



what is ADVOCACY?

(YOU DON'T EVEN
NEED A SUIT!)

By:
Patrick James Lynch

Advocacy is a funny word.

It can evoke images of people in navy suits standing behind microphones or impassioned groups marching in parades. But advocacy is more than that. It must be. It must engage with members of a community on multiple levels, not just these outstanding ones. It must be channeled in practical ways that people can apply to everyday life. Advocacy is big and small. It can be as apparent in casual conversation between friends as it can in yearly meetings with state representatives. It is a letter to Congress and it is a blog on your website. It is bold, and it is subtle.

This thinking was part of the driving force behind our Teen Connection video from Symposium 2012. I wanted to guide our group in creating content unlike anything that is already out there, and, equally important, I wanted to empower them as advocates in the process. I wanted them to know how powerful they could be, and that they did not need to be 30-something years old with a degree in public health to have a great impact. I wanted them to understand that with some specific expressions and a few entertaining moments, they could create something as valuable to our community as any two-minute video

released by a "medical professional." So we took the time to have some honest dialogue about how bleeding disorders have affected our lives. I asked them to speak openly, without judgment or self-censoring. I pushed them to define what a bleeding disorder has meant to their lives. *What have been the greatest obstacles? What have been some of the unexpected positives? What do they wish their peers could understand?* The more we spoke, the more candid the group became. Our conversations concluded in a room surrounded by poster boards, hung to catch the most prominent themes

DON'T
MISS

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ad • vo • ca • cy Noun \

'advəkē: support for or recommendation
of a particular cause.

Dear HFA Family & Friends,

On June 28th, the United States Supreme Court released its much-anticipated ruling on the Affordable Care Act and decided to uphold most of the health care law. Patients in the bleeding disorder community experience the impact of this legislation in numerous ways, including the elimination of insurers denying coverage to children with pre-existing conditions, the inability of insurers to cancel coverage when people get sick, the elimination of lifetime caps on coverage, and the allowance of young adults to stay on their parents coverage until age 26.

At HFA, we are reviewing the ruling and will closely monitor its impact. Beyond this law, we are committed to ensuring adequate and affordable access to care for all people with bleeding disorders. Our education and advocacy efforts to improve the health care system will continue. We encourage you to continue to work with us, raise your own voice and know how important you are as an advocate.

In this issue, HFA focuses on advocacy in many forms. Whether it is access to care and medical treatment, appropriate accommodation in school and the workplace or other, please remember, YOU are an advocate.

Warm Regards,



Matthew T. Compton
Board President



Kimberly Haugstad, MBA
Executive Director

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CONTRIBUTORS

Special thanks to HFA community members, staff and speakers who contributed to this issue.

Rich Pezzillo, Communications Manager
Shelly Mattson, Editor
Gina Dochnahl, Graphic Designer
Jonathan VanderBrug
Janet Chupka
Kimberly Haugstad
Eboni Morris
Linda E. Wyman-Collins
Patrick Lynch
Allie Boutin
Chris Smith
Ryan Seeley
Ian Muir
Mark Antel
Paul Brayshaw
Wendy Owens
Janel Johnson Momanyi

PHOTOGRAPHERS

Rich Pezzillo

Michael Schultz

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Tammy Davenport and Linda Wyman-Collins



The Power of Empowerment and Awareness

by Linda E. Wyman-Collins BSN, RNC-NIC

Women: You are your own best advocate when it comes to topics that affect your health and family. As women affected with a bleeding disorder, we have long been faced with medical professionals not taking our complaints or symptoms seriously. It is still in the mindset of the medical community that we do not have a bleeding disorder, and we are just referred to as a carrier. If you encounter resistance, then you need to stand up for yourself. Seek the information and resources that you need to make a case for yourself. You also do not need to do it alone. Consult with your local chapter and national organizations. See what information and support they can lend to you. Find out if other women have encountered the same obstacles and how they sought a solution or resolution to their problem or need.

Fifty percent of carriers of hemophilia have low factor levels. Have you ever been asked to have your levels tested? Do you

know your family's genotype or the particular gene mutation that causes the bleeding disorder in your family? If you have symptoms of a bleeding disorder, have you discussed them with your physician?

Get involved with your chapter on advocacy issues pertaining to women. Become knowledgeable on legislation that affects women and families. One person can make a difference. Don't be afraid to share your personal experiences. It may help another woman also.

I personally struggled for years, and no one seemed to listen. I had easy bruising, nosebleeds, gastrointestinal bleeding, bleeding from dental work, heavy periods and muscle/joint bleeds. I was told it was because I was fair and a redhead. I changed doctors

"I became informed and empowered to make change for myself and others."

until I found one that listened. I became involved with my local chapter and then with national organizations (NHF and HFA). I got elected to the Board of Directors of HFA and joined the advocacy and women's committees. I got involved in lobbying efforts on the state and national level on issues that affected myself and others with bleeding disorders. I became informed and empowered to make changes. I started

educating others to recognize the signs and symptoms of a bleeding disorder.

