Carrier IQ, diagnostic software installed on more than 140 million mobile phones: carriers such as AT&T and Comcast say this software helps them assess and troubleshoot their networks. Carrier IQ logs everything users do, from browsing websites (even websites that use security encryption designed to prevent tracking) to writing text messages. This software could be on your own phone right now without your knowledge. And look at a recent case before the US Supreme Court: the Obama administration had argued that police should not be required to get a warrant to affix a GPS tracker to your car, if you are suspected of being involved in crimes.

Another reason for the erosion of our privacy is that it's now easier to collect data. Computer programs allow data collection; crafty marketing ploys encourage it. And social media demands it, luring users into sharing email addresses, street addresses, family members' names, even factor deficiencies.

Make no mistake: as a bleeding disorder patient, you are now living in a goldfish bowl. You're watched by the companies and organizations that make

your drugs, distribute your drugs, insure your drugs, and even provide your healthcare.

## Privacy Is Law

Privacy about your health information as handled by certain organizations is protected by law. All medical facilities, healthcare providers, pharmacies, and insurers that you deal with—called *covered entities*—are legally required to keep your health information confidential, and to notify you if a security breach occurs. The Health Insurance Portability and Accountability Act (HIPAA) of 1996 is a set of federal rules and regulations designed to standardize the way that all healthcare covered entities protect the privacy of patients' identifiable healthcare information.<sup>1</sup>

Physicians and any of their business associates are restricted in how they use and disclose a patient's health information, called *protected health information* or PHI.<sup>2</sup> They must avoid identifying the patient in any media (electronic, paper, or oral) that relates to the patient's past, present, or future physical or mental health; to healthcare services; or to payment for healthcare. For example, a physician generally cannot disclose PHI unless the patient has given written authorization. There are exceptions, discussed in the next sec-

tion, in which PHI can be disclosed without authorization: for example, for payment, treatment, or surgical procedures.

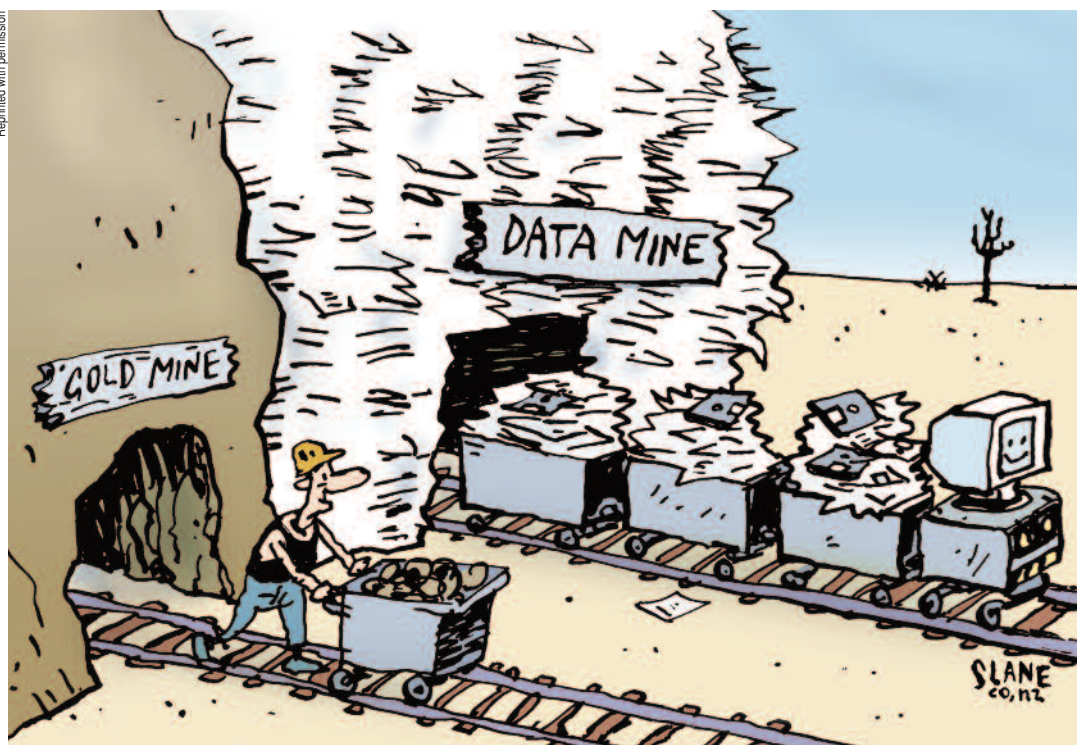
In general, the privacy protection system enforced by HIPAA works well. One study even found that young people are more likely to trust their doctor than their own families with their PHI because they felt the doctors were more confidential!<sup>3</sup>

## Is It Illegal to Gather Your Health Info?

Some of your personal information is out there in the public domain, and there isn't much you can do about that. Go to [intelius.com](http://intelius.com) and pop in your name and state, and see what comes up. For under \$10 you can purchase information about anyone in public records, including age, household members, phone numbers, and even criminal records. You can locate pretty much anything in the public domain.

