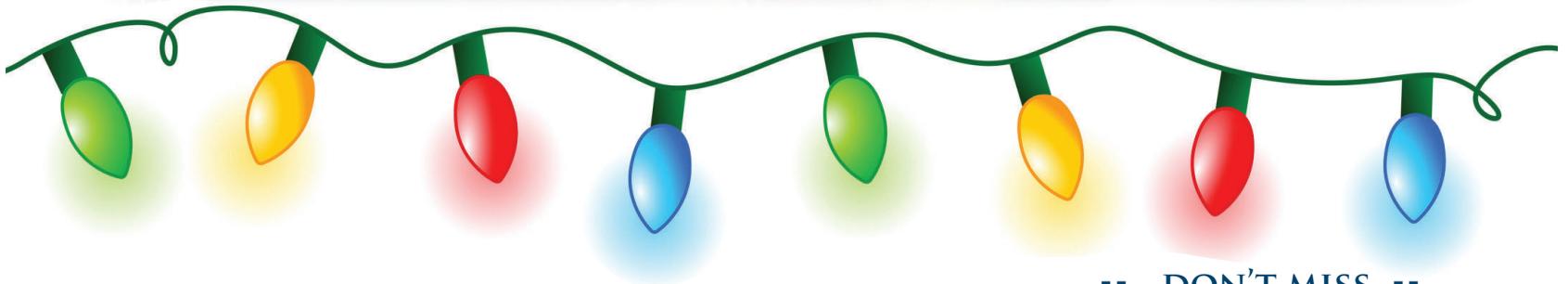




Meeting Our Mission!

GIVING THANKS AND CELEBRATING THE SEASON AND COMMUNITY



"Give thanks for a little and you will find a lot."



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EAGLE SCOUTS - ACHIEVEMENT	5 & 7
COMMUNITY ADVOCACY	6 & 19
GEARS FOR GOOD RIDE	10-11
HEALTH & WELLNESS	18

SYMPOSIUM - Registration is Open! Visit www.hemophiliafed.org



Paul Brayshaw, wife Frances and new baby Porter!

EXECUTIVE CORNER

Giving Thanks 🙏 for Hope in 2012.

In this last issue of HFA *Dateline* in 2011, I would like to take this opportunity to give thanks and recognize some of the very critical achievements at HFA in the last year—as well as forecast a few pending issues for which the best advice may be to hope for the best but expect the worst in 2012.

Over the last 12 months, HFA has experienced great strides in its organizational growth through fund development, submission of grant applications, and funds awarded. Through these endeavors, HFA continues to serve as a key resource for our membership. Our membership has grown and we currently have 33 local/state organizations in our national network along with ever growing individual membership. On all counts, HFA is a growing family community, and I am happy to report I have added my own new community member with the arrival of my baby boy, Porter.

Driven by the HFA Mission, staff and volunteers have attended Essential Benefit meetings to provide information regarding rare disorders and critical access to clinical and specialty care; collaborate with other stakeholders to coordinate comments in response to proposed regulations; partner with state and local community stakeholders, and engage industry leaders to represent community based issues affecting the bleeding disorders community.

In the coming months and throughout 2012, it is imperative for each of us to engage caregivers, colleagues, community members, and other stakeholders and to seek viable solutions for people with bleeding disorders in relation to issues of grave importance. While I am optimistic the voice of HFA and people with bleeding disorders will be heard by people and families who are affected, I am cautiously anxious about several ominous threats if people with bleeding disorders are left out of discussions impacting our clinical care model and access to health care.

Many states are grappling with diminished Medicaid budgets and considering specialty tiers as a way to control the cost of health care delivery. States are also confronted by additional resource constraints exacerbated by Medicaid expansion, as well as costs associated with the development of Health Exchanges proposed by Health Care Reform.

Other threats involve progression of the Hepatitis C virus (HCV) among people with bleeding disorders. As the leading cause of death, treatment options for people with bleeding disorders and HCV lack efficacy and include serious side effects. Current standard of care therapy for HCV has improved, but people with bleeding disorders who are null or nonresponders to interferon/ribavirin therapy are left with only glimmers of hope for access to clinical trials of promising new drugs in 2012.

For those of us who hope for the BEST in 2012, we can take pride in knowing the achievements of HFA in 2011 provide our community great strength and capacity to confront the issues that most immediately threaten our ability to access health care.

Paul Brayshaw
Board President

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The Hemophilia Federation of America is a national non-profit organization that assists and advocates for the bleeding disorders community.

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Miracles Great and Small

By Lauren Neybert

Today many people are often bombarded by negative messages. Stories of tragedy, hopelessness, and fear can be consuming and make those positive situations seem much less attainable. The Hemophilia Federation of America would like to share a story of generosity to inspire and restore hope.

Susan Swindle, HFA Development Director, was returning home from a meeting in Denver, Colorado this past August when she had an amazing, inspiring experience! Susan commented, "Going on standby for a much needed earlier flight home wasn't exactly what I had hoped for when I arrived at the Denver airport five hours earlier than my 7 PM departure time. An unexpected waived flight change fee and actually landing one of two standby seats among the four of us attempting to get on the overbooked Southwest flight appeared to be the best gift I could have possibly hoped for—little did I know these were circumstances setting the stage for a real blessing destined for HFA.

As Susan boarded the packed plane, a gracious, humble gentleman in a seat next to the only empty seat on the plane offered to help her get settled quickly in her seat as the plane was already backing away from the terminal onto the tarmac. Susan shared her "little miracle" story of getting a free flight change and her good fortune of taking one of the last seats on the plane. An interesting conversation ensued between them. He spoke passionately

about the business he founded with one shop that had grown to 100 locations—a faith-based, family centered automotive repair business that had garnered him much success over the years. Susan shared HFA's core mission of assisting and advocating for the bleeding disorders community. He asked numerous questions about hemophilia and the organization's history. They discussed the high cost of medication and healthcare challenges of our community. She also shared the challenge of securing funding for one of HFA's core programs, Helping Hands.

When the flight reached its destination, Susan and her flight companion exchanged business cards and thanked each other for the good conversation. As they prepared to exit the plane, Susan's small miracle increased as Marcus A. Carr, owner and founder of Christian Brothers Automotive, offered a substantial personal donation to the organization. Less than a week later, Susan received an invitation to visit his corporate office and was introduced to his amazing business. She also experienced Mr. Carr's great generosity and giving philosophy first hand, receiving a \$50,000 donation to the Helping Hands program.

