Advocacy: It’s in Your Blood
by Jonathan VanderBrug

At the beginning of this year, HFA launched a new campaign: “Advocacy: It’s in Your Blood.” Advocacy is in all of us. Whether it’s educating our doctors, fighting for proper care in the E.R., or correcting misperceptions at school, we in the bleeding disorders community are advocates every day. This advocacy readies us for another important type of advocacy: legislative and policy. Each one of us can take meaningful steps – signing a petition, for example, or calling a state representative – to help advance policies that benefit our community. To do so, however, we need the right tools and resources.

The “Advocacy: It’s in Your Blood” campaign provides these tools and resources to individuals and HFA member organizations across the country. This advocacy support includes five components, each based on the feedback HFA’s membership gave late last year through a nationwide survey.

First, HFA has created new toolkits, one version specifically designed for individual advocates and another version for legislators. The Advocate Toolkit includes talking points, issue briefs, and sample letters. It also includes materials on how to build and maintain coalitions, organize advocacy activities, communicate with the media, and run successful advocacy campaigns. Advocates can give the second version of the toolkit – the Legislator Toolkit – to elected officials, providing them with issue briefs, fact sheets on bleeding disorders, bill summaries and other helpful information. HFA can tailor each toolkit to meet your particular interests and the specific issues in your state.

Second, the “Advocacy: It’s in Your Blood” campaign is beginning several online initiatives. HFA is making the toolkits available online and has created special webpages focused on specific policy issues. At the beginning of the year, for example, HFA developed a webpage full of helpful resources on essential health benefits (ehb.hemophiliafed.org). In addition, HFA’s expanded Legislative Action Center includes an interactive legislative map with regularly updated information about what’s happening in your state. HFA also encourages its member organizations to take advantage of its CapWiz tool, which enables you to send action alerts throughout your own state network of contacts.

Third, HFA launched its new “Advocacy/Policy Third Wednesday Webinar” series at the beginning of this year. These webinars, which are held on the third Wednesday of every other month, offer training in key advocacy skills and provide policy education. The January webinar covered health insurance exchanges and essential health benefits, and it attracted a record number of participants for an HFA webinar. This excitement was matched by HFA’s March webinar on messaging. Sherry Prowda, Director of Communications for The Herndon Alliance, a national leader in health care messaging, presented the latest research on which words to use (and not Continued on page 12
EXECUTIVE CORNER

Dear Readers,

Welcome to the spring edition of Dateline Federation! As this issue goes to press, spring has undoubtedly sprung across the country, taxes season is over, the national economy seems to be improving, and we continue to move along to what’s shaping up to be a very long and boisterous presidential election year!

HFA continues its mission of serving the bleeding disorders community with a three-fold theme that we rolled out during our Annual Educational Symposium in Santa Clara: technology, advocacy and wellness. These themes will be reflected in much of what we do throughout 2012; often combined together to enhance the message.

From an advocacy standpoint, states across the country continue to grapple with a variety of issues around budget shortfalls and vital programs facing challenges and potential cuts, such as Medicaid and Medicare. State-based implementation of exchanges continues to be a challenge and we look to the Supreme Court’s coming ruling on the Affordable Care Act – which implemented several key components that have been positive for our community. I encourage you and your family to reach out to HFA or your local bleeding disorders organization to get involved and have a voice during these difficult times. You and your personal situation matters!

“Politics should be the part time job of every citizen.” - Dwight D. Eisenhower

On a technology note, we hear technology and think of Facebook, Twitter, webcasts, websites and the Internet. In fact, HFA has recently introduced a new Wellness App through the Apple Store and Android Marketplace. This initiative will help promote awareness and education about bleeding disorders and encourage healthy lifestyle through regular fitness. It will also serve as a fundraiser for HFA by encouraging individuals to be motivated by the opportunity to give back to a charitable organization while promoting health and wellness. If you own a smart phone, please support this effort by using the app and telling your family and friends about it.

