

Advocacy: It's in Your Blood

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

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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 free 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!

Kimberly Haugstad, MBA
Executive Director

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

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Reproductive Technology – Pre-implantation Genetic Diagnosis (PGD)

by Dr. Danielle Nance

More choices are now available for couples with bleeding disorders who want to have children, but who want to reduce the chance of having a baby with a bleeding disorder. Pre-implantation genetic diagnosis can help couples achieve a pregnancy that does not carry the bleeding disorder gene. This technique greatly reduces the need for termination of pregnancy, because embryos are chosen without the gene before they are transferred to the uterus.

Daphne and Tom recently married and are excited about starting a family together. Tom has severe he-

mophilia and he is worried about passing the hemophilia gene on to his children. He knows that all of his daughters would be carriers, but a son would be free from the disease.

Tiffany and Bruce have been married for several years. Tiffany is a carrier and she already has a son with severe hemophilia and a daughter who is unaffected. They would like to have a child together, but they are worried about hemophilia.

Men and women with bleeding disorders have several options for family planning to reduce the risk of passing the bleeding disorder to their offspring. Prenatal testing can give families early information about the health of the developing fetus, but does not reduce the chance that the fetus has of getting the disorder. Pre-implantation genetic diagnosis (PGD) is another option

for couples who want to have children and reduces the chance that a developing fetus will have the disorder. PGD was first developed in the 1980s to reduce the chance of chromosomal abnormalities and single gene diseases such as Down's syndrome, hemophilia and cystic fibrosis. It involves the use of in vitro fertilization, or fertilization in the laboratory, and first requires that the couples' eggs and sperm be collected.

“Men and women with bleeding disorders have several options for family planning to reduce the risk of passing the bleeding disorder to their offspring.”

For women, this procedure involves hormone supplements and a special procedure in the clinic (that does have a risk of bleeding for those women with bleed-

ing symptoms) to collect the mature eggs. The eggs and sperm are then incubated

together, or a sperm might be injected directly into an egg, and the developing pre-embryos are allowed to grow. When the fertilized egg has divided and is 4 to 8 cells big, one cell is removed and tested to see if the disease gene is present. All of the developing pre-embryos are tested this way. Ones found to not have the gene are kept for implantation into the woman. Usually, only 1 to 2 pre-embryos are implanted and the rest are saved and frozen. Just like all in-vitro fertilization procedures, the attempt to achieve pregnancy may fail. However, in couples where the problem is not fertility but rather selection, successful pregnancy outcomes may be higher.

For more information, talk to your hematologist or primary care physician about options near you. ■■



Dadgets

By Craig Alan Williamson

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 into that category, as the ability to take pictures of your little ones and instantly e-mail them to your family is truly useful – if only to ensure that your mother-in-law feels sufficiently connected to her grandchildren that she doesn't have to visit quite so often.

As well as enhancing your experience as a father, technology also has the potential to enhance your experience as a husband. For example, when all communications break down following a particularly heated debate about who's had the least sleep, I often find my wife's Facebook status



updates to be particularly useful. Once the "I'm soooooo tired" updates have been replaced by "I've nearly lost all my baby weight 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 at 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 bi-products to recharge your child's wearable computer;
2. The Reprimander, 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 primeval 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. ■ ■



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- > Motivated by 1 goal: to make progress for the hemophilia community
- > Driven to deliver one of the most anticipated therapeutic milestones in hemophilia—long-lasting clotting factors
- > Creating therapies, programs, and resources with the potential to change lives



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 *

**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

Did plunging temperatures and falling snow turn you into a couch potato? Are you ready to get off the couch and get moving again before getting back into summer clothes? Finding safe and effective exercises can be challenging for those with a bleeding disorder, especially when springtime rains or cold days make being outdoors even more hazardous. While it can be challenging to stay active, it is important to maintain activity levels, not only for physical health, but also for your emotional wellbeing.