The donation could not have come at a better time. The Helping Hands program has faced a difficult past couple of years with limited funding opportunities. However, the need continues to grow. Last year, the program directly assisted 216 households

with funding requests such as housing, utility bills, and transportation expenses amounting to over \$90,000 in direct assistance. In 2011, the HFA Gears for Good Bike Ride fundraiser, Grifols, Inc., Novo Nordisk, Inc., numerous organizational and individual professional memberships, and the generous donation from Mr. Carr all combined will now cover the program's expenses for the remainder of the year! ■■

**"I am only one, but I am one.
I cannot do everything,
but I can do something. And
I will not let what I cannot do
interfere with what I can do."**

Edward Everett Hale

his corporate office and was



Giving Thanks

Mr. Carr has inspired all of us at HFA with his generous donation. It is our hope that by sharing the story we can inspire you to do the same. As the quote above states, he is only one person and cannot do everything, but he did something. We hope this story inspires you to do something. Maybe you will share your voice and become an advocate. Perhaps you will provide a donation to the Helping Hands program to help a family pay their electric bill. You may decide to volunteer. Whatever your gift may be, realize that though you may be one person, you can do something to make a difference.

Protect HFA's Helping Hands program by making a contribution today!

<http://hemophiliafed.org/donate/>

1-800-230-9797



Preparing for Surgery

By Danielle Nance, MD

Women of all ages may be considering elective surgical procedures for all kinds of reasons—some medically necessary, like correction of a deviated septum or removal of skin moles, and some for corrective or plastic surgery. In the past, women with bleeding disorders were discouraged from any surgery because of the risk of bleeding associated with even minor procedures, especially from the mucous membranes. If you are considering a procedure, even though not medically necessary, your hematologist will be able to help you plan for the procedure safely. Most surgeries and procedures can be performed safely with preplanning.

Tracy, 38, is a carrier for FVIII deficiency with a FVIII level of 35%. She reported a sore knee she had been suffering with since her early 20's after a hiking accident. She saw a knee specialist who recommended a small surgery

on her knee to repair the injury. Tracy had previously had a DDAVP trial and we knew that she responded well to DDAVP, so we planned to give her DDAVP before the surgery. We arranged for her to get a fresh bottle of DDAVP nasal spray and also made sure she had factor at home in case the DDAVP did not completely control her bleeding. We talked with her knee surgeon before the surgery and made sure that he and his staff could assist Tracy in giving the DDAVP an hour before the procedure. We also gave the surgeon a 24-hour phone number to call in case he had questions or saw bleeding or bruising more than he expected. We also routinely speak to the pharmacist at the hospital or clinic to answer any questions they have about the medicines. Most pharmacists don't fill orders for DDAVP and factor on a regular basis and they are not familiar with their use.

After the procedure, Tracy called us to let us know how she was doing so we could decide

if the DDAVP had been enough to control the bleeding or if she needed additional factor. She took the second dose of DDAVP at home without any problems, was able to limit her fluids as we directed, and was doing well. At her post-operative visit, the surgeon reported success of the procedure and Tracy was able to start physical therapy on schedule.

Surgical procedures in women with bleeding disorders require preplanning and coordinated care between all the team members. The hematologist should always be involved at the beginning of the process

“Surgical procedures in women with bleeding disorders require pre-planning and coordinated care between all the team members.”

and is a great resource to find the surgeons most familiar with bleeding disorders. For any surgery, whether

planned or in an emergency, women should call their HTC or hematologist on the way to the hospital or as soon as possible because the hematologist can help the surgeon choose the right therapy to prevent bleeding symptoms. The HTC can call the surgeon on your behalf directly and will help you get what you need faster. ■■

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The Eagles Keep Landing!

By Ogden M. Forbes, Ed.D.

Only four percent of all Boy Scouts reach the rank of Eagle, so it is an amazing accomplishment for five young men with severe hemophilia from Southern California to attain this prestigious and honorable leadership position. Dustin Huerta, Raphael Forbes, Gabriel Forbes, Michael Forbes, and Emmanuel Forbes – all scouts of the California Inland Empire Council – are the most recent members of the hemophilia community to reach the rank of Eagle Scout. Four of these young men are my sons; for each, reaching the rank of Eagle Scout was a unique accomplishment. They may share a bleeding disorder diagnosis, but each boy has a unique personality, strengths, temperaments, goals, skills, knowledge, and individual fortitude that contributed to his success.

As a former Navy Officer, I have seen the difference among sailors who had been



Dustin Huerta, Eagle Scout!

Eagle Scouts and those who had never been in scouting. I recall the confidence of these young men, their collective “can do” spirit, remarkable abilities to get all kinds of tasks completed, and adaptability to new ideas with sustained enthusiasm. As my sons matured, I hoped they might be given an opportunity to seek out such training. But how can young men with hemophilia ever dream of becoming Eagle Scouts? The answer begins with a common sense appreciation

“Only 4% of all Boy Scouts reach the rank of Eagle, so it is an amazing accomplishment for five young men with severe hemophilia from Southern California to attain this prestigious and honorable leadership position.”



Raphael Forbes, Gabriel Forbes, Michael Forbes, and Emmanuel Forbes – all scouts of the California Inland Empire Council

of limitations to what their bodies can endure and a matching awareness that this is a universe full of significant opportunities—provided due caution and wisdom are exercised. For our family, a rigorous prophylactic infusion schedule combined with almost daily training in competitive swimming allows the boys to lead their lives with few to no bleeding episodes. And, fortunately, the Boy Scout Troop they joined was filled with wonderful leaders—talented and understanding, experienced and open-minded people.

I view their achievements as a “Dads and Moms in Action” reality. There is no way my boys could have reached the rank of Eagle Scout without the ongoing help of their mother, Jane Forbes, RN. She did so much to support their ambition, including serving as Camp Nurse, teaching leaders about the medical practices of caring for children with hemophilia, and assisting in the preparation of camp medical bags. I made it a point to participate in all of their outdoor activities, always ready for emergencies. Ultimately, each adventure had to be negotiated with our children, giving forethought to what they could and could not do on these outings. For example, rock climbing at Joshua Tree National Park was not an option. In this case, we agreed to go on hikes, take photographs of nature, and focus on a myriad of merit badges that needed to be earned. The troop gave us room to opt out from time to time, yet welcomed us to participate in as many activities as possible. The biggest challenge collectively was to have each child learn how to self-infuse as a fundamental requirement for participating in any of the camps. Each of my sons accepted the challenge, meticulously self-infusing early in the morning at camp, often before any of the other troops were awake.

