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GEAR UP TO TELL YOUR STORY....

Where is it? If you haven't recorded your personal healthcare story, you are missing out on the opportunity to help shape the changing climate of healthcare for all those with chronic disorders!

WHY MY STORY?

1. Your healthcare story is unique. Your experience can only be told by you. No one else has your experience.
2. Telling your story helps others appreciate your struggles and accomplishments.
3. Your story is your legacy. It will provide inspiration to others facing similar challenges and increase the knowledge of others who don't "get it" in regards to living with a chronic bleeding disorder.
4. At the end of the process, you will have gained a greater appreciation of what you have accomplished and feel good about having recorded your story.

WHY YOUR STORY IS IMPORTANT?

The Ricky Ray Hemophilia Relief Fund Act and the Ryan White CARE Act made a made a significant impact on the lives of members of the bleeding disorders community. Yet it was the voices of the advocates that ultimately catalyzed change. Although vital



Some stories take a little more prep time than others! See HFA Voices Campaign Ad on page 15 for details!

medical advances have been made over the years and significant medical policies have been changed, many community members are still heavily burdened and affected by the issue of reimbursement, formulary restrictions, lifetime insurance caps, and reductions in state Medicaid budgets.

Please share your story with the HFA so that we can assist YOU in taking on an active, grassroots approach to affecting change in your state and in Washington. 

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MISSION

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DISCLAIMER

The material provided in Dateline Federation is provided for general purposes only. The HFA does not give medical advice or engage in the practice of medicine and recommends that you consult your physician or local treatment center before beginning any form of treatment.

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EXECUTIVE'S REPORT – WHAT KEEPS YOU U

By Kimberly Haugstad and Chad Stevens

As an adult with hemophilia, our HFA President, Chad Stevens has both lived through and lost a great deal in his history. I'm a typical mom who has a young child with hemophilia, doing my best to tackle the here and now and learn the past, desperately hoping it will never be repeated. To add, I'm a woman with a separate factor deficiency whose only treatment option is plasma (FFP), as needed, so I've got an arm in that game too.

That said, I'm going to take a big risk and speak from my heart in the hope it reaches you.

We got a call from a community member the other day. The consumer wanted to know just what HFA was doing about a legislative issue in their state. It was great to get the call and we were pleased to answer that we were actively engaged in working with that local chapter on the issue.

Then, my heart broke. We asked that individual what they were doing to advocate for themselves and the message we got was, "That's what you guys are supposed to do."

We respectfully disagree with that message. In fact, each one of US that is able is accountable. We are not entitled to anything but we DO have rights. Right now, making sure we are heard is absolutely imperative.

Do not doubt that HFA is here; we're raising voices and making real efforts to bring a grassroots community together. We can be very proud of this organization, our staff and our amazing volunteers. However, don't think we're "on it" and your job is done. Our staff is less than 10 covering the entire country, but the power of our community is THOUSANDS strong. Let's engage and champion our needs!

We have some amazing folks in our community and then a whole bunch of others who don't always wind up on the amazing list but are relentless in their efforts. Just last week, I was on Facebook one night until the wee hours with an advocate in Iowa learning about all he'd been working on.



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UP AT NIGHT?

I could cite others in Florida, Maryland, Connecticut, Virginia, Massachusetts, California, Texas, Denver... Who can you point to that you know that is "amazing"?

How do they do it? It starts with a simple look around and an investment in time. There are many print and on-line resources available at no cost. Read a few, think a lot and ask questions to clarify. Then ask yourself, what doesn't set well and keeps me up at night? For me, the show-stopper question that I worry my young son will someday ask if I don't get involved, "Mom, where were you?" What is yours?

We challenge you to work together and take the risk. Get connected! Work with your local chapter and get involved where you can, when you can, and as much as you can. Be a sponge, listen and learn. As an advocate in Florida often says, "Call, write, and visit!". I'd add, tell your story! There are several references to HFA's Voices Campaign in this issue; please read and respond! The right time is now. ♦



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Women today continue to be undiagnosed with bleeding disorders, because many doctors are still convinced and argue that “women aren’t affected by blood disorders.” Women who live with these disorders know there is something wrong, but a diagnosis is often overlooked. Laveane Lovelady tells her story of the births of her two babies, two life-threatening bleeding incidents, and the final diagnosis which confirmed her lifetime struggle with her own bleeding disorder, and the realization that unbeknown to her, she had passed Hemophilia A on to her son, Ryan.