The same is true for some of your health information (see sidebar next page, "Sleuth"). It's not hard to find the names and addresses, even diagnoses, of bleeding disorder patients—and it's not illegal for a company that is not a covered entity to make lists or databases of this info, or even to share it.

Reprinted with permission





Sharing someone's personal health information becomes a legal issue when whoever holds that health info is a covered entity—like your healthcare provider. Again, HIPAA requires your provider to never release any information about you to third parties.

## Why Protect Your Privacy?

But what happens when your information is being gathered by *non-covered* entities? This would include market researchers, your local hemophilia chapter, your national hemophilia organizations, even LA Kelley Communications. Why safeguard your health information then? It isn't to ensure that no one ever knows you or your child have a bleeding disorder. But you should maintain as much control as possible over what medical information you give to whom, and when and how you give that info. Why do you need control? Because your health information might affect your insurance coverage or your employment. Or you might worry about how others will regard your child.

Paul Brayshaw, president of Hemophilia Federation of America (HFA) and person with hemophilia, recalls, "I was cautious to disclose any health conditions growing up, to avoid health benefit exclusions or stigma associated with chronic illness." He advises, "It is important to know the law of your particular state to ensure the cost of care for a bleeding disorder ensures the possibility of a quality health outcome, similar to anyone born without a preexisting genetic condition. In states where payers are challenging mandates, or if you work for an employer with a bottom line, it is possible to be excluded by being an added cost. A high-cost employee affects the cost of insurance premiums, and could possibly affect your ability to get a job. That is why privacy protection is so important."

Sometimes, if you can control what information is divulged, when, and how, then you might have greater influence over what someone will do with that info. So protecting your personal info now may benefit you in the future.

## When Is Sharing Your Health Info Okay?

Obviously, sometimes you need to share your health information. To receive medical care, you must share your health info with your primary care physician, dentist, hemophilia treatment center (HTC), and emergency room. You may need to share some of this info with your child's school, karate or swimming instructor, and maybe even an airline when traveling.

You also must share your health information with your health insurance company, so that bills related to hemophilia or VWD can be reimbursed.

And voluntarily sharing your health info can assist with medical research studies. For example, you can authorize your HTC to share your child's treatment information with a medical database such as American Thrombosis and Hemostasis Network (ATHN). In this case, your health

# SLEUTH

## If a Student Can Do It, Who Else Can?



In the mid-1990s, the Massachusetts Group Insurance Commission (GIC) released de-identified data on state employees that showed every single hospital visit. The state removed identifiers such as name, street address, and social security number.

But Latanya Sweeney, a graduate student in computer science, wondered just how private this info really was. So she requested this public data, looking specifically for Massachusetts governor William Weld's hospital records. She knew that Weld lived in Cambridge, Massachusetts. For \$20, Sweeney purchased the voter rolls of Cambridge, containing address, ZIP code, birthdate, and gender of registered voters. Only six people in Cambridge shared the governor's birthdate; three of them were men; and only one of them lived in Weld's ZIP code. Sweeney then mailed the governor's health records (including diagnoses and prescriptions) to his office. Sweeney has since proved that 87% of the US population is uniquely identified by birthdate, gender, and ZIP, making it easier than we thought to find people with hemophilia.

### Sources:

1. <http://latanyasweeney.org/work/identifiability.html>
2. <http://dataprivacylab.org/projects/identifiability/pharma1.html>
3. Nate Anderson, "Anonymized" Data Really Isn't—and Here's Why Not." *Ars Technica*, Sept. 8, 2009. Viewed online Jan. 18, 2012: <http://arstechnica.com/tech-policy/news/2009/09/your-secrets-live-online-in-databases-of-ruin.ars>

information is *de-identified* (identifying information is removed) then *aggregated*, or combined, with treatment data from other patients.<sup>4</sup> Combined, all of the treatment data concerning bleeding patterns, product usage, and infusion frequency gives healthcare providers and pharmaceutical companies a better picture of how products work, how different treatment regimens work, and how to improve them. This benefits all patients in the long run.

“There’s positive benefit to the community when sharing personal medical information within protective boundaries,” believes Dana Kuhn, person with hemophilia and president and founder of Patient Services Inc. “Researchers can collect good data, which could help people with better treatments.” In many countries, this kind of aggregate data is often collected to form a national database on bleeding disorders. In fact, the United States is one of the few developed countries that has lacked a comprehensive national database for bleeding disorders.

To address this lack of data on the effectiveness of various bleeding disorder treatments, ATHN was established in 2006 as 501(c)3 non-profit to be a repository of national data on bleeding disorder patients. The network has enabled clinicians to have a source of patient data that can track bleeds, product usage, and treatment regimens over a patient’s lifetime. Over 125 HTC’s are currently participating in the research. This requires collecting patients’ health information, which is de-identified and aggregated to protect patient privacy.