I feel not only pride but personal satisfaction in knowing my four sons are at least marginally trained in survival skills and will benefit from a vast outdoor curriculum that most schools—public or private do not have

Continued on page 7

State Advocacy: HFA Listens and Learns

By Jonathan VanderBrug

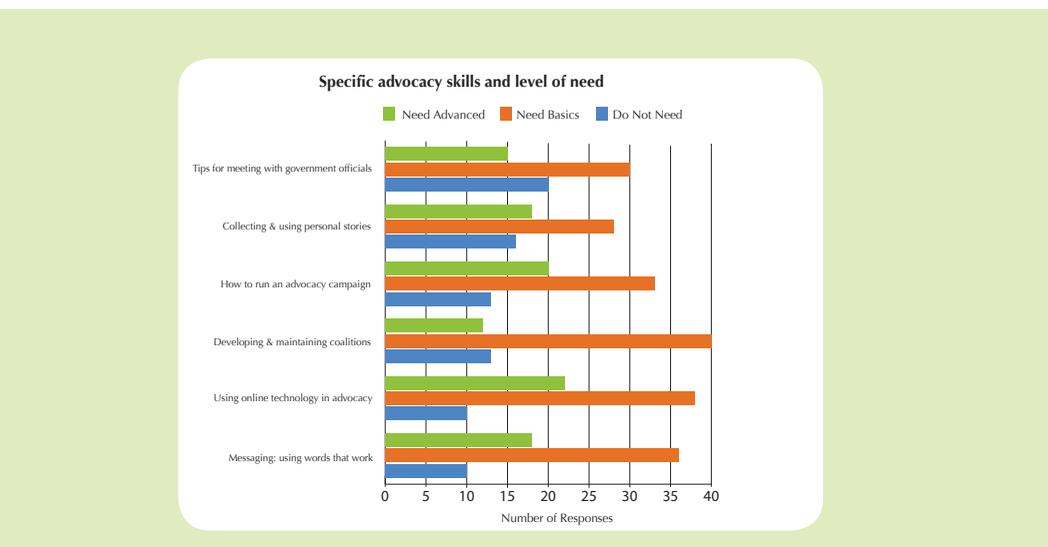
HFA is rooted in the community and led by its needs. When it came time to plan its state-level advocacy for 2012, HFA began by listening to its members and learning from them. First, it conducted a “State Advocacy Assessment.” This involved over 30 hours of interviews with key leaders within HFA’s membership, as well as a complete review of the advocacy resources HFA currently provides. The assessment gave HFA a better understanding of its strengths and weaknesses in state advocacy and paved the way for a second listening step with the online “State Advocacy Survey.”

HFA recently wrapped up this survey after gathering feedback on the capacity of member organizations to conduct legislative and policy advocacy at the state level. It also gave members the opportunity to express their views on the role HFA should play in this advocacy. HFA sent the survey to its board and then to the director of every HFA member organization, each of which was encouraged to forward it to one or two other individuals. It should be noted that 90% of the board took the survey, as did every member organization except one. While the survey had limitations, this diverse participation contributed to the representative nature of its findings.

Nine of the survey’s findings stood out as the most important:

#1 – Mission: Not wanting to make assumptions, HFA began by asking member organizations if they view state advocacy as part of their mission. The answer is overwhelmingly yes, and the vast majority (3/4) of the member organizations want to be more active in it.

#2 – Activity: HFA’s organizational members vary greatly in their level of state advocacy activity, ranging from none to very active, but a minority view themselves as successful at it.



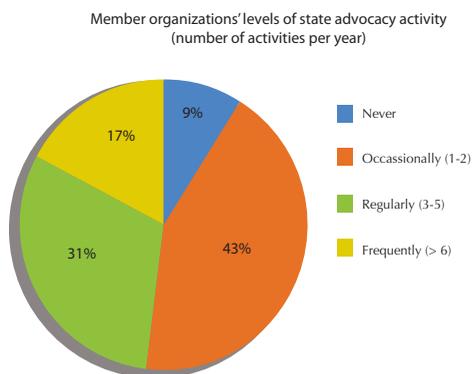
#3 – Need: Organizations overwhelmingly voiced need in all general areas of advocacy capacity: skill building, knowledge, engaging fellow advocates, and policy analysis.

Under each of these four general areas, the survey listed specific capacities (such as “messaging: using words that work” or “understanding health care policy”) and asked member organizations their level of need in each: no need, need basics, or need advanced.

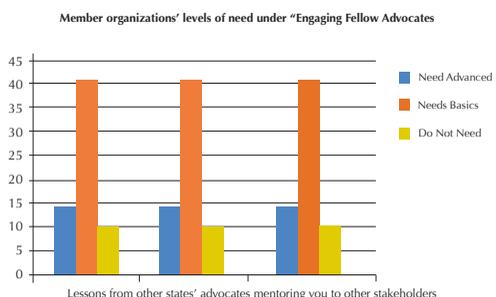
Of those indicating need, at least 2/3 in most cases stated they need *basic* support, as opposed to advanced. This is a strong statement of both need and a desire to learn.

Skill Building: Advocacy skill building was expressed as the priority area of need. It received twice as many “most important” rankings as any other area.

#5 – Specific Skills: Organizational members want to build four skills in particular. Listed in their close order of need, these skills are messaging, employing online technology in advocacy, developing and maintaining coalitions, and running advocacy campaigns. Over 80% of participants indicated a need, with over half indicating a basic need.



For every specific capacity listed, at least 2/3 of member organizations indicated need. In fact, for the vast majority of capacities, 80-90% of member organizations expressed need.



#6 – Policy Knowledge: Organizational members are also very interested in increasing their knowledge of health care policy. This specific capacity had the highest rating, with 94% of participants saying their organization had need and 2/3 of them indicating a basic need.

#7 – Advocacy Community: There is a strong need to engage advocates across state lines. On average, 87% of survey participants said their organization needs support in the specific capacities listed under “engaging fellow advocates.”