The CDC recommends that children get at least one hour of physical activity each day. For adults and older adults (with no limiting health issues), 150 minutes of moderate intensity aerobic exercise every week and muscle strengthening activities 2 days a week are the recommendations. About 150 minutes each week sounds like a lot of time, but it's not. That's 2 hours and 30 minutes that can be spread throughout the entire week. Break it up into smaller chunks of time, such as three 10 minute intervals during the day. Be sure to keep the intensity moderate to vigorous to gain the most benefit from your activity. There are many safe, affordable and effective ways of keeping your fitness routine

on track even in inclement weather. The bonus is they are also a lot of fun!!

Utilize technology Exergaming 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, Tae Kwon 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.*



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CONNECT TO THE COMMUNITY. make the LINK.

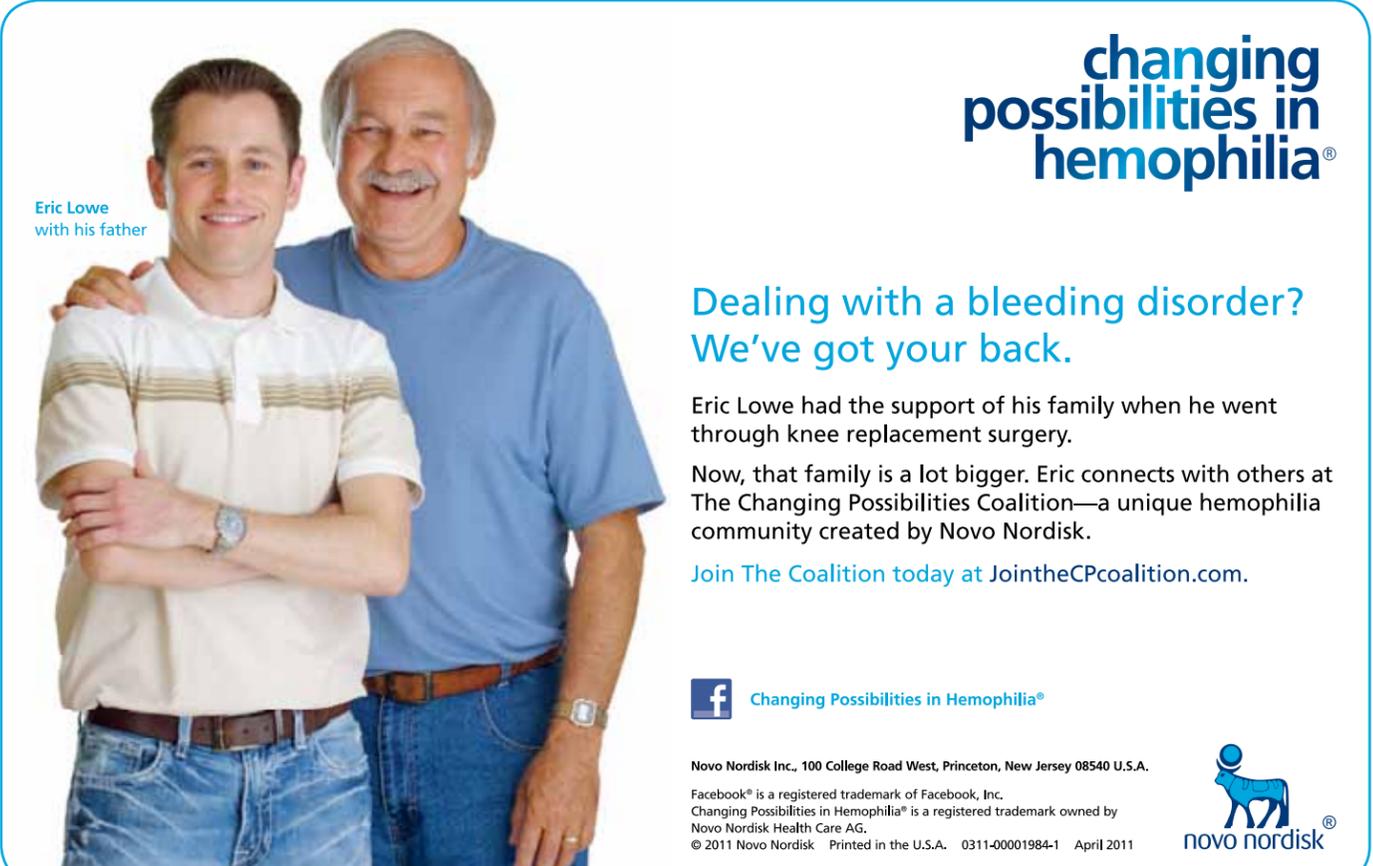
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LINK educational programs provide an interactive forum for patients and caregivers to provide feedback while learning about the latest in the community. Program topics range from health insurance to treatments to lifestyles. So, if you're seeking the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