Her story is not uncommon. Her goal is to educate doctors, hospitals, and other women of the risks of being undiagnosed, and of the fact that women, too, can be hemophiliacs.

Read Laveane’s powerful story in its entirety on the HFA website at www.hemophiliafed.org.

HEMOPHILIA: MY STORY *by Laveane Lovelady*

This story is about me, but it all started when my son Ryan was born August 15, 1989. It was after his birth when I was finally diagnosed with mild Hemophilia A, because he was diagnosed with severe Hemophilia A.

All of my life I had bled for long periods of time with the smallest cuts, and I always had a bruise some place on my body. Comments were made to me like, “You take after your grandpa; he would bleed and have bruises on his body for no reason.” My mom and dad would say, “If I had a bruise like that I would know what happened to cause it!” Every time I had a tooth pulled, that night and the next day would be awful due to the bleeding. My parents would take me back to the dentist and he would order a shot of vitamin K. I remember one incident of bleeding for 20 hours after having a tooth pulled, but the unusual thing was the bleeding started about two weeks after the tooth extraction. Doctors would always shake their head and say, “I just don’t understand why she bleeds so excessively; females don’t have bleeding disorders.”

Although I have a diagnosis for my excessive bleeding, I don’t have a specific doctor or place to go for help with my bleeding problems. Many women are like me. When we give birth to a boy with a bleeding disorder is when we finally get diagnosed, but that is as far as it goes. We have no regular checkups and most of the time we have to tell the medical personnel how to treat our bleeding episode. My mission is to have hospitals, medical clinics, emergency rooms, doctors and nurses become aware that women are hemophiliacs too, and not just symptomatic carriers. I continue to work in the hemophilia community in my state of Arkansas, because there is always someone like myself, who needs someone to talk to, a shoulder to cry on, or just a friend to hang out with who already knows what having a bleeding disorder is like. 💧

Helping Hands™

Hemophilia Federation of America

By Drew Matz

The maxim “when it rains, it pours” aptly describes the situations and circumstances of many Helping Hands applicants. Job loss, benefit cuts, sudden illness, and unemployment highlight the difficult realities of living with a bleeding disorder during a recession. Yet what is equally striking in these personal stories is the unfathomable determination these applicants have to “get back up.”

Take, for instance, the plight of a married mother of two who has been out of work for months because of a work-related injury that severely limited her mobility. Rather than retreat into her own pain, she continues to support her family, especially her 12-year-old son who suffers from von Willebrands and epilepsy, by managing her child’s bleeding disorder, cutting unnecessary expenses from her family’s budget and securing help from local assistance programs. In an effort to make her mortgage payment, she even pleaded with her doctor to return to work early, which could jeopardize her long-term recovery.

Fortunately, the Helping Hands program was able to assist this applicant with her mortgage payment, thereby giving her the time necessary to heal from her injuries before returning to work. Her story, though, calls attention to the mission of HFA’s Helping Hands program - helping those in need so that they can ultimately help themselves. Through the generosity of Wyeth Pharmaceuticals, the Helping Hands program has been able to assist people in building bridges to their own recovery, something possible by the strength and tenacity this community exhibits in weathering these formidable storms.

Unfortunately, requests to the Helping Hands program have continued to grow. At the end of May, the Helping Hands committee had already received over 100 applications, a nearly 20% increase from last year’s numbers. With that in mind, the HFA sincerely appreciates the individual donations we receive from the community to continue this much-needed program. 📌

TEEN Connection™

Hemophilia Federation of America

Helpful hints and scholarship information for Teens headed to college in the fall!

Check out the college.gov website for important money management tips like the ones below.

Money Management Tips: Spend with Care

1. Make a budget and stick to it. A budget is just a self-imposed guideline for how much money you can spend and what you can spend it on. You will be amazed at how much farther your money goes when you have a budget.