#8 – HFA’s Role: Member organizations believe that HFA has an important role to play in state advocacy.

Over 3/4 of participants said they want HFA to be more active in their state. No member organization expressed the desire that HFA be less active. *Continued on page 19*

The Eagles Keep Landing

Continued from page 5

the will, means, or awareness to provide. As a father, I am comforted to know my boys have been given sets of information that will continue to grow within their minds and can provide them with the means to take care of themselves. I think many dads want to know their children are going to be okay and that they are going to be able to thrive in this world. It has been a great voyage with my sons, providing a collection of memories each of my sons will take with them going forward. My hope is that other dads [and moms] might find a way to help their sons along such a path.

What do these new Eagle Scouts say to members of the hemophilia community interested in scouting and obtaining the rank of Eagle?



"The best part of being a scout is the ability to do a variety of outdoor activities that the average person can't do!"

Dustin Huerta –

"Persevere and go for it!"

Raphael Forbes –

"You learn a lot. It's lots of fun. And it goes by fast!"

Gabriel Forbes –

"Join up!"

Michael Forbes –

"Do what you can. It is all good!"

Emmanuel Forbes –

Top Recommendations for Scouts with Hemophilia

1. Parents of scouts should get involved in Scouting as early as possible and be willing to become active members.
2. All scouts on campouts and other scouting activities need to take enough factor, medical supplies, and travel letters.
3. Make sure the troop has sufficient communications systems.
4. Make sure the troop has reliable transport systems.
5. Recognize that not all outdoor activities will work. Know your own physical limits.
6. All leaders and fellow scouts should be fully apprised of what it means to have hemophilia.
7. Discuss and gain approval from your doctor and the hemophilia treatment center regarding proposed activities.
8. Seek to maximize all of the things that can be done in scouting that do not threaten the health of scouts with hemophilia.
9. Focus on the multitude of merits badges that are possible for boys with hemophilia.
10. Know self-infusion skills thoroughly.
11. Have fun! ■■

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Attitude is Everything, Baseball is My Life

By Janet Chupka and Faith Hunter

Nick Cleghorn is your typical eight-year-old boy who loves baseball. If he isn't outside practicing baseball, he is at the field watching the games. You could say baseball is his "THING." However, there's something very special about Nick. He has hemophilia. The big question is how can a child with hemophilia play baseball? That is where Nick's "can do, play it safe" attitude makes a difference.

Nick started playing t-ball when he was 5, and he now plays on a kid-pitch team (vs. a coach-pitch team where the coach pitches to the kids). Nick understands the importance of regular exercise for people with hemophilia and that it helps you strengthen your muscles and joints. He also knows firsthand that it helps to prevent bleeds from happening. During the "season" (which never seems to end), he practices at least twice a week with games 1-2 times a week. He also takes hitting lessons once a week. To say the least, that's one active and healthy little boy.

Nick's parents, Tracy and Lance Cleghorn, are extremely supportive in Nick's commit-



Nicholas in action



Baseball star pitcher CJ Wilson

ment to playing baseball. Not only do they play with him in the backyard, but Nick's dad is a coach on his baseball team. They are also teaching Nick how to take care of himself and the value of staying healthy so he can continue to do what he loves. Nick is also learning how to self-infuse, and how to play it smart on and off the field.

Over the years, Nick has made many friends through baseball and other organized sports like basketball. One of his most memorable moments was when he traveled to Texas for the "Getting in the Game" event, where he connected with other boys his age with hemophilia that also have a passion for baseball. While in Texas, he met Texas Ranger pitcher C.J. Wilson. C.J. provided an inspiring discussion about sports and doing what you love. During the weekend, the boys also talked about wearing their medic alert bracelets and sharing their diagnosis with teammates.

Travelling with his father, Nick also went to Ohio recently to meet with a group of dads and kids to talk about "Sports and Bleeding Disorders". Nick had the opportunity to share his story, talking about how he prepares for sporting events and what they have done when incidents happen on the field. Nick and his dad were a great team and provided some awesome tips for parents and kids to follow when preparing to participate in sports.

At the end of the day, baseball is Nick's first love. He knows the importance of staying healthy so he can continue to do what he loves ... BASEBALL! ■■

Partnering with Pain Foundation

By Gina Salemme

My name is Gina Salemme and I have hemophilia A. As a person with a bleeding disorder, I also deal with chronic pain from the damage in my joints from years of bleeds. Kimberly Haugstad asked if I would attend a Pain Education Event in Troy, NY hosted by the American Pain Foundation on October 15, 2011, so I decided that I would go check it out.

First, a little about what brought me to even consider going to this event. In April 2011, I had a synovectomy done on my right ankle. I have severe joint damage in both of my ankles and my left knee. Since the age of 16, I have been used to the fact that my left leg didn't work right, but I was still able to walk and occasionally run and live a fairly normal life. After having the synovectomy on the right ankle, my life has changed. I am dealing with pain that I just cannot seem to get a grip on. Favoring my right ankle has caused my left ankle and knee to hurt like they haven't in years.

I felt that I could probably learn a few things from the Pain Education Event and I did! I learned there are so many resources available for people who suffer from chronic pain. Regardless of the cause of a person's pain, there are others out there who understand the emotional and the physical toll that pain causes. We have our blood sisters and our blood brothers to talk to about our bleeding, but I believe that the American Pain Foundation can give us more tools to deal with the pain that is secondary to our bleeding disorders.

I hope to see The American Pain Foundation join with HFA in the future. To learn more about The American Pain Foundation, you can call them at 888-615-7246 or visit their website www.painfoundation.org

We don't have to live in silence with our pain. ■■

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➤ Visit www.BiogenIdecHemophilia.com to watch the Fc fusion video and sign up for updates on our research.

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Jennifer and Donovan Guerrero,
a mom and son meeting the
challenges of an inhibitor

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The Dirty Dozen (Almost) – 1st Inaugural Gears for Good Bike Ride

By Kimberly Haugstad

Day 1: 32 miles. We're off! The group met in Georgetown, next to Washington D.C., loaded up gear and bikes, and drove several hours northwest to our launch point. We started out at the Paw Paw Tunnel on the C&O Canal.