LEARN MORE ABOUT EVENTS IN YOUR AREA AT www.LINKmeetup.com

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Eric Lowe with his father

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Embracing Our Future through *Advocacy, Fitness & Technology*

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.

"Thanks for having us; it was great to be around new families. I look forward to being more involved." - Mikey



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



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. Break-out 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.

Embracing ur Future *Symposium* HFA 2012



"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

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 use 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! ■■



"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





"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 Landseadel, 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 and Marketing at Skidmore College and is a mother of a young man with severe hemophilia and inhibitors. She currently resides with her family in Massachusetts.

Matthew Landseadel



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. ■■



Continued from page 1

use) when advocating to others to support your cause. HFA's Communications Manager, Richard Pezzillo, discussed how to apply this research to the specific issues affecting the bleeding disorders community. Upcoming webinars will cover issues such as prescription drug policy, Medicaid, and how to advance your advocacy agenda through online social networks. (For more information, visit apw.hemophiliafed.org.)

Fourth, HFA is developing videos and podcasts that will explain complex legislation in clear, easy-to-understand language. The videos and podcasts will also include training in skills such as how to talk with elected officials and how to organize successful advocacy events. Keep an eye out for these creative resources, all of which will be available online.

Fifth and finally, HFA offers one-on-one consulting for individuals and member organizations that want to build their advocacy capacity. Whether it's a conference call for your organization specifically or an in-person workshop at your annual meeting, we provide member organizations and their constituents with practical, hands-on training in advocacy. Need information on legislation your state's general assembly is considering? We can research relevant bills, connect you with other states facing the same policies, and help you develop up-to-date fact sheets and issue briefs. We also provide guidance in organizing events such as State Capitol Advocacy Days or initiatives such as letter-writing campaigns. Feel free to contact Eboni Morris, HFA Policy Analyst (e.morris@hemophiliafed.org), or Jonathan VanderBrug, HFA State Advocacy Consultant (j.vanderbrug@hemophiliafed.org) any time for assistance.

HFA is ready to actively support you in reaching your advocacy goals. The "Advocacy: It's in Your Blood" campaign is already giving members the tailored tools and resources they need for advocacy success – and once you've experienced that success, you will find that you are ready for more. After all, advocacy is in your blood. ■■

WHAT IS YOUR ABR?

ANNUAL BLEED RATE



Minimize the impact of bleeds on your life.

The first step you can take to help lower your bleeds is knowing your ABR, or the number of times you bleed in one year.

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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 and debate began on how quickly the Supreme Court would be deciding the future of the law. In November 2011, the United States Supreme Court agreed to consider several issues regarding constitutionality of the ACA based on two cases in the 11th Circuit Court of Appeals. Arguments were scheduled to be heard from March 26–28, 2012. A ruling is expected by the end of June.