2. Avoid credit cards. In college, you’ll get tons of credit card offers from banks. Your best move? Shred them. As attractive as they might seem, the interest on credit cards can put you in a very deep financial hole.
3. Buy used books. Many students and their parents are surprised how much textbooks cost. They can average \$1,000 a year. Most campus bookstores sell used books that can help reduce this cost. You might also save money by buying textbooks online.
4. Leave your car at home. Cars consume more than just gas money. There are insurance, parking (and parking tickets!) and repair expenses, too. Walk, use public transportation and/or ride a bike.
5. Watch the ATM fees. Choose a bank with free ATMs near your school. ATM fees can add up quickly. 📌



HFA Welcomes North Carolina as the Blood Brotherhood Pilot Site #7!

Hemophilia of North Carolina is excited to be a Blood Brotherhood pilot site. The member organization saw the necessity for the population of adult men affected by a bleeding disorder. The ability of joining HFA's Blood Brotherhood program is a great opportunity to help the community connect and make a difference in their lives. Offering a range of educational topics, physical activities, and website forums, the Blood Brotherhood is a great tool in bringing these brothers together. The program is designed to keep everyone involved through local events, webinars, and teleconferencing. The choice to get involved in the Blood Brotherhood is available to everyone thanks to HFA. Hemophilia of North Carolina announced this program to its members at their Annual Meeting on May 30th in Durham, NC. There will be an opportunity to enroll in this program and complete a short survey that will help us determine the direction of the program. For more information on upcoming meetings, see <http://www.hemophilia-nc.org> 🩸



My name is Matt Igleman and I live in Zebulon, North Carolina. I'm really excited to play a role in the Blood Brotherhood program in North Carolina. Early in my hemophilia treatment I acquired an inhibitor, living with that inhibitor until our family moved to North Carolina. I was introduced to Hemophilia of North Carolina as a kid attending events, and became involved at age 17. Being part of such a great community has always been a benefit and reward, and I soon found that the challenges hemophilia has provoked throughout my life were easier to overcome with the help of others in the same situation.

The Hemophilia of Indiana's Blood Brotherhood group, also known as the Bruisers, were on their toes and looking sharp at their May meeting on Friday. Twenty-three people met at a local restaurant and listened to Judy Moore of the Indiana Hemophilia and Thrombosis Center led the discussion on the ADA and how that pertains to us and how to advocate for our rights. Seventeen then traveled over to BladePoint Fencing and learned about the history of swordplay, donned our fencing attire, learning a few moves, and dueled. What a great time spent together learning and lunging. Thanks Eric for planning such a great event! 🩸

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GOOD LUCK AT MED SCHOOL

HFA would like to wish Drew Matz well as he leaves HFA and begins medical school this fall. Drew has been with us for seven months and during that time he has become a wonderful part of our community. As Special Projects Coordinator, he spent countless hours assisting Helping Hands applicants and Educational Scholarship applicants while also working hard developing HFA's new website and Voices Project. Drew is a top-notch editor and writer, and his talent shines in HFA's brochures, articles, grants, and anything else that was presented to him to meet deadline. If you are lucky enough to visit DC, you will see Drew's care for the office as well, with the beautiful green plants he picked out and the cherry red conference room furniture that he searched for all through Washington, DC.

HFA will miss Drew's dedication and perseverance, but most of all, we will miss his kindness and willingness to help with anything and everything. As a coworker he helped make our jobs easier; as a friend he will always make us smile. We wish Drew the best of luck on his new venture at the University of Virginia Medical School and hope he comes back to visit us often! 💧



HEMOPHILIA FEDERATION ADDS STATE POLICY EXPERTISE

Hemophilia Federation of America (HFA) is proud to welcome Stephen May in the newly created leadership position of Public Policy, State Affairs. The position was created to ramp up state-level advocacy in response to community concerns of an ever-changing, turbulent healthcare landscape. His responsibility includes pro-active public policy monitoring by collaborating and offering support to HFA member organizations.

Before joining the HFA, May provided advocacy for the bleeding disorder community at the New England Hemophilia Association. His previous experience includes extensive work in organized labor, public policy and state political campaigns.