Just before we entered the tunnel, two cyclists—adult men with bleeding disorders who were standing in front of me—did a great big High 5 to each other saying, "I'm feeling good. Here's to making it another 10 years." They hopped on their bikes and were off! I stood there a minute, so moved by those words. This was inspiration for me and I felt so proud of HFA for pulling this ride together. It deeply reminded me of the worries of so many of our adult men in that very same place—managing their hemophilia, but remaining fearful of the long-term impact of HCV.

A week of rain prior to our ride left a trail of mud and running water in some places to ride through. This was not something I'd trained for since I'm a sunny day rider who perceives rain as a day off! (Lesson learned.) Almost immediately each of us was soaked and speckled with mud. The speckles became splotches after another few miles and by the time we stopped at around mile 15, we were covered in mud. Sound awful? Just the opposite! It turned us immediately into a united team, enduring the mess and choosing to laugh about it. Despite the mud, it was a pretty fall day with leaves drifting down on the trail and picturesque views. After 32 miles in mud (feels like 62) and we were exhausted! (For full disclosure, we were all very happy to reach the hotel that night, shower off the layers of mud, have dinner, and hit the sack.)



Lockhouse Boys

THREE WORDS: INSPIRATION, ENDURANCE, & PERSEVERANCE

Day 2: 64 miles. Up early and off again. This was an endurance day, but a pretty ride. The trail had dried out a little and it was time to get some serious miles logged. On the way, we took a side route to visit Antietam National Battlefield, site of a bloody Civil War battle. You can feel the presence of so much loss, the bloodiest single-day battle in American history with about 23,000 casualties. It was impossible not to think a little about the parallel to our own bleeding disorder community loss and the tie to blood. We spent the night at the adorable historical town of Harpers Ferry. Andy had the best dinner he'd ever had. (For full disclosure, I logged just over 30 miles and rode in the SAG van for a while.)

Day 3: 60 miles. Up early again for a perseverance day. A few bike adjustments and seat switching were needed while we all gathered our determination to reach Mile 1. The weather was holding but cloudy and the trail was in good condition. Time for some serious productive peddling! At this point, we're all thinking about the end and how amazing it has been to get to know the team on this ride. We were a motley mix of people with bleeding disorders, family members, and bicy-



Barry Haarde - The Miles Man



Andy Matthews - The Speedy Southerner



Paul Brayshaw - Rocky Mountain Racer

clists who loved this particular trail and signed on for the ride to support our cause. Rain and a few new bike repairs slowed things down mid-day, but perseverance reigned. We'd inspired each other in different ways and wanted to keep the momentum going. Conversations on the trail turned to "what is next" and how to touch base following the ride. By the time we reached Mile 1, the weather had cleared and we wrapped up the ride as happy peddlers! Amazingly, despite aches, exhaustion and pains, we're all committed to coming back for year 2!

Fundraising Update: Back at the DC office, the HFA team continued to work on the fundraising side. Donors continued to support the ride until October 15th and we're delighted to share that we successfully have raised over \$31,000. This ride was created to assist the Helping Hands Emergency Assistance Program in staying online through the remainder of 2011. In addition, we ran an HFA Membership Campaign with proceeds to support Helping Hands. However, a large funder for the program declined to support in 2011 and the program has been in jeopardy. Blood Buddies and Grifols stepped up early in the year with support for the Gears for Good Ride and additional support came from Bayer in September for the ride. These contributions along with many individual donations have helped secure enough support for our emergency assistance program through the end of the year. We thank you! ■■

The 3 Rs of the September 15-17, 2011 Ride:

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Thank you to everyone who supported this event both with donations and in Financial encouragement. This ride was a fundraiser and we DID raise some money for a cause we believe in!



Nick Cady - Carolina Cruiser

Understanding Your Choices (Part 2)

This is the second in a series of articles about health insurance choices. I don't know about you, but every time I have to choose an insurance plan, I feel totally daunted. I know that the wrong decision has the potential to cause my family serious financial damage and a lot of heartache and headache dealing with claims and physician choices. So I need the right information and tools for making a good choice: the people who would ultimately suffer from a bad choice are my family and me.

The first article (Insurance 101) provided you with some insurance terminology and a basic understanding of the types of health insurance to consider what type of plan would work best for you. I focused on private insurance and TRICARE (insurance provided to military personnel, retirees, and their dependents), but I plan to provide information on Medicaid and Medicare in a future article, so stay tuned.

I'm not an insurance professional. I am a consumer who (possibly, like you) has had some really frustrating moments with insurance companies and medi-

cal providers. Getting more information out there will hopefully help people in the bleeding disorders community to make more informed decisions and prevent potential frustrations. (How many of us have received a bill for \$15,000, or maybe even \$100,000, and were faced with fighting the insurance company for coverage? A future article will cover strategies for winning that particular battle.)

This article will discuss factors to consider when you have a choice of plans, either through your employer or on your own. Is a health maintenance organization (HMO) better for you than a preferred provider organization (PPO)? How do you figure it out? If you have a choice between insurance companies, how do you decide which is the best company? Most of us have had to compare plans at one time or another.

Do you ever feel like you need 6 months to read all of the material and understand it well enough to make an informed decision? Insurance providers can give you pages and pages of information to sift through to "help" you choose the right plan.

Luckily, in March of 2012, insurance companies will be required to provide you with a uniform summary of benefits and coverage (SBC). This document will help you compare health insurance coverage options before you enroll and understand your coverage once you enroll. The SBC must be no longer than four double-sided pages and use words understandable to the average consumer. It cannot contain "fine print." It will describe the plan's premium, coverage features, patient cost-sharing (how much you pay), and rules regarding use of network providers. While the SBC will include how the plan would cover common medi-

eductible and pay all of your out-of-pocket expenses). If you start your planning and analysis early in the process and look at one consideration per day, the whole process might seem a little easier for you.

The Network

Does the insurance plan have a network? And, if so, is your hemophilia treatment center (HTC) on the network? If not, does your plan cover off-network healthcare? (Mine does not, so be really careful about analyzing this. If your insurance provider won't cover medical services outside the network, I highly recommend that you ensure that your HTC is on the network!) If your plan does cover out-of-network care, how much does it cover? For example, some plans will cover 80% of care within the network, but only 60% of care outside the network. One other important issue to research: on many policies, you have two different out-of-pocket maximums, one for in-network care and one for out-of-network care. This means if you want to have surgery at a non-network facility, even if you've fulfilled your entire out-of-pocket maximum for in-network care, you will have to fulfill your out-of-network in its entirety as well.