Research isn’t the only reason to share your medical info. Brayshaw believes it’s important to strategically share our personal health stories about bleeding disorders to get the attention of Congress. “For health-care reform,” he says, “it’s important to describe life with a bleeding dis-



order, the physical as well as the financial impact.” Brayshaw was selected in 2011 by White House staffers, following a letter he wrote about his healthcare concerns, to meet President Obama. With that kind of photo opp, Brayshaw’s hemophilia made front-page news and promoted awareness of our community.

### What Privacy Concerns Should You Have?

Just because they are required by law to safeguard your PHI doesn’t mean that your physician or medical insurance plan can never share it. There are times when healthcare providers and insurance companies legally don’t need your written permission to share your PHI. For example, insurance companies can disclose your PHI without your written permission in cases involving workers’ compensation, payment to medical providers, or public health concerns, and when you need an emergency operation and are unable to communicate. And insurance companies can subcontract with disease management companies, which may track your child’s factor usage and hospital visits; they will have full access to your PHI without needing your permission. In general, these situations are

recognized and acceptable in the insurance and medical arenas.

But you should have some concerns about who has your info. Remember, companies that are not covered by HIPPA rules that protect your health information. Some may engage in unethical data handling practices. Companies may divulge your health info for profit, or may solicit or collect it through questionable channels, for marketing purposes. “There is private use of data in ways that I don’t think are completely explained,” says Brayshaw. Too often, parents or patients give away their medical info without fully questioning why it’s being collected, and what will be done with it.

### Tinker, Tailor, Healthcare Spy

Healthcare in the United States is generally a for-profit industry, and marketing directly to patients is a legal way to woo new patients and insurance subscribers. To solicit patients to use a particular home care service or factor product, a pharmaceutical or home care company needs to deliver its promotional material to you, the patient. For that, the company needs your personal contact information—name and address. Because HTC’s and hemophilia non-profits will not divulge patient information, a company rep can ask the HTC staff to pass along marketing materials to patients at clinic visits or events. Or, the company may send literature directly to patients, using information provided by the patients themselves, or via third-party marketing firms that provide mailing services using their own confidential mailing lists.

These are legal ways to market to patients, as long as the patients have willingly signed up to receive these materials. Patients should request a privacy policy from the company or

organization requesting their personal info. And they must take the time to read the policy to ensure that they approve of how their health information will be protected and respected, both short term and long term.

Some companies will try to get your health info without mentioning a privacy policy. Some company reps even masquerade as bleeding disorder patients only; they're not being completely honest if they don't disclose to you that besides being patients, they also work for "industry"—a home care or pharmaceutical company.

For example, around 2005, just prior to the Facebook revolution, a website debuted. The website creator, a relative of a person with hemophilia, asked hemophilia organizations to send patients to the site, which would serve as a chat room, a virtual social place for patients



to meet online. But to enter the website, you had to divulge an email address and create a password. No privacy policy was posted. And worse, the site did not disclose that its creator was starting a home care company, and was seeking potential customers.

Last year on Facebook, a market research company posted an ad for the hemophilia community announcing paid interviews. After clicking on the ad, you were taken to another page and asked to register by providing your contact info and some health info. Not only was there no privacy policy, there was no mention of the company running the research! Only after signing up and providing contact and health information did patients then learn something about the company. When the site administrators received a complaint query from LA Kelley Communications regarding the lack of a privacy policy and the subtle way in which patient information was being mined, the company posted a privacy policy and its name within 24 hours.

Just recently, some patients received a mailing from a home care company, announcing a contest for a free iPod Touch. To enter the drawing, all you needed to do was write your contact information, factor deficiency and severity level on a business reply card and return the card. No mention of privacy protection, and no direction to a privacy policy online.

Even National Hemophilia Foundation (NHF) posted an invitation on its website to participate in paid research, the HERO study. NHF assured applicants that their responses would not contain identifiable information (all responses were de-identified and aggregated) and that privacy was guaranteed, but it wasn't clear from NHF's website what would happen to your contact and health info once you'd given it: Would it be destroyed? Shared? Sold? There was no website address listed on NHF's recruitment page for Kantar Health, the market research firm conducting the study, and no directions to a privacy policy. You had to figure out on your own to go to Kantar's website and then search for its

**CONNECT TO THE COMMUNITY.**  
**make the LINK.**

**Learning. Insights. Knowledge.**

LINK educational programs provide an interactive forum for patients and caregivers to provide feedback while learning about the latest in the community. Program topics range from health insurance to treatments to lifestyles. So, if you're seeking the latest on real life issues connect, learn and make the LINK.

**link**  
learning, insights, and knowledge

LEARN MORE ABOUT EVENTS IN YOUR AREA AT [www.LINKmeetup.com](http://www.LINKmeetup.com)

Bayer HealthCare

© 2011 Bayer HealthCare Pharmaceuticals Inc. All rights reserved. BAYER, the Bayer Cross, and LINK are registered trademarks of Bayer. 04/11 Printed in USA. KNT000001

privacy policy, which clearly states that should Kantar Health be sold, your medical information goes to the new owner. Did you know that when you signed up?

In the four examples just outlined, it wasn't illegal to request the information in the first place, and it wasn't illegal *not* to post a privacy policy. Why? Because these examples are not covered entities. But it would have been smarter—and perhaps more ethical—to post a privacy policy.