Other technology advancements in bleeding disorders are resulting in many new treatment options such as new longer-lasting recombinant products, advancements for rare bleeding disorders, and promising new developments with gene therapies. This progress will dramatically impact the future of the bleeding disorders community. It has also created many new clinical trials for these products for increased community participation. Currently, there are 87 studies/clinical trials open for hemophilia and 26 for von Willebrand (www.clinicaltrials.gov). Deciding whether or not to participate is a complicated and very personal question that requires deep consideration.

I’ll close with the quote below, which perhaps pulls advocacy, technology and wellness together. Enjoy this issue of Dateline Federation and thank you for being a valuable supporter of HFA and the bleeding disorders community!

Technology is nothing. What’s important is that you have a faith in people, that they’re basically good and smart, and if you give them tools, they’ll do wonderful things with them. - Steve Jobs

Kimberly Haugstad, MBA
Executive Director
The birth of your first child certainly marks a new chapter in your life. There’ll be no more sleeping until noon on a weekend, no more avoiding your mother-in-law. However, the arrival of your little bundle of diarrhea-dripping joy does not necessarily herald the end of buying expensive gadgets. In fact, fatherhood turns out to provide some pretty special opportunities for purchasing cool technologies, and wife-approval is surprisingly easy to secure.

What better time to start loading up on the goodies than during the birth itself? In the spirit of the best politicians, you just need to bury the bad news amongst even worse news: “Darling, I’m afraid the anesthetist can’t give you an epidural for at least another half an hour. Oh, and I’ve just ordered a new full-HD 3D camcorder so we can capture every amazing moment of our newborn’s first years. Now, let’s focus on your breathing ...”

Camcorders and cameras are actually some of the easiest tech to gain approval for, as their benefits are so obvious, even to your wife. You can also bundle smart phones as hiding your PS3 game controllers. The same can be said for your Blu-Ray player. The same can be said for their benefits, except for the part about “oh, and I’ve just bought some new shoes!”, that’s my signal.

But for all the joys and benefits these wonderful inventions can bring, we do need to guard against them negatively affecting our family lives. The day that you begin paying more attention to your laptop than your child is the day that you are destined to discover just how difficult it is to extract a slice of buttered toast from your Blu-Ray player. The same can be said for your wife, although she’ll find slightly less expensive ways to make her point such as hiding your PS3 game controllers. The important lesson here is that, no matter how cool or compelling the gadget, the primary purpose of the very top of our job description is to pay attention to our children and listen to our wives. While that message has held true since the beginning of time, I certainly do feel very fortunate to be a father in this era of affordable gadgetry. When our parents were raising us, they only had a few rocks and a piece of old cloth to keep us entertained – The Stone Age was certainly a rough time to be a parent. But just imagine what incredible technologies our kids will have available when they are raising their own children.

Please accept this as my wish list:

1. A self-cleaning diaper system that rapidly decomposes collected waste and uses the by-products to recharge your child’s wearable computer;
2. The Reprintmunder, a robot discipline machine with a built in naughty step and child-strength tazer capability;
3. A no-spill cup that actually works for more than a month.

I know, I know, that last one was a bit far-fetched, but you’ve got to aim high. Fatherhood will clearly always be a fertile ground for continuing man’s primal need to lovingly stroke metal boxes containing circuit boards and batteries. Sure, our wives won’t always understand it, but that’s also true of complicated movies and instruction manuals. But when did you ever think you’d get wife-permission to buy an intercom with built-in night vision camera? And when did you ever dream that she would sign-off on an in-car DVD player? We’re 21st century dads and we’re living the dream. ...