The Medication

The single-most frustrating part of my analysis every year is how factor will be covered. First, I have to figure out if it's covered as a prescription or as a medical service. Then, I have to figure out how it's covered; will I have to pay a percentage; a co-pay? Then, I have to figure out how much of it is covered: what percentage do I pay and how much is the co-pay? Do I get a certain number of infusions per year? If it's covered as a prescription, is there a monetary limit on claims? And to top it off, when I have phoned the new insurance company to ask how factor is covered, they often can't answer my questions because I'm not covered by them yet. Here is the very limited advice I can offer you: know the approximate cost of your factor per year. I know that it fluctuates based on how many bleeds we have, but there is a sort of "baseline" you can come up with, either by using last year's costs for factor or by averaging several years.

"Getting more information out there will hopefully help people in the bleeding disorders community to make more informed decisions and prevent potential frustrations."

cal events, bleeding disorders hardly fall into the "common medical" category. However, the SBC will certainly come in handy for our initial analysis, especially regarding network care rules.

Considerations

I like to break the considerations down into "digestible" chunks when doing any sort of complex analysis. (And let's face it: insurance is pretty complex!) Doing this helps me not feel so overwhelmed, so I can just focus on one facet of the issue at a time. When I put them all back together, they make more sense (usually). The one consideration to keep in mind is that bleeding disorders are extremely expensive to treat properly; you should probably assume you will pay the maximum amount your plan can make you pay (fulfill your entire

The Premiums

If your job offers you a choice of plans, you'll want to look at the premium costs for each plan you think might work for you. You need to ensure that you can pay the premium for any plan you choose. Check out the resources at the end of the article for information on how to get help with premiums if you need it. If it comes out of your check before taxes, you can skip this step; but you still might want to calculate how much the premiums will cost you per year. (See "The Bottom Line" section for more information about this.)

Possibly the most important thing to remember when considering your premium is whether it is your only cost. If you are choosing insurance through your job, your share of the premium may come out of your paycheck before taxes, so consider the tax savings if you think it's



relevant. The Affordable Care Act has a process for states and the Department of Health and Human Services to review "unreasonable" premium increases and provide information to consumers about the process. The rules governing this rate review process went into effect 9/1/2011.

Your Share of the Cost

Your share of the cost is what you should combine with your premium cost to figure out your annual cost. (See The Bottom Line.) It can be in the form of co-pays, deductibles, or coinsurance (percentages that you pay). This is also called cost sharing. When you are evaluating your insurance plans, be sure that you understand all of your costs, especially less obvious costs. Examples of less obvious costs might be having to fulfill your out-of-pocket for the year in your network and out of your network; paying higher co-pays for specialty prescriptions or specialists; or paying the remainder of your prescription costs if you max out the prescription cost limit. (Many plans cover factor and other infusibles under the medical part of the plan, so this might not apply to you, but check.)

Continued on page 19

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.. POLICY NEWS ..

Health Insurance Exchanges and Essential Health Benefits

By Eboni Morris

Starting in 2014, individuals and small business will be able to purchase health insurance plans in a “virtual marketplace” called a health insurance exchange. So the exchange will not technically be a physical location, but rather a place where individuals can go online and browse insurance offerings based on personal criteria they identify (i.e., age, health status, and other personal characteristics). However, there must also be an in-person option for individuals to apply for and purchase a health plan (e.g., a person should be able to apply for coverage at a local health department or social service office).

By law, the states must have an exchange set up by 2014. The Department of Health and Human Services (HHS) has so far awarded 16 states and the District of Columbia multimillion dollar exchange establishment grants. If they decline or are not fully completed in their exchange implementation, the federal government will operate the exchange on the states behalf—this is similar to what occurs in the Pre-existing Condition Insurance Program (PCIP).

States will have various options in developing and operating their exchange. States can operate the exchange themselves; have the federal government operate the exchange; or use a state/ federal partnership model that combines state and federal functions. States may also have the option of a “federally facilitated exchange.” In this option, a state can decide to take over operation of the exchanges or hand it back over to the federal government after 2014.

When someone applies for coverage, the exchange will make a determination of their eligibility for the premium tax credits (this will go toward the payment of the health insurance premium based on income and family size) as well as for Medicaid, the Children’s Health Insurance Program (CHIP), and the Basic Health Plan (if states chose to offer it).

Though 2014 may seem far away, it isn’t in terms of implementation. States must show progress by January 2013, but states do have some additional flexibility in implementation if they are not prepared. For most states, creating an exchange requires the state to pass legislation to create such an entity. Depending on when the particular state legislature convenes, they may have only one legislative session to do so. Also, exchanges must be a governmental agency—an existing executive branch agency or an independent public agency—or a non-profit entity established by the state.

In addition, the federal government has established minimum criteria for certification of health plans that can be offered in the exchange. These standards include offering the essential benefit package (which is discussed below); cost-sharing limits; being licensed and in good standing to offer health insurance; quality standards established in the law; offering at least one qualified health plan at the silver and gold benefit levels; child-only plan to children under 21; and no discrimination on basis of race, color, national origin, disability, age, sex, gender identity and sexual orientation. The law also requires HHS to establish provider network adequacy requirements to ensure health plan enrollees have a sufficient choice of providers. States can require that health plans sold in state health insurance exchanges also cover state mandated benefits; however, a state must pay for the coverage of these benefits. This is of great concern because without the financial incentive many fear that states will roll back their state mandates, leaving many without the standards of care they have worked hard to receive.

Essential Health Benefits

Health plans sold in the exchange or in the individual or small group market must cover federally mandated essential benefits. Essential benefits refer to what the plans will actual offer in coverage as a baseline for services, treatments, etc. It is a starting point for health insurance plans; they will be mandated by law to offer these benefits to the public for purchase. It is important to note that the law exempts large-group health plans, as well as

self-insured ERISA plans and ERISA-governed multi-employer welfare arrangements from the essential benefit requirements. Be aware of the type of plan you have in order to determine what parts of the law apply.

Here are the general essential health benefit categories required by law: emergency services; hospitalization; maternity and newborn care; mental health and substance use disorder services; prescription drugs; rehabilitative and habilitative services and devices; laboratory services; preventive and wellness services; chronic disease management; and pediatric services, including oral and vision care.