In the highly profitable hemophilia marketplace, health info about people with hemophilia is extremely valuable. And our community has been burned in the past by “overexposure” of such info. Soliciting patients’ factor deficiency, severity levels, and product usage yields helpful data, yet it’s also sensitive data. Companies that collect this data need to respect it, inform patients how it will be used, and take appropriate measures to protect it.

Increasingly, many patients don't ask what happens to their contact or health information once they participate in a survey or raffle, or sign up for a newsletter. But don't lose sight of how important it can be to safeguard your personal health info.

## Facebook: Privacy's Wild West

Privacy may not seem essential to families anymore, at least to those connected on Facebook, where bleeding disorder patients number in the thousands.

It's not unusual for families with bleeding disorders to seek each other on Facebook and through referrals from other families. Many parents or patients, who would be horrified if their physician

divulged their information, willingly post details about their disorder for most of the world to see.

“I love that Facebook helps open my small world,” says Carri Nease, mother of twins with hemophilia. “I feel as if I really have an extended family if I need advice on a specific problem, or need support, or need to vent aggravations. It feels good to have input, and if something sounds like it might help us, I can bring it back to my treatment team and see what they think.”

Should families worry about what they share? Be warned that insurers are using social media to learn more about their customers. Market researchers already patrol websites looking for patients to recruit for paid surveys, and pharmaceutical companies have established pages to gain “likes.” Problem is, Facebook is unregulated, so you may not have the privacy guarantees that you'd expect when dealing with organizations and companies outside of Facebook.

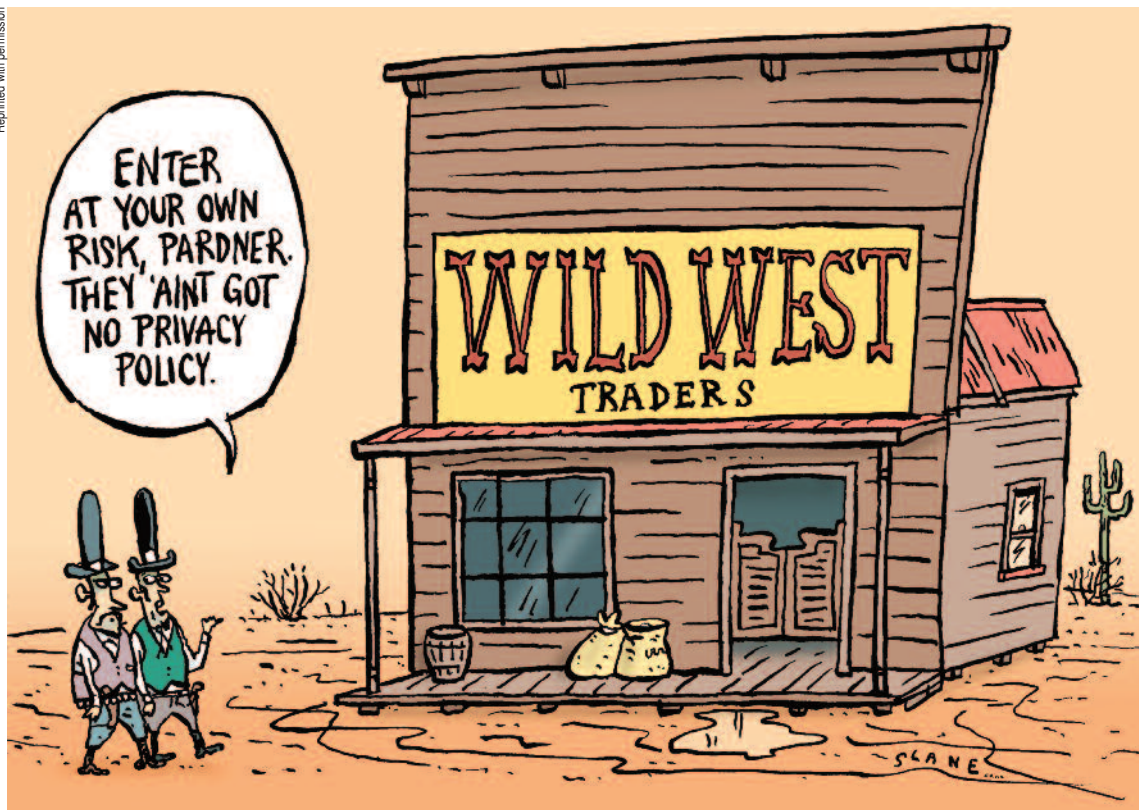
Patients may not be aware that Facebook records all conversations, photos, and “wall” postings, amassing

a huge database, rich with consumer information. Max Schrems of Austria was shocked when he sent a formal request to Facebook in early 2011, asking for a copy of every piece of personal info that Facebook had collected on him. He received a CD with 1,200 files on it! Nothing was deleted, even though Max had deleted many messages and photos himself. Every “like,” every account, every person, photo, and conversation was preserved.