Steve holds a Master's degree in Social Work from the University of Vermont and an MA in Political Science from the University of Rhode Island, in addition to a Bachelor's degree in Politics from Ithaca College. 💧

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COMMUNITY NEWS

Have you always wished that you could tell your health care story? Here's your opportunity. Advocacy for Patients with Chronic Illness, Inc. and the University of Michigan Center for Managing Chronic Disease have been awarded a grant by the National Institutes of Health (NIH) to study the obstacles facing the chronically ill and caregivers, interventions that do and do not work to surmount those obstacles, and ways in which the work done by the NIH, including research and clinical trials, may be helpful to patients with chronic illnesses. If you are interested in participating in the survey, go to <http://chronicdisease.survey.sgizmo.com>. Contact Jennifer Jaff, ED of Advocacy for Patients with Chronic Illness, Inc. For more information regarding this survey at 860.674.1370.

Congratulations to Phyllis E. Baker, RN, MSN, CNS-BC named Indianapolis, 2009 Nurse of the Year. Ms. Baker recently presented as a topic expert at the HFA Educational Symposium, March 13, 2009. She is a Hepatitis C patient and advocate who works as a Psychiatric & Mental Health Care clinical nurse specialist. She facilitates a Liver Wellness Support & Education group, and works within a substance abuse outpatient clinic. Her unique position of knowing healthcare from both sides of the coin, as the patient and the healthcare professional, gives her a chance to help both groups bridge effective communication and goal setting needs to enhance the outcome of chronic illnesses.

(Continued on pg. 11)



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HFA NATIONAL NOTES

by Kisa Carter

HFA Public Policy Director, Federal Affairs



CHAOS IN CONGRESS

If there is one word to describe the halls of Congress over the last several months, chaotic fits the bill. The halls of Congress are filled with lobbyists, stakeholders, and advocates from across the country, each trying to make his or her message heard. For example, consider supporters of the single-payer health system. On May 12, 2009, several of these supporters were arrested for disruptive behavior during a health-coverage roundtable discussion hosted by the Senate Finance Committee. While waiting in line for nearly two hours, I had a front row seat to the action taking place.

Of course, the single-payer health system supporters are not the only loud and clear voice. The rare disorder groups have forged together to ensure that the 30 million people with rare disorders are not forgotten. We are a unique group with unique needs, and we need to make certain that policy-makers understand how our health needs may differ from the needs of others. Thus, we have worked together to clearly define our needs, which include:

- Access to leading health care providers
- Timely access to the full range of specialized treatment
- Access to quality, affordable health care coverage, regardless of pre-existing conditions
- Elimination of unreasonable lifetime or annual limits on benefits

The voices of the rare disorders groups must continue to be heard! For more information on how to become involved or to read the Rare Disorders Health Care Reform Principles, please visit the Advocacy section of the HFA website at www.hemophiliafed.org

HEALTHCARE REFORM HAPPENINGS

There is no shortage of healthcare reform proposals in Congress. On May 20, 2009, Senators Tom Coburn, MD (R-OK) and Richard Burr (R-NC) and Congressmen Paul Ryan (R-WI) and Devin Nunes (R-CA) introduced "The Patients' Choice Act of 2009". Then in early June, Senator Edward Kennedy (D-MA) and Democratic members of the Health, Education, Labor and Pensions (HELP) Committee introduced a landmark 615-page health-care reform bill. During the last few weeks of June, the HELP Committee reviewed their "Affordable Health Choices Act" and made recommendations for changes. More recently, Senator John D. Rockefeller IV (D-WV) introduced a bill detailing a public option plan. The "The Consumers Health Care Act", was introduced on June 17, 2009.

The Senate Finance Committee Chairman Max Baucus (D-MT) and Ranking Member Chuck Grassley (R-IA) have released three policy options papers to be discussed before the committee. They make up yet another set of leaders expected to introduce a bill for consideration by the Senate Finance Committee sometime before the August recess.

These plans, and those surely still-to-come before August, include a variety of different measures that will be debated within and between parties.

Not to be overshadowed, leaders in the House of Representatives have also put forth healthcare reform proposals. For example, the House Ways and Means, Energy and Commerce, and Education and Labor committees released a "Health Reform Draft Proposal" outlining key components of reform legislation. Introduction of legislation and deliberation are slated to occur before the congressional recess in August.