The process for determining the specifics for essential health benefits is ongoing. After the law was passed, the HHS instructed the Institute of Medicine (IOM) to do a study on how the essential benefits should be designed. The IOM provided recommendations on various items, including how benefit packages should be developed and updated over time, coverage decisions and defining medical necessity. As of the printing date for this issue, the regulations have not been issued.

HFA has a set of recommendations around the development of essential health benefits:

Health plans should look to medical literature and treatment guidelines recommended by medical and patient organizations to determine standards of care for patients with rare and chronic conditions such as bleeding disorders. The benefits should be designed to encourage patient access and not impede patients from obtaining needed treatments and specialized care. An essential benefits package should always include a process to appeal a claim denial. That process should provide assurance that the insurer has an obligation to first confer with the patient’s physician to discuss a possible denial and the grounds for rendering such a decision.

Physicians should be allowed to formulate the best treatment regime with their patients at the appropriate site of care whether in the hospital, outpatient clinic, office of the physician, hemophilia treatment center (HTCs) or the home setting. As advances in medical evidence

or scientific advancement are being uncovered and approved through the FDA, as well as a peer reviewed medical journals stating the improved/decreased health outcome, HHS must put in place expeditious pathways for the inclusion of new therapies and treatments in the essential benefits package when these new products or new information become available.

HFA opposes any additional limits on specific or total benefits in the packages. HFA recommends prohibiting the implementation of treatment caps, prior authorization, utilization management or other types of restrictions by cost or in limits on treatments (in particular those approved by the United States Food and Drug Administration (FDA). Any governing body moving to phase out a given state mandate should be made cognizant of the possible disruption in coverage that might ensue for these affected. ■■

What YOU can do

- ☑ Make your state officials—including health insurance exchange boards, governing organizations (if created in your state) and legislators—aware of standards of care for individuals with bleeding disorders.
- ☑ Use the MASAC guidelines, already implemented standards, or pending standards legislation as examples.
- ☑ Stay updated on your state's actions in health care reform, especially on health insurance exchanges.

States have been and will be holding public hearings and introducing and passing legislation to set up various aspects of health reform. Below are some resources to help keep on top of the frequent changes.

<http://healthreform.kff.org/tags/exchanges.aspx>

<http://www.ncsl.org/default.aspx?tabid=21393>

<http://statehealthfacts.kff.org/healthreformsources.jsp>

<http://www.iom.edu/Reports/2011/Essential-Health-Benefits-Balancing-Coverage-and-Cost.aspx> ■■

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Get involved locally....

Blood Brotherhood in Indiana

By Steven A. Riedle

The Blood Brotherhood group in Indiana (known as the Bruisers) is a great way for adult men with bleeding disorders to get together and learn things specific to our needs. This outlet has been a great help as we get older with Hemophilia or vWD. About six years ago, we had our first Blood Brotherhood meeting. Every month since then we have had these meetings and came up with our own nickname of "Bruisers Club." The speakers for these events are always aware of our situation and tailor the topic to our needs. We are the first generation to have great clotting meds, but we still have needs as we get older. Since we are living much longer and are much healthier than generations before, we welcome the Blood Brotherhood to provide us with information we need to meet the challenges of adult life.

Overall, HFA's Blood Brotherhood program has allowed us to get together for truly fun and educational events. And, as time has gone by, we have all become close friends. We share answers to the problems anyone has with life: employment, dating, insurance, and how to be the best person we can. Better factor products and prophylaxis have made the younger generation so much healthier than I could have ever been. Now the challenge is to live a completely normal life. This is made possible for me with the help of my HTC and support of the Blood Brotherhood (Bruisers) group. We are gaining knowledge at these meetings. Even if you don't know just what you want to do with your life, these meetings are still a lot of fun. It's up to you, so give these HFA Blood Brotherhood meetings a good look to see how the program might help you!

■ ■

Get Involved Online.....

By Axel Freese

Hello Blood Brothers!

In case you didn't know, the Blood Brotherhood program also has an online component - the Blood Brotherhood Forum Website - here is the link: www.bloodbrotherhood.com

The website is a closed website. This means you have to apply to be a member (Blood Brothers only!) and then be approved. Once you are approved, you can visit with our entire roster of over 280+ bleeders from all over the country, as well as read our incredible content. Our site currently has over 6300 posts in over 430+ topics. Some of the content is specific - ankle fusion, elbow replacement, total knee arthroplasty - and some are quite general, like topics on hobbies, jokes, and many other fun features. Since we are a closed site, this is also a safe place to read, discuss, and mentor each other within a group that instantly "gets" what living with Hemophilia and other co-infections can really be like - it is a true Brotherhood! We also have a Chat feature on the site that allows members who are on the site at the same time to conduct real-time conversations with any and all other Brothers. We look forward to having you join us, so check us out and join the Blood Brotherhood Online Forum site today! ■ ■



In Memoriam

Tim Kennedy

Tim Kennedy of Algonquin, IL, passed away October 29, 2011 after a short illness. Tim was known for his kindness, positive attitude, and sense of humor. He served as a fine role model to many young men in the hemophilia community. He leaves behind his wife, Tammy, and two young sons. His spirit lives on in all those whose lives he touched.

Diane Yvonne McClure

Diane passed away peacefully on October 28, 2011. Diane was an active contributor and supporter within the bleeding disorders community. Her kind and giving spirit was shared with many. She served on the board of directors of COTT and as Chairperson of the Marcus McClure Big Dreams Foundation, as well as supporting many other church and charitable organizations. Her kindness and gentle smile will be missed by all.

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For more information and to get started, visit www.FactorPlusprogram.com.