Nease warns, “Sometimes, especially when you are new to [social media], you can make mistakes that could open you up to annoyances and breaches of confidence. Once I was so angry at my home care company, I vented about it on Facebook. Someone told me that I may want to delete talk like that, because it's better in private messages and only to friends whose advice you respect and trust.”

No one is sure where this lack of privacy will lead, especially regarding health information, but the trend could have vital implications for employment and discrimination

Reprinted with permission



down the road, even while the lure of Facebook remains strong to its 800 million subscribers.

“Facebook is an open door to infringe upon healthcare,” warns Kuhn. “I think Facebook is dangerous; people share too much on it, such as young parents documenting their child with hemophilia. We need to develop password-protected blogs and chat rooms, so at least you can share information without worry.”

### Protecting the Protector

Some organizations and companies recognize the dire need to protect patient health data. And while there are measures that companies and nonprofit organizations can take to protect their patients' health info, no electronic database is perfectly secure.

Hemophilia of Georgia (HOG) is ahead of the game in this aspect. Despite having superior, airtight privacy policies and security, HOG has also purchased a privacy and net-

work liability policy, called *cyber insurance*, for \$1 million in coverage in the event of a breach. Why? Because HOG operates differently than do most NHF chapters, in that it sells factor and provides home nursing services to its patient base of 1,400. HOG is considered a covered entity, is bound by HIPAA rules, and must protect its patients' PHI.

And it's impressive that HOG also pays for third-party security auditors annually or biannually to conduct security checks. Of course, cyber insurance helps protect the organization after a breach has occurred. As a patient or parent, you need to do your part to make sure you are protecting yourself *before* a breach happens.

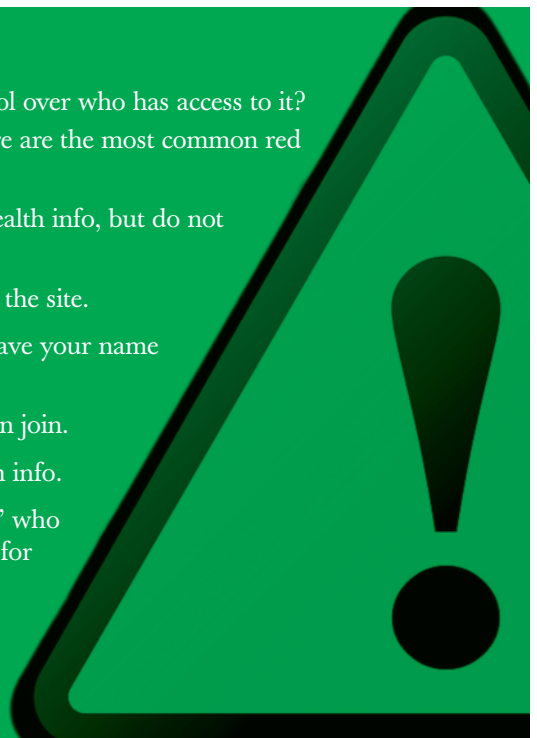
### Saving Private Data

So how best to protect yourself and your health data? If you are asked to share your health information, whether for treatment, customer research, or contests, be sure to ask the following questions and get answers from your pharmaceutical

## BREACH

Do you want to safeguard your health info? Do you want more control over who has access to it? Watch for warning signs that your privacy is not being protected. Here are the most common red flags for the bleeding disorder community:

- ✓ Business reply cards, websites, or mailings that request your health info, but do not specify a privacy provision or a website with a privacy policy.
- ✓ A website that asks you to sign up without disclosing who runs the site.
- ✓ Hemophilia events where you can visit company booths and leave your name for more info.
- ✓ Pharmaceutical or home care company mailing lists that you can join.
- ✓ Contests, raffles, or promotional events that require your health info.
- ✓ Websites, events, or mailing lists run by “community members” who have not disclosed their entire affiliations with the community—for example, also being a home care rep.
- ✓ Recruitments for surveys and studies that request your health info, but do not detail privacy policies or explain how your contact or health info will be used after the study.



company rep, your home care rep, your HTC, or any new company seeking your business:

- How will my personal contact info and/or health info be used?
- Will my health info be de-identified, coded, and used in aggregate?
- Will I be added to any mailing lists?
- What will happen to my personal contact info and health info once the contest/survey/study is over?
- What other entities will receive my health info?  
Third-party researchers? Other medical facilities?  
Pharmaceutical companies?
- Will my health info be sold now, or at any time in the future?
- Do you encrypt emails that contain my PHI?
- Is my PHI allowed on any laptops of employees?  
If so, how is it protected?
- Where is your privacy policy located, and how can I see it?
- Do you notify patients in case of a privacy breach?
- Does your company have a firewall to protect against hackers?

## Uncharted Future of Privacy

The days of passively protecting your private medical information are over. You must be vigilant and proactive to ensure that your data is not collected, shared, or sold without your consent. You do have privacy rights:

- *You have a right to receive information about privacy protection.* Covered entities—your HTC, home care company, pharmacy, insurance company—are required by law to provide their privacy policies to you. But even your local hemophilia organization should have a privacy policy handy.
- *You have a right to receive an accounting of disclosures.* Who are the people handling your private information? Are they professionals? Do they have the necessary software, hardware, and expertise to protect your data? What data do they possess about you?
- *You have a right to decide how you want to receive information.* Snail-mailed to you? Sent electronically?