(continued on pg. 10)

Ultimately, all components of reform are up for debate this summer. In the meantime, members of both chambers of Congress continue to deliberate over the following:

- Cost of health-care reform
- Financing the health system
- Insurance market reform
- Employer and individual mandates
- Inclusion of prevention and wellness programs
- Program structure (public-option, health exchange, co-ops, private)
- Tax credits and subsidies to individuals, employers, and businesses
- Modernization, expansion and improvements to public programs (Medicare & Medicaid)

To follow legislation and important updates on health care reform, please visit the Advocacy section on the HFA website.

BILL HIGHLIGHTS

House Concurrent Resolution 147 (H.Con.Res.147)

Introduced by Congresswoman Carolyn McCarthy (D-NY), H.Con.Res.147, provides greater awareness and education of bleeding disorders, seeks to enhance diagnosis and treatment of bleeding disorders, suggests students at institutions of higher education should be screened for von Willebrands (vWD) and increases research funding for bleeding disorders.

Ryan Dant Health Care Opportunities Act of 2009 (H.R. 1441)

Introduced by Congressman Kenny Marchant (R-TX), H.R. 1441, will allow states to permit certain Medicaid eligible individuals with extremely high annual lifelong orphan drug costs to continue receiving Medicaid benefits notwithstanding increased income.

Pre-existing Conditions Patient Protection Act of 2009 (S.623, H.R. 1558)

Introduced by Senator John D. Rockefeller IV (D-W.VA) and Congressman Joe Courtney (D-CT), this bill will end insurance discrimination against those who live with pre-existing condition or chronic illness.

Please visit the Legislative Action Center on the HFA website to learn more about bills that impact the bleeding disorders community. ♦

HFA STATES IN BRIEF

by Steve May

HFA Public Policy Director, State Affairs

DOLLARS AND SENSE

Facing the worst economy since the Great Depression, state lawmakers have been forced to focus on cost cutting. Forty-eight of the 50 states are currently running budget deficits, and unlike the Federal Government most states must balance their budgets by the end of the fiscal year on June 30. This means the states have been left to make deep cuts to services, including Medicaid and Human Services.

Different states have managed the crisis differently, but almost all of the states have made choices that impact the bleeding disorders community. In Illinois, Governor Pat Quinn's proposed budget included a \$700K cut to the state's Hemophilia program; and **California's** budget problems continue to impact the Genetically Handicapped Persons Program. Other states have attempted to manage cost by driving down the price of factor products. **Washington** had been considering a sole source contract, but community action forced lawmakers in Olympia to reconsider. **New York** and **Maine** have been considering a multi-source arrangement, but these arrangements have been snarled by red tape. Some State Public Health officials have taken a keen interest in how much factor is being used; **Maryland** is about to impose a mandatory infusion log, while **Nebraska** has proposed a system of utilization reviews for Medicaid patients who use \$50K or more of product.

Legislative successes for the bleeding disorders community have been difficult to come by in this political climate. Missouri Standards legislation received a favorable hearing, as did the **Massachusetts** Advisory Committee bill. **Texas** has been successful in changing the Medicaid reimbursement rates for factor.

State Public Health officials will likely focus on cost well into the future by both addressing the cost of factor product and analyzing individual patient use. In light of all of these many challenges, it will be essential that the bleeding disorders community deepen and broaden its focus on healthcare at the state level. ♦

IN MEMORIAM

We have lost another member of our community. Ralph Warner of Tampa, Florida passed away peacefully after enduring several years of hemophilia-related severe illnesses. Ralph was the widower of Rachel Warner, a beloved and highly respected community activist who, among her many excellent works, founded the A.C.C.E.S.S. Program. In addition, she was an enthusiastic advocate for health care reform, well known in national and Florida governmental circles. Ralph was a delightful man, interesting and possessed of a strong sense of humor. He faced his illnesses with courage and a determination to live.