Dateline Federation | Spring 2012

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HFA Accepts Applications for Items Program

As of April 3, 2012, HFA began accepting applications for the Bleeding Disorder Items Program, a program designed to reimburse patients with bleeding disorders for durable medical equipment and items. Patient Services, Inc (PSI) had managed this program for many years and HFA was pleased to work with PSI to keep this valuable community program intact and relocate it to its new home at HFA. The Bleeding Disorder Items Program aligns well with HFA’s Helping Hands Emergency Assistance Program. Each year, HFA aids hundreds of families with emergency/urgent funding to assist in crisis situations such as housing, transportation, and utility bills. Now, HFA is able to assist with items such as:

- Protective Gear
- Braces and Supports
- Walking Supports
- Heating/Cooling Items
- Over the Counter Items
- Nutritional Drinks
- Prosthetic Items
- Prostheses

*Requires physician statement of medical necessity

PSI has worked with HFA to ensure the program continues to run smoothly. The Bleeding Disorder Items Program is made possible through donations from CVS Caremark, Specialty Therapeutic Care, and the University of California, San Francisco Adult Hemophilia Treatment Center. If you are in need of item assistance, please contact HFA at 1-800-230-9797 or fill out an online application at http://hemophiliafed.org/what-we-do/programs-and-services/items-program. 
Fitness Fun & Games
By Janet Chupka and Faith Hunter

Fitness Fun & Games is the latest workout craze. It combines video games with exercise for a fun challenge while you work out. Intensity is important, so be sure to engage yourself in the activity as much as you are able. Dancing, yoga, boxing, bowling and golf are only a few of the options available on a variety of gaming systems. Exergaming is a great way to get the whole family exercising together. Set up a tournament and offer small rewards for the winners as extra incentive to play. Rent or share games to keep costs lower and to keep your workouts varied. So give it a try; you will get a healthy dose of exercise and laughter!

“Play your favorite TV shows while getting fit.”

Watch TV - That’s right, television can be good for you if you are watching the right shows and participating. Many stations offer fitness classes that can be done in the comfort of your own home. Tune in and workout with an expert. Most of the activities and exercises on these shows can be modified for individuals at varying fitness levels. Can’t find a TV class that fits into your workout schedule? Rent a video from the library and work out at your convenience.

Dust off that equipment - Treadmills, stationary bikes and elliptical machines can all provide a safe, effective, cardio and strengthening exercise. Play your favorite music, or catch up on your favorite TV shows while getting fit. The key is you have got to get on them to make them work. Make it fun!

Climb the stairs - if you have access to stairs where you live, make a few trips up and down them each day. Climbing burns calories and will work the muscles in your legs. The more times you climb, the better the workout you will get.

Take a class - Most communities offer indoor activities like aerobics, Taekwon Do, fitness boot camps, indoor walking, martial arts and yoga through their Recreation Departments. Many of these activities are available at low cost and can be great fun for families to do together.

Find a pool - Swimming is very often recommended as a safe type of exercise for people who have a bleeding disorder. A swimming pool can provide both a place for kids to play with less risk of joint injury and an excellent way to exercise your whole body. The key to success is finding activities that are enjoyable to you, so that you will stick with them. It is also a great idea to vary your workout to keep it different, challenging and exciting. Exercise as a family or find a buddy that will keep you accountable to your workouts. Spring is in the air and soon it will be time to get back outdoors. In the meantime, why not supplement your fitness routine adding technology and indoor activities to help you get from couch potato to fit. **

“As with any new activity, or if you are having joint or bleeding problems, make sure you check with your physician or physical therapist to be sure you are ready to get started.

Dealing with a bleeding disorder? We’ve got your back.

Eric Lowie had the support of his family when he went through knee replacement surgery. Now, that family is a lot bigger. Eric connects with others at The Changing Possibilities Coalition—a unique hemophilia community created by Novo Nordisk. Join The Coalition today at JoinThePCoalition.com.

changing possibilities in hemophilia®

Get In Gear this summer with HFA. Use the App to track your progress and share with friends! iPhone and Android marketplace.
HFA’s annual Symposium was held in Santa Clara, CA on March 30–31. Nestled in the heart of Silicon Valley, Santa Clara is home to many of the world’s largest technology corporations. The location was ideally suited to begin the dialog about the impact of technology on our community!