1. To assist physician practices, the American Medical Association has made available its document "HIPAA Security Rule: Frequently Asked Questions Regarding Encryption of Personal Health Information." See [asha.org/practice/reimbursement/hipaa/securityrule.htm](http://asha.org/practice/reimbursement/hipaa/securityrule.htm) 2. Protected health information, or PHI, includes any information handled by covered entities about your past, present, or future mental or physical health, combined with any information that can be used to identify you: your name, address, birthdate, phone number, email address, and even your employer. For bleeding disorder patients, PHI includes factor deficiency, severity, drugs ordered, and the name of the HTC or home care company you use. 3. Aarathi Prasad, Jacob Sorber, Timothy Stablein, Denise Anthony, and David Kotz, "Exposing Privacy Concerns in mHealth." Dartmouth College, Institute for Security, Technology and Society (ISTS). This paper results from research at ISTS, and is supported by NSF under Grant Award Number 0910842 and by HHS (SHARP program) under award number 90TR0003-01. See <http://www.hhs.gov/ocr/privacy> 4. Aggregated data is grouped data, not necessarily stripped of all identifying information. It may be hard to match up personal data to individual names, but not for someone with the right tools and information. Medical databases often must include some of the HIPAA identifiers (for example, an age range). These are called limited data sets and may be more easily re-identified than other data. Also, small samples (like inhibitor patient info) can be easily re-identified. Remember, your personal medical information is never really 100% secure. 5. See [www.hhs.gov/ocr/privacy/hipaa/complaints/index.html](http://www.hhs.gov/ocr/privacy/hipaa/complaints/index.html)

# PSI



Patient Services Inc. is a national nonprofit organization committed to providing a variety of services to patients living with specific chronic illnesses. Call or visit us online today to see if you are eligible for assistance!

[www.patientservicesinc.org](http://www.patientservicesinc.org)

1.800.366.7741

If you believe your privacy has been violated by a covered entity, you can take action. Contact the secretary of the US Department of Health and Human Services. Under HIPAA, an entity cannot retaliate against you for filing a complaint.<sup>5</sup>

"People really need to have their medical information held closely," warns Kuhn. "Every company needs to have a private health information protection statement. If private health information is in a position to be shared with third parties, there has to be informed consent. That's where it starts."

We're already in uncharted cyber territory in the second decade of the millennium. Be sure to use good old-fashioned common sense about who you allow in to your cyber world, and be sure to protect your health information as much as possible. It's valuable, and you are the gatekeeper to its riches. ☺



### Advate's New Claim to Fame!

Advate is now the only factor VIII product FDA-approved for routine prophylaxis in both adults and children. A phase IV study showed prophylaxis on Advate reduced annual bleed events in hemophilia A patients from 44 to 1, when compared to an on-demand regimen. **Why this matters:** Although most factor VIII products are often used off-label for prophylaxis, it's important for a doctor to feel comfortable prescribing a product with FDA approval for a treatment regimen.

### New Recombinant VWF Product in the Works

Baxter Healthcare has started a phase III clinical trial to evaluate the pharmacokinetics, safety, and effectiveness of BAX 111, a recombinant von Willebrand factor (rVWF). This multi-center, open-label clinical trial will enroll a minimum of 36 patients with severe VWD in study sites based in the US, Canada, Europe, Australia, Japan and India. **Why this matters:** This is the world's first rVWF product to enter clinical development.

### New Study on wilate

Octapharma has launched an international multi-center clinical study to investigate the efficacy and safety of wilate, its von Willebrand factor/factor VIII concentrate, for prevention of excessive intra- and post-operative bleeding in pediatric and adult patients with type 3 VWD who undergo major surgical procedures. **Why this matters:** It's preferable to have FDA approval for physicians to prescribe wilate for surgery.

### Inspirational Results

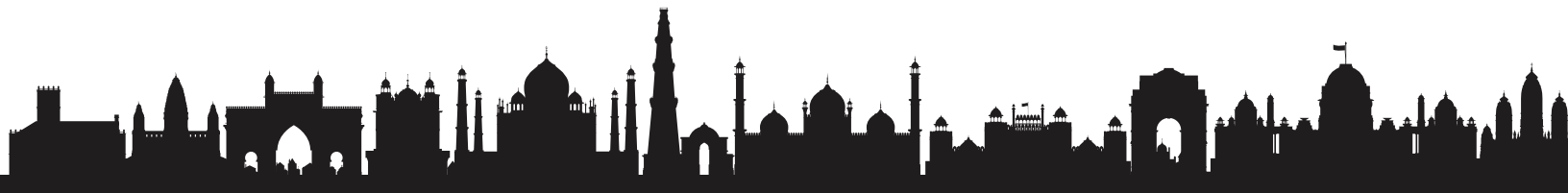
Inspiration Biopharmaceuticals presented key data on its two lead hemophilia programs: IB1001, a recombinant factor IX product; and OBI-1, a recombinant porcine factor VIII product for inhibitor patients. Especially important, the pharmacokinetic profile of IB1001, following prophylaxis over 4 to 18 months, was similar to the profile established during the initial phase of the study; there was no evidence of inhibitor development. **Why this matters:** IB1001 will offer hemophilia B patients choice, as there is currently only one approved recombinant factor IX product.



## Leadership Summit in India

Novo Nordisk Haemophilia Foundation (NNHF) funded a three-day summit in Goa for more than 75 people with hemophilia, being groomed as future leaders, to teach them how to plan to improve care for hemophilia. Activities included the development of a leadership manual, allocation

of roles and responsibilities, and workshops to create a sense of brotherhood. **Why this matters:** Engaging young people with hemophilia and giving them a sense of responsibility ensures continuity of leadership in the national organization.



## NHF Washington Days: A Capital Idea

March 7-9, 2012

NHF's annual Washington Days empowers people in the bleeding disorder community to impact the legislative process. Meet face-to-face with lawmakers and staff who shape national healthcare policy.

**Why this matters:** Becoming more informed on political and insurance issues, and learning effective grassroots advocacy techniques will help preserve your continued access to quality care.

**For info:** [www.hemophilia.org](http://www.hemophilia.org)





## How Does ATHN Protect Personal Health Information?

ATHN has established reasonable and appropriate physical safeguards to protect its electronic information infrastructure, related hosting site, and equipment from natural and environmental hazards and unauthorized intrusion. These safeguards include hosting its database at an SAS 70 Type II certified facility. The data is also backed up securely and synchronously to a disaster recovery site in a geographic location separate from the primary site.

The following technical safeguards are also used to protect patient data and control access to it:

- More than one approach to authenticate users.
- System-generated, unique patient identifier instead of a patient name.
- Data encryption. This means that people cannot read the information when they look at it. The encryption key is held by a third party in a physical location separate from the data. All data is sent through a secure Internet-based data transfer mechanism that is password protected and encrypted.
- Business rules governing the parsing and transfer of data from hemophilia treatment centers (HTCs) to ATHN.

Finally, with administrative safeguards, ATHN selects, develops, implements, and maintains security measures to protect electronic personal health information and to manage the conduct of ATHN's workforce. Administrative safeguards include business associate agreements with software developers, hosting site, disaster recovery site, technical support personnel, and all authorized agents or subcontractors. ATHN

monitors and audits all data uses and disclosures, and has developed risk-assessment and breach-notification systems that comply with the HIPAA privacy rule as amended by the Health Information Technology for Economic and Clinical Health Act (HITECH).

## Why Should Patients Trust ATHN?

ATHN is affiliated with HTCs. HTCs are required by law to protect patient health information. HTCs and ATHN enter into a Data Use and Business Associates Agreement (DUBAA) that constrains ATHN's use of the data, and that obligates ATHN as steward of the database to protect it. ATHN is bound by DUBAA, and is required by federal privacy laws to protect patient information. HTCs share non-identifiable patient health information with ATHN for research purposes only if a patient signs an ATHN patient authorization form.

We are pleased to report that as of December 1, 2011, more than 7,200 patients across the US have opted to share their non-identifiable data in the ATHNdataset. Half of them have hemophilia A or B, and one-quarter have von Willebrand disease (VWD).

Open and transparent processes guide the collection, management, and use of all patient and healthcare provider information. Consistent with its mission and core values, ATHN policies and practices respect and safeguard data with which ATHN is entrusted. Toward that end, researchers who seek to use the ATHNdataset must also enter into a data use agreement and ensure that data obtained through ATHN is used only for its intended purposes. Neither ATHN nor researchers have unrestrained access to and use of patient data.

## Why Participate?

The value of the ATHNdataset lies in patient participation. The more patients contribute their health information, the more certain we can be that the ATHNdataset represents the whole community, and the more valuable its research and outcomes become.

In short, ATHN is securing patient data. By working together, we can advance knowledge about bleeds and treatments, and hope to transform care. @

Diane Aschman is president and CEO of the American Thrombosis and Hemostasis Network. ATHN supports 130 federally funded US HTCs and the patients they serve, by providing stewardship of a secure electronic information infrastructure and a dataset for outcomes analyses, research, advocacy, and public health reporting. Diane is a pharmacist with over 25 years in the healthcare field.

The views expressed in As I See It are the author's own, and do not necessarily reflect the views of PEN or of LA Kelley Communications, Inc.



**Confidential.** All information used to identify individuals is removed.

**Simple.** No special blood tests, procedures, or treatments are required.

**Secure.** The database will be used only for research and advocacy.

## Privacy in a wired world

According to NHF, online forums, blogs, and social networking sites are now key ways for geographically isolated inhibitor community members to connect: a virtual support group is available anytime. “It’s in sharing with each other that we learn more about how to cope with a bleeding disorder, and we can develop networks of people and resources that maximize our chances of living a high-quality life,” says Derek Nelson, who has a son with inhibitors and now works for a home care company.