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COMMUNITY MEMBER CLIMBS MT. RAINIER TO RAISE MONEY FOR INNER-CITY YOUTH AND INTERNATIONAL BLEEDING DISORDER ASSISTANCE



Cincinnati, Ohio (April 28, 2009) — On August 5, 2009, two BioRx employees, Jeff Salantai and Eric Hill, will climb Mt. Rainier as part of a national fundraiser called Summit For Someone. The fundraiser benefits at-risk, inner-city youth who do not have the privilege of experiencing life outside the city. Plus, all proceeds exceeding \$8,000 will be donated to “Save One Life.” Save One Life provides financial support, in the form of direct sponsorship, to children and young adults with bleeding disorders in developing countries who do not have the means to acquire their much needed treatments. So Jeff’s and Eric’s climb will benefit two charitable organizations. For the full story, visit the HFA website at www.hemophiliafed.org. ♦

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Just go to www.goodsearch.com and be sure to enter Hemophilia Federation of America, as the charity you want to support. And, be sure to spread the word! ♦

TO OBAMA HEALTH ROUNDTABLE

If President Obama's effort to overhaul the nation's healthcare system ultimately succeeds, Louise Hardaway of National Cornerstone Healthcare Services can look back and feel a sense of personal accomplishment.

On April 24, Louise, manager of consumer services and marketing for the NCHS Factor 4 Life Division, was part of a contingent of about 20 small business representatives invited to participate in a two-hour roundtable discussion moderated by Nancy-Ann DeParle, director of the White House Office of Health Reform. Also participating in the meeting, held adjacent to the White House in the Eisenhower Executive Office Building, was Lawrence Summers, director of the National Economic Council.

Louise, from Nashville, TN, was invited to attend based largely upon her longtime advocacy for healthcare reform. Also represented were the Small Business Majority, the National Federation of Independent Businesses, and other organizations.

"We talked about different issues, primarily those involved in the rising cost of healthcare," said Louise, who experienced the increase firsthand when she tried to start a small business and found the cost of health insurance prohibitive. "The private insurance industry simply is not working for small businesses. Something needs to be done."

Naturally, with Louise there, the discussion eventually turned to hemophilia.

"I talked about chronic disease and how people who have high-cost diseases are often discriminated against in the marketplace," she said. "It's not uncommon for an insurance company to notify an employer about the cost of factor for the child of an employee, and all of a sudden the employee may be out of a job."

She added, "I told them I understand the issue from both sides. I tried to start a small business and realized there was no access to affordable health care insurance. Fortunately, we were able to obtain health insurance through the NCHS employee plan."

The roundtable was one of many being held with stakeholders—including doctors—as President Obama ratchets up his effort to change the system. If the session that Louise attended was any indication, participant comments are not falling upon deaf ears. Both DeParle and Summers appeared to be listening intently, taking in everything they were hearing, she said.

"Healthcare reform is not only a moral imperative, it's an economic imperative," Louise said. "The meeting was very productive, and I felt honored to be able to go and represent a population that really needs to be heard. This was a once-in-a-lifetime opportunity." ♦

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VOICES CAMPAIGN APPEAL

What is the Voices Campaign?

The Voices Campaign is the HFA's grassroots Advocacy initiative to drive awareness and communicate the bleeding disorder community's health issues to the public and legislatures by way of personal stories. HFA utilizes these personal stories in two ways.

1. Educate the public on the health issues, challenges, and concerns associated with living with a bleeding disorder.
2. Provide crucial "personal touches" for legislatures and federal agencies when they debate issues that impact our community.

"We know the statistics, but it is the real live stories of families across this country that motivates us by putting a face on the challenge of affording quality health insurance..." U.S. Senator Blanche Lincoln (D-AR)

What is involved? Because your VOICE is an important part of the debate surrounding healthcare reform, we

want to know YOUR stories and concerns on the issues that impact you and the community. Lifetime caps on insurance, access to public and private health insurance, availability of factor product, or the overall need for healthcare reform are just a few examples.

After recording your story, we are determined to help make YOUR story a part of healthcare reform as it relates to the bleeding disorder community.

How can I be a part of the campaign and have my Voice Heard?

1. Email info@hemophiliafed.org to indicate your interest
2. We will contact you to collect your story and discuss how it may be distributed
3. Be sure to also sign-up for the Legislative Action Center at www.hemophiliafed.org to receive updates about upcoming legislation that impacts our community. 

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