The court chose four questions to be addressed based on two major provisions in the Affordable Care Act: the individual mandate and the Medicaid expansion. The questions are:

- Is the challenge to the individual responsibility provision premature under the Anti-Injunction Act, which prohibits challenging a tax prior to that tax being imposed?
- Is the individual responsibility provision constitutional?
- If the individual responsibility provision is unconstitutional, what other parts of the law, if any, must also be struck down (referred to as “severability”)?
- Is the Affordable Care Act’s expansion of Medicaid constitutional?

Here’s a brief overview of the major issues concerned and arguments for each concern.

Individual Mandate

The individual mandate requires most people and their dependents to maintain a minimum level of health insurance coverage beginning in 2014. Congressional authors of the law contend that without the individual mandate,

the exchanges and private insurance market reforms would not work because many healthy people will not purchase insurance if they do not have it through their employers; moreover, insurance companies in the private market are targeting healthy individuals for coverage while looking for ways to drop or limit coverage for high cost patients. If a person does not satisfy the individual mandate, there is a financial penalty; however, there are several exemptions from the individual mandate.

Several constitutional issues have also come to the forefront with the individual, including these key areas: Commerce Clause, Necessary and Proper Clause, and the federal government’s Taxing Power.

Taxing

First the Court must decide whether the federal Anti-Injunction Act (AIA) prevents the courts from deciding lawsuits about the ACA because the AIA is a part of the tax code that bars lawsuits regarding the assessment or collection of a tax before it is assessed. The Court may decide it does not have jurisdiction to hear challenges to this part of the ACA until after the tax has been assessed, which would be sometime in 2015 (well after 2014 tax returns are submitted). If the Court instead decides that it is a “penalty” under the AIA, then the current case can proceed, and the Court can issue a decision about the constitutionality of the individual mandate now.

Commerce Clause

The plaintiffs (opponents of the law) argue that a decision to not purchase health insurance constitutes inactivity, which is not connected to interstate commerce, and is not subject to federal regulation under Congressional commerce power. They maintain that the individual mandate compels people to enter commerce, which is an unprecedented use of this power. The federal government argues that everyone will use health care at some point in their lives and Congress can require people to buy insurance to limit the costs imposed by the uninsured on the public resources. ACA supporters also argue that Congress already requires nearly all Americans to purchase health insurance by collecting taxes for Medicare and Medicaid.

Necessary and Proper

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 overtime. 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 prohibiting insurers from denying coverage to people, including children, with pre-existing conditions
- Rules prohibiting insurers from canceling coverage when people get sick
- Allowing young adults to stay on their parents coverage until age 26
- Prohibiting insurers from imposing lifetime caps on coverage

- 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, if 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 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.

Of course, being an election year, all of the Republican presidential candidates have pledged to repeal the Affordable Care Act and some Democrats are reluctant to fix a piece of legislation that has been so controversial.

You can continue to let elected officials and others involved in implementation, know how you feel about the Affordable Care Act and what provisions have benefited you! ■ ■

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/>

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A Blood Brother's Journey

By Jeff Watkins, Illinois Blood Brother

I am a 48-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!

www.bloodbrotherhood.com

1-800-230-9797 ■■



Bleeding Disorders Alliance Illinois – Blood Brotherhood



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..INSURANCE ..

Leveraging Technology with your Insurance

By Lori Long

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 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 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 your 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 functions that might be available to you on your insurance provider's secure network:

- Secure login. (Cautionary note: If your providers "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.
- Access to your explanations of benefits (EOBs), where you can look up how your medical care is covered by

incident. This might be the handiest feature on a secure insurance website. When you have a claim that is not covered in the manner you expected, you can look up how much the care will cost, how much of that cost your insurance paid, and (perhaps most importantly) how much you owe.

- Access to your pharmacy, where you can order or update prescriptions (this requires some coordination with your doctor, usually having your doctor's office fax your prescription to the pharmacy).

Another use for websites is researching plans, policies, and regulation that might apply to you. My advice in this area is this: If you are searching for a new policy and 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 smart phone, 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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