Nearly 600 attendees from around the country gathered at this year’s event to attend educational sessions and targeted breakout sessions revolving around the theme of the meetings. The annual award luncheon gave us the opportunity to honor our hard working volunteers:

Volunteer of the Year - Donald Akers, Jr.
President’s Award - Mark Antell
Tea Award – Morgan Cook

A particular high note of the meeting was the moving and inspiring keynote address from Ben Turpen, Program Examiner for the Office of Management and Budget in Washington, DC. Ben was diagnosed with cerebral palsy shortly after birth and became paralyzed at the age of 20. Through the challenges presented by his health, Ben discovered the power of positive thinking and resilience.

Throughout the meeting, attendees were given useful information that included updates on the 2014 health insurance exchanges; advocacy workshops with practical tips to talk persuasively about issues relevant to the bleeding disorders community; and opportunities to practice messaging skills. General sessions also covered topics such as how to receive appropriate care in the ER, making healthy and economical nutritional choices, ways to encourage fitness and wellness, and responsible ways to utilize social media. Breakout sessions highlighting HFA’s successful programs included Dad’s in Action, Blood Brotherhood, and Blood Sisterhood.

A particularly memorable aspect of the meeting was when Jeanne White-Ginder shared the story of her late son, Ryan White, with the attendees. Both Ryan and his mother were imperative in spreading the message that people living with HIV should be treated with respect, love, and decency. Jeanie captivated the audience with her tenacity to rid the stigma associated with HIV/AIDS.

“We had a great time! It was our first! We all wish we were still there. Thanks for putting it all together.” – Marcie

“Excellent job Hemophilia Federation of America! Thank you for all of your hard work to bring our community together. From start to finish, this was an excellent symposium–keep up the great work!” - Justin

HFA hosted over 100 children in our youth and teen program this year. Keeping true to the theme, the teen agenda focused on better use of social media and technology. The teens also created a video which will be used to raise awareness and educate others about bleeding disorders. Stay tuned to see their great work coming soon to the HFA website and Facebook.

Overall, the 2012 Symposium proved to be another productive meeting for our community members and provided us with many great learning and networking opportunities. We are looking forward to HFA Symposium 2013!

“Embracing Our Future through Advocacy, Fitness & Technology”

“After attending the HFA Symposium my family and I feel empowered and we can’t wait until Symposium 2013! Year after year, we always look forward to it.” - Laura
“As a first time attendee, I was impressed and inspired on how this meeting was so focused on patients and families. I made so many great connections and was able to take a lot of useful information back to my local community.” - Aimee

“Thanks to everyone at HFA for a great experience at my first Symposium. I enjoyed every aspect of the event from the sessions to the exhibit hall to the social events and connecting with new friends. I’m so glad to be a part of this amazing community!”

-Wendy
Earlier this year, we welcomed four new additions to our staff: Jane Cavanaugh Smith, Matthew Landseade, Pat Brown, and Richard Pezzillo. Each person brings enthusiasm and professional experience to help support our advocacy, education, and outreach programs that will better serve our community.

**Jane Cavanaugh Smith**

formally served as the Program Director for the New England Hemophilia Association (NEHA) and has been a strong advocate and leader in the bleeding disorder community for nearly 20 years. Jane now coordinates HFA’s Dads in Action Program and assists with other program initiatives. Jane earned her BS in Business Management at Skidmore College and is a mother of a young man with hemophilia and inhibitors. She currently resides with her family in Massachusetts.

**Matthew Landseade**

grew up in Kokomo, Indiana. Before joining HFA, was the IT Department Manager at Web Software, LLC. He earned his BS in Information Systems from Indiana University and an Associate Degree from Purdue University. Matthew designs, develops, and implements new IT projects to further HFA’s mission and provide technical support to HFA employees. Matthew and his wife adopted two young boys with severe hemophilia and reside with his four other adopted children in Indiana.

**Pat Brown**

is a native of the DC area and previously served as the Conference Planner and Office Manager for the National Association of Councils on Developmental Disabilities.

Pat has nearly 20 years of experience successfully managing and planning large meetings and developing programs and budgets. She is a Certified Meeting Professional (CMP) and earned her BS in Business Management at the University of Maryland. Pat organizes and oversees all of HFA’s daily activities in the DC office.