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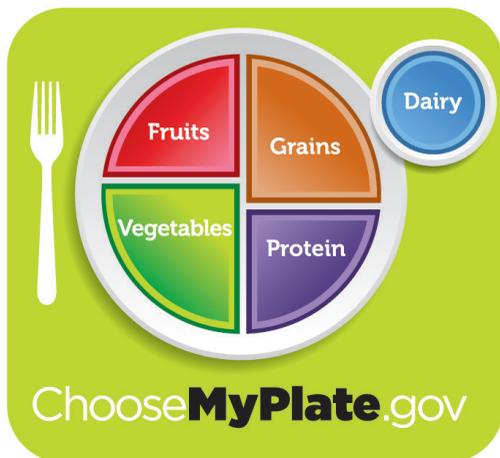


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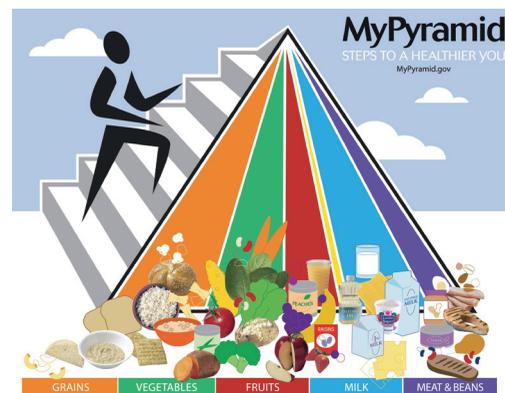
Food Pyramid Becomes a Plate

By Janet Chupka



an effort to make healthier food choices easier to understand, the U.S. Department of Agriculture has replaced the Food Guide Pyramid with a simple and familiar visual, a place setting. MyPlate is the USDA's primary food group symbol, a food icon that serves as a powerful reminder to make healthy food choices.

Not sure what to pack for your child's school lunch? Confused with the revised food pyramid? Visit www.choosemyplate.gov/ for many ideas for school lunches as well as an interactive site for kids. Planning and packing school lunches can be a fun time spent with your child. On this site there are suggestions for using leftovers from last night's dinner, fun recipes to make together, using what you may have in your garden as well as important information as to what foods give energy and what



foods may slow you down. The pyramid is explained using a colored plate to help children understand the types of foods that are most important to include in daily meals. Also on this site is information for parents, kids and for teens. Learn more about Body Mass index (BMI) and why knowing this is important to your overall health. Learn the risks of being overweight and what you can do to become a healthier you. Set your own personal goals, search foods and create a menu planner. It is easy to keep track of your food intake and analyze and make changes to your menu planning. Visit www.choosemyplate.gov/ to begin your journey of health and fitness. ■■

There are a lot of health and wellness resources available today in print, online and even on TV! HFA's Health and Wellness program, FitFactor is another great resource.

Visit <http://fitfactor.hemophiliafed.org/> to see what we're working on with active fitness enthusiasts in our own bleeding disorders community!

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Understanding Your Choices Part 2

Continued from page 13

The Bottom Line

Here is what you need to figure out:

- How much is your insurance going to cost you? (Remember, the cheapest plan, premium-wise, might not be the cheapest plan overall.)
- Will your insurance allow you to see the doctors you need and use the home care company you want?
- Does your plan provide you a case manager to assist you with managing your health in the best way possible? (Many plans offer this option now. My experience is that sometimes, they are very helpful and worth leveraging, and sometimes, contacting them is just waste of time. You won't know which until you try, and since that costs you nothing, it's probably worth considering.)

So, how do you figure it out? Well, you can look up the doctors you want on the network (usually on the Internet). You can phone the insurance company to ask if they provide a case manager. And you can calculate your costs (approximately) by using the formula in Table 1. This table assumes that the HMO covers factor at 100% and that the HTC (or any other doctor you might need) is on the network for the PPOs. If you have an out-of-network situation, you would need to calculate that separately. It also assumes that there is more than one person in the family with a bleeding disorder (meaning that the family out-of-pocket will have to be fulfilled).

So, you can see that the cheapest premium might not be your best choice in the end.

Type of Plan	Annual Premium Cost	Estimated Annual Cost-Sharing	Total Cost
HMO	\$10,000	Co-Pays (number of appointments × amount of co-pay): \$200 Deductible: N/A Out-of-Pocket: \$500 per person, \$1,500 per family Annual Cost of Medication: 0	\$10,000 + \$200 + \$1500 = \$11,700
PPO Level 1	\$8,000	Co-Pays (number of appointments × amount of co-pay): \$200 Deductible: \$1,000 Out-of-Pocket: \$500 per person, \$1500 per family Annual Cost of Medication: 0	\$8,000 + \$200 + \$1,000 + \$1500 = \$10,700
PPO Level 2	\$6,000	Co-Pays (number of appointments × amount of co-pay): \$400 Deductible: \$2,000 Out-of-Pocket: \$1000 per person, \$3000 per family Annual Cost of Medication (10% of cost after first \$50,000, payable in addition to the deductible and out-of-pocket costs): \$5,000	\$6,000 + \$400 + \$2,000 + \$3000 + \$5,000 = \$16,400

Of course, this isn't the only factor to consider. It might be worth paying more to see the doctors you want to see. Or you might have another medical issue in your family that also must be considered. Don't forget as you are figuring all this out that there are resources that can help you figure out what you need to know. Talk to friends who know more about insurance than you do. Also, go to the websites listed below and see what they have to say. Contact your insurance agent or human resources department with questions. Remember that your insurance agent, even if they aren't selling you medical coverage at the moment, will probably be happy to answer questions for you or refer you to someone would can answer some questions. Contact the insurance provider with questions as well. You can even contact your homecare company if you are comfortable with that—leave no stone unturned! Whatever your situation, I wish you the best of luck and hope you feel confident that you have made the best choice possible! ■■

<http://www.kff.org>

www.hemophilia.org

<https://www.patientservicesinc.org/>

<http://www.medhealthinsurance.com/>

(This site sells insurance, so use it as a resource, but be careful about providing your contact information if you're not looking to buy.)

http://www.kelleycom.com/newsletter_archives_2011.html

(This site is paid for by industry. Pulse is a newsletter all about insurance and insurance issues.)

www.tricare.mil

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State Advocacy: HFA Listens and Learns

Continued from page 6

Overwhelmingly, member organizations believe that HFA should play a support role (vs. a lead role) in state advocacy; that is, organizational members should take the lead in their own state, and HFA should assist them. Over 84% of them expressed this view.

#9 – Vehicles of Support: Organizational members prefer in-person trainings but recognize the cost. They also view the website, webinars, and conference calls as effective mechanisms for delivering advocacy resources and support.

HFA is already using the above findings and other information from the assessment and survey to develop its 2012 Advocacy Plan, making sure the plan is based fully on the direct input of its members.

Thanks to everyone who has participated to date. HFA will continue to listen and learn from its members and wants to hear from you. To share your views and ideas, please contact Jonathan VanderBrug at 773-407-8350 or j.vanderbrug@hemophiliafed.org ■■



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