The downside? News can travel very quickly in the small, tight-knit inhibitor community. You can be lulled into a false sense of security—and divulge health information—if you think that everyone out there is a “friend.” Who knows who is writing or reading the other postings? “It’s up to us as consumers to be smart regarding how we share information, and who we share it with,” stresses Derek.

If you’re interested in joining a social network site or message board, research who is funding or hosting it before providing any health info. Some people only join groups that are initiated and moderated by a consumer or patient, not a company. But be careful: some patients have dual roles as company reps. And be careful about divulging medical information online. Consider all postings to be public information. Remember, even though it’s not legal, insurance companies or employers could use information to discriminate against inhibitor patients. Some companies routinely now do



Internet or Facebook searches on prospective employees.

Today’s social media and online communication make it harder to protect your privacy. Anyone with teenagers knows how popular Facebook is! It’s smart to take time to figure out and use its privacy settings so your health information isn’t broadcast all over the web. Teach your children how to use websites safely. Be careful who you “friend”—remember, the request could be coming from an employee of a factor provider or a drug company. Do some research on hemophilia-related groups before you “like” them: are they true support groups, or are they really just fishing for your health info?

You may be asked to take part in a survey of inhibitor patients or marketing study, sometimes for money. Surveys can provide valuable information for companies, but the info can also be used inappropriately if it falls into the wrong hands. Find out who is using your health information and how they are protecting your identity before you decide if you feel comfortable participating.

## What can you do?

Anxiety about safeguarding your family’s health information can make it hard to trust anyone—but you need to! Yes, companies want your business, but they also want to *keep* your business, and they generally act responsibly. Most do care about you and your family.

If you’re a patient of a home care company or HTC, you should know that by law, these are considered *covered entities* (see feature article): they are required to follow guidelines of the Health Insurance Portability and Accountability Act (HIPAA)\* to protect your health information. HIPAA spells out who sees your medical records and under what circumstances. Even so, you may want to research your home care company’s privacy policies concerning health info, and find out if company employees are trained to protect it. A sales rep for a home care company can become quite close to a family that he or she services. What happens if that rep switches companies, or forms a new home care company? Is the rep allowed to take your health info along?

“You need to be savvy about how and where you share your personal information and how you choose what product and what service provider you use,” advises Sonji Wilkes, mother of a son with inhibitors.

As Derek explains, “It has become harder and harder for home care companies to ‘fly under the radar’ [of soliciting patients] these days. Consumers are demanding more transparency in the business of healthcare.” Inhibitor patients should be ready to advocate for their rights, and willing to speak up if they think their privacy is being violated. Research your legal rights if you feel uncomfortable about a situation. And as always, be careful what information you post, and where you post it online. ☺

\*For details on HIPAA, the Health Insurance Portability and Accountability Act: <http://www.hhs.gov/ocr/privacy>.

Jo Schaffel is a freelance science writer who has taught biology to general and special education students for 15 years. She lives in New York’s beautiful Hudson Valley with her husband and teenaged son.



*Inbox... from p. 2*

I AM PLEASED TO INFORM YOU THAT MUHAMMAD DAUD SHAH HAS recovered and is ready to go home. His entire family is praying for all of you, as this donation brought happiness back into their lives.

*Saif-ul-Islam*

*President, Pakistan Haemophilia Patient Welfare Society  
Rawalpindi*

I WAS EXTREMELY HAPPY AND GRATEFUL WHEN YOU DONATED FACTOR.

My right elbow is giving me some trouble, so I can't write much more. Once again, from the bottom of my heart, you have my deep gratitude for your kindness.

*Le Huu Hung*

*Vietnam*



## NEW Project SHARE Director

Project SHARE welcomes Zoraida Rosado, our new director.

Zoraida has worked for LA Kelley Communications for nine years as manager of projects and production. She brings her expertise and bilingual skills to this important role.

Kathryn Ondek will continue at LA Kelley Communications as marketing director.

To learn more about Project SHARE:  
[www.kelleycom.com/projectshare](http://www.kelleycom.com/projectshare)



Become our fan on Facebook today!

## Parenting Moment

*The bond that links your true family is not one of blood, but of respect and joy in each other's life. —Richard Bach*

*Feelings of worth can flourish only in an atmosphere where individual differences are appreciated, mistakes are tolerated, communication is open, and rules are flexible—the kind of atmosphere that is found in a nurturing family. —Virginia Satir*



## OUR CORPORATE SPONSORS

### Baxter

800-423-2862

[www.thereforyou.com](http://www.thereforyou.com)

Baxter is a registered trademark of Baxter International Inc

### CSL Behring

888-508-6978

[www.cslbehring.com](http://www.cslbehring.com)



novo nordisk®

800-727-6500

[www.novonordisk-us.com/biopharm](http://www.novonordisk-us.com/biopharm)



888-999-2349

[www.hemophiliavillage.com](http://www.hemophiliavillage.com)



65 Central Street  
Georgetown, MA 01833 USA  
www.kelleycom.com

*Visit Your HTC Annually!*