**Richard Pezzillo**

grew up in North Providence, Rhode Island and prior to joining HFA, was the Deputy Press Secretary for US Senator Sheldon Whitehouse. Rich has hemophilia and over 10 years of leadership experience working with the bleeding disorder community. He is the former co-chair of the National Hemophilia Foundation’s (NHF) National Youth Leadership Institute (NYLI). He manages HFA’s communications department. Rich earned his BS at Western Connecticut State University and currently resides in Washington, DC. **

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You are encouraged to report negative side effects of prescription drugs to the FDA.

Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

12 Dateline Federation | Spring 2012
The Supreme Court and Health Care Reform: How will the Justices Decide?

By Eboni Morris

The idea of reforming our health care system is certainly not new. National insurance has been debated among our nation’s leaders at least for the past century. By 2010, Congress and the President were able to enact sweeping reforms of the current health care system through the Patient Protection and Affordable Care Act (ACA). Almost immediately states moved to file legal challenges against the law. The federal government argues that the rest of the ACA should survive because many provisions like the ones listed above have already taken effect and it would be extremely harmful to repeal them now.

Is the Affordable Care Act's expansion of Medicaid constitutional?

The federal government also asserts that the individual mandate is a valid exercise of Congressional power to enact laws that are “necessary and proper” in regards to the commerce clause. The plaintiffs maintain that the Necessary and Proper Clause is not an independent source of federal legislative power and the mandate is an invalid exercise of the commerce power, so it cannot be salvaged by the Necessary and Proper Clause.

Medicaid Expansion

The ACA again expands the Medicaid program’s mandatory coverage groups by requiring that participating states cover nearly all people under age 65 with household incomes at or below 133% FPL beginning in January 2014. The federal government will cover 100% of the states’ costs of the coverage expansion beginning in 2014, gradually decreasing over time. The Court will decide whether the ACA’s Medicaid expansion is a valid exercise of Congressional spending power (Spending Clause). Opponents to the expansion argue that it unconstitutionally coerces the states by requiring the expansion in order to receive federal funds. They argue that Congress should not be allowed to regulate the states in this way. The federal government argues that Congress may attach conditions to the receipt of federal funds based on its Spending Clause power, and the court has no precedent to invalidate this expansion. In addition, Congress has the right to amend the Medicaid Act and has done so over time since its creation.

What will the future hold?

Striking down the Affordable Care Act would take away protections that have benefited the bleeding disorders community, including:

• Rules restricting the use of annual limits until their eventual elimination in 2012
• Rules regarding the use of plain language in explanation of benefits

For proponents of the ACA, both the individual mandate and the Medicaid expansion are struck down, the ACA will lack two major provisions toward the effort of expanding access to health insurance. The federal government argues that the ACA should survive because many provisions like the ones listed above have already taken effect and it would be extremely harmful to repeal them now.

• If the individual responsibility provision is unconstitutional, what other parts of the law, if any, must also be struck down (referred to as “severability”)?
• How would the IRS collect taxes for Medicare and Medicaid?

For more information

Supreme Court:
http://www.supremecourt.gov/

ACA Litigation Blog:
http://acalitigationblog.blogspot.com/

Hemophilia Federation of America:
http://hemophiliafed.org/what-we-do/advocacy/
A Blood Brother’s Journey
By Jeff Watkins, Illinois Blood Brother

I am a 46-year-old severe hemophiliac and one of four severe hemophiliacs in my family. My parents got my family involved with the local hemophilia chapter fairly early. After being involved for some time, however, I fell away from the community and lost touch with a number of friends.

About two years ago, I met a new friend that was very active in the bleeding disorders community. He shared his story with me and explained how important it is to get involved in the local chapter. After talking for a while, I agreed to participate more in the community and truly began to see all I could do not only for myself, but also for others with bleeding disorders. I contacted Bob Robinson, the Executive Director of the Bleeding Disorders Alliance Illinois, to set up a Blood Brotherhood meeting. Bob was more than enthusiastic about us working together and helping to get the program going.