There is an excellent opportunity to share your opinions and experiences as a hemophilia carrier. Dr. Sidonio from Vanderbilt University is looking for females to take a survey about attitudes, care and testing of hemophilia A carriers. I encourage you to take the survey and give your input. The information is confidential and no personal information will be shared with others. Dr. Sidonio is going to be doing a study to look at the bleeding tendency in hemophilia A carriers. The data he collects will hopefully help improve care of all women with bleeding disorders in the future.

To participate in the Vanderbilt Hemophilia Carrier survey go to: <http://tiny.cc/16kdiw>

HFA is also looking for patients not cared for at a HTC. It is called the CHOICE Project (Community Having Opportunity to Influence Care Equity). It is a new project driven by HFA and supported by the CDC. Please see page 17 for more information about the choice project.

Both these opportunities are ways you can get involved and help make a difference! ■■

THE UNEXPECTED ADVOCATE

By Chris Smith

If you asked me 20 years ago what the word “advocacy” means, my initial thought would have been advocacy = politics. Follow that with a question about whether I saw myself as an advocate, and my answer would have been a definite ‘no.’ It’s not that I am uninterested in the political process. I just was not the kind of guy who carried a sign or collected signatures. My limited definition of what makes an advocate is one of the many things that has changed since the birth of my son, almost 20 years ago. Leland has severe hemophilia A with a high inhibitor. He is my first-born (I also have a fabulous daughter, Taylor, age 16) and when I added “father” to my resume, it wasn’t long before I also added “advocate.” Who would have thought? I might have, had I known that the word advocate actually meant to speak, plead or argue in favor of. Heck, I am in sales – I advocate for a living!

Seriously, if your child has a chronic illness like hemophilia, whether you know it or not, you are absolutely an advocate. Every time you walk into the hospital or doctor’s office, call your insurance company, or deal with an issue at school, you are advocating. In my case, it even grew to include being involved in the political process. My family has attended Washington Days several times, and it is an experience I highly recommend – educational, enlightening, and empowering. However, our most consistent and important role in advocating for Leland has been in school. It has been an interesting journey.

Pre-school and kindergarten went smoothly, but soon after first grade began, Leland got off the school bus one afternoon and was barely able to walk. My wife was stunned. We had met with everyone before the school year began to make sure they were



Chris and Leland Smith

educated about hemophilia and prepared to help manage his unique situation. Yet there was no phone call about something that so obviously warranted attention? It was an ankle bleed that went downhill fast, and when Leland tried to tell his teacher that he needed to go to the nurse, she told him to put his hand down – it was not time to ask questions. As a respectful six-year-old, he did what he was told. Leland spent the next six weeks in a cast and wheelchair (welcome to

the wonderful world of inhibitors). How did we advocate to make sure this never happened again? Before Leland returned to school, there was a meeting attended by every staff member with whom he interacted. Among the issues discussed was the fact that he would never again have to ask permission to see the nurse. Leland was given a pass that he could hand to a responsible adult in the room and leave, with no questions asked. We moved the summer before fifth grade, and the new school system recommended that

“The journey through K-12 was not just about getting Leland what he needed; it was about teaching him how to advocate for himself.”



Hemophilia Federation of America™

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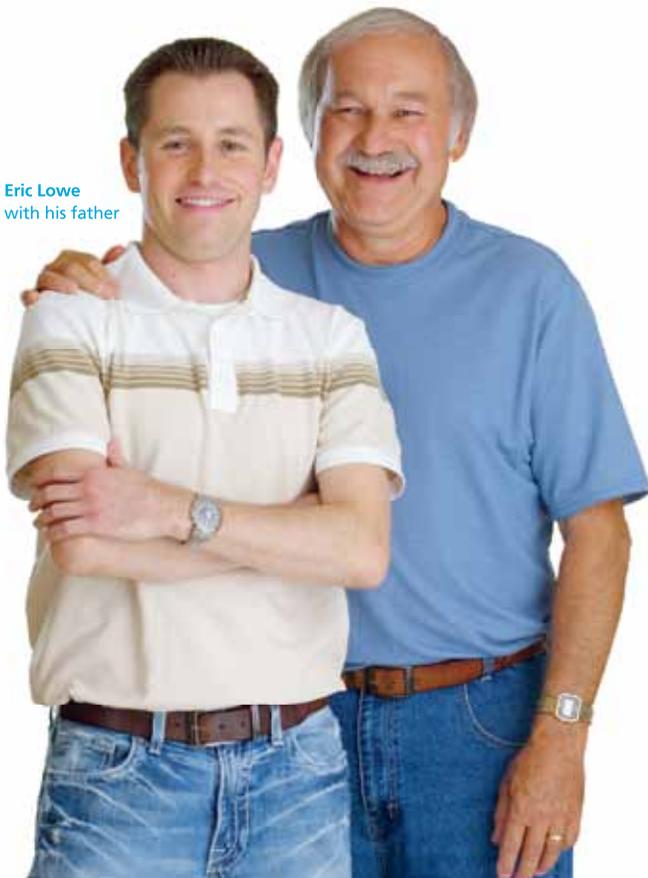
For more info, email us at hfaprograms@hemophiliafed.org

he have a 504 plan. In our old town, accommodations had been successfully managed through the nurse's office, but we were open to the suggestion. As the frequency and severity of Leland's bleeds increased during adolescence, the 504 plan became more and more important. The plan included points related to educating school staff about hemophilia and being allowed to infuse at school, as well as extended time to travel between classes, an extra set of books at home, priority locker selection, a permanent pass to the elevator, and more. For a list of school accommodations specific to students with bleeding disorders email us at hfaprograms@hemophiliafed.org By the time Leland reached high school, his absences had increased significantly, and we advocated to transition from a 504 plan to an Individualized Education Plan (IEP) because he needed something that focused more on academics rather than just physical accommodations. For example, most students graduate with more credits than they actually need. The IEP allowed us to streamline his course load and focus on quality versus quantity. It also provided for tutoring and specialized classes devoted

to setting goals and time management. One point on which the school system would not bend was graduation. Leland would not be allowed to walk across the stage with his class unless his coursework was 100% complete. This seemed next to impossible for a kid who ended every term with incompletes. However, with creative strategies, a positive, collaborative relationship with school staff, and a lot of hard work on Leland's part, he did it. My wife and I were beyond proud.

An important piece of this story is that Leland was present at every meeting we had with school personnel and played an ever-increasing role in decision-making. The journey through K-12 was not just about getting Leland what he needed—it was about teaching him how to advocate for himself. The journey has not ended yet, but it's now his journey, not ours. This was never more evident than when we recently met with the disabilities coordinator at the university he will attend this fall. Leland ran the whole meeting, and my wife and I barely said a word. It turns out the unexpected advocate has spawned an exceptional advocate...who would have thought? ■■

Eric Lowe
with his father



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Eric Lowe had the support of his family when he went through knee replacement surgery.

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ADVOCACY THROUGH SOCIAL MEDIA

By Ryan Seeley

Social media use within the bleeding disorders community has exploded over the past two years. A few years ago, there were only a small number of websites, a few blogs, and a few discussion groups on sites like Facebook. Now, people within the bleeding disorders community have launched many blogs, created online discussion and support groups on Facebook, and are actively using Twitter as well.

The bleeding disorders community is a pretty small group, considering the population of the world. That

is not just true for the United States, but around the world. Social media sites, such as Facebook and Twitter, have enabled many individuals living with a bleeding disorder, their parents or friends and family affected by bleeding disorders, the opportunity to connect with many others who are in the same situation. Additionally, social media can be used as a tool for advocacy within the bleeding disorders community.

Government Advocacy

Social media is a very useful tool to advocate for the bleeding disorders community. Most senators, congressman and other government officials have individual websites, Facebook pages and Twitter accounts. These social media avenues can be used to provide information and education for the bleeding disorders community to these lawmakers.

When you think about it, the chances are slim that a senator or congressman will know a lot about a bleeding disorder like hemophilia or von Willebrand disease. That is scary considering they hold the power in their votes to greatly help or hinder the bleeding disorders community. The Affordable Care Act is a perfect example. That act provided much needed and long overdue security to the bleeding disorders

community. The elimination of pre-existing condition clauses and lifetime caps provided freedom and peace to those living or dealing with bleeding disorders.

Imagine if that had been repealed. Many in the bleeding disorders community traveled to Capitol Hill in March to meet with senators and congressmen to provide them with knowledge and personal stories about how their votes could affect them. Twitter and Facebook were utilized to impart information on their pages and make not only them, but also their followers, aware of the issues facing the bleeding disorders community.

Advocating For One Another

A little over a year ago, I was communicating with one of my Twitter followers, a fellow hemophiliac, who lives in India. During our tweets, we were talking about



the possibility of me integrating yoga into my own life. He mentioned that he had tried it and ended up having bleeding issues because of it. I asked him how he was doing now and he told me that continuous bleeds had weakened his ankles and elbows and that he had not infused factor to treat the bleeds due to financial issues. My heart sank hearing this news. I have been in that situation several times during my life and know how scary that can be, but also the horrific pain and damage that can be caused from even one bleed left untreated.

Several other Twitter friends saw our tweets and reached out to help. We started asking questions of our friend in India to determine what was going on and if there

Continued on page 16



CONGRATULATIONS TO HFA'S 2012 SCHOLARSHIP WINNERS!

Sachin Rudraraju
Cornell University
Economics and Biology



Donna Pairadee
Western Governors University
Masters in Nursing

"Receiving this scholarship means a great deal, not just to me, but for my family, my children and for my entire community. With this scholarship, I will become a Nurse Practitioner and be another provider in a rural part of Washington State."



Julia Jackson

The Richard Stockton College of New Jersey
Doctor of Physical Therapy

"I would not be where I am today if I did not receive the help from the bleeding disorders community and physical therapy facilities. Physical therapy will allow me to combine my most passionate interests of medicine and exercise."



Derek Blumenstock

Mount Marty College in Yankton
Pre-Medicine



Nicholas Popp

University of Chicago
Biochemistry



Lauren O'Doherty

University of North Texas
Pre-Physical Therapy