Blood Brotherhood gave me the opportunity to reconnect with old friends and, of course, make some new ones. The program itself gives men living with hemophilia and other inherited bleeding disorders the chance to talk with people that are a lot like themselves. At meetings, you can talk about anything, but especially things that relate to you, this ranges from family problems to sexual problems or concerns. I talk a lot about my own battles: coping with a joint replacement, concerns about whether I would be able to walk normally and play with my kids; and dealing with joint bleeds and bleeding before and after surgery. It’s good to have a safe place to talk about these issues with people who understand.

Being involved in the program gives all of us brothers the chance to inform and advocate for ourselves and the community. I always try to take the time to tell as many blood brothers, family members and friends as possible about the upcoming events, programs and resources so that we can all benefit from the local Blood Brotherhood chapter. By being involved, you can let others know what you can do and show we are not limited to just what society tells us we can or can’t do. Some of us may be older, but we can still do anything we put our minds to do!

Get involved with Blood Brotherhood!
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Bleeding Disorders Alliance Illinois – Blood Brotherhood
They say, “there’s an app for everything,” and when I discovered that there are apps out there for insurance, I started to think it might be true. In case you don’t know what “app” means, it’s short for “application,” and it’s a little computer program that accomplishes a specific task. Apps are usually referred to with respect to smart phones and iPhones, but they can also be created for larger media, like computers and iPads. In addition to apps, websites are becoming more functional and useful. You can do everything from socializing to shopping to calculating your retirement needs.

How can we use all this technology for insurance? Many insurance companies at least have websites where you can use to track benefits, review your policy, or even order prescriptions. If your state sets up a health insurance exchange (and hopefully, all states will, one way or another), they will have to provide an exchange website where you can shop for insurance if you must purchase it on your own.

Website Technology

Let’s talk about websites first because they are still more common than apps. Most of the major insurance companies (e.g., Aetna, United Healthcare, or Blue Cross) have two kinds of websites. One is the open site – this site is informational and open to anyone who wants to learn about the company and what kinds of plans they offer. They might also provide a general network that so that you can determine if your doctor or your hospital is on their network. (Cautionary note: Even if you see your doctor on their open site, ensure that you doctor is on the network for your specific plan before you commit to that plan. The open site is not always up to date on this, and some plans limit your network based on the insurance company’s contract with that doctor.)

“you can do everything from socializing to shopping to calculating your retirement needs.”

Your insurance company’s secure website might be the most useful to you. Here are some of the features that might be available to you on your insurance provider’s secure network:

- Secure login. (Cautionary note: if your provider’s “secure” site does not require you to create a password or provide some other form of obvious protection, your information might not be protected properly when you log in, so get more information before committing.)
- Access to your policy, where you can look up for yourself what your coverage is on a certain issue. This is quite helpful when you encounter a specific problem, and you don’t want to just take the word of whoever picks up the phone when you call to ask about it. Health insurance policies are quite complex and most of those people answering the phone are trained in generalities, not specifics. Your policy might be available as a PDF, which you can search electronically for your issue. The website asks for personal information in order to continue, be careful what information you provide. Generic information, such as which state you live in or your gender, is probably okay to provide. If the site asks for your home address or name and birthday, they are probably looking to contact you for further marketing (or other nefarious purposes), so I would stop there. There are tons of sites out there where you can get information without giving up private information. The article on advocacy, “Advocacy: It’s in Your Blood,” provides a lot of resources for researching policies and regulations, so be sure to check that out.

Smart Phones

To access your insurance company from your smartphone, first access your insurance company’s website through your phone browser. If your insurance company’s website has mobile capability, your phone will automatically be directed to that. Once you get there, look to see if there is an app and download it if you want to try it. Either the app or the mobile website should offer you functionality similar to what you would find on the website. Again, before you access personal files, you should be asked for a password that is either provided or that you set up yourself. It’s that simple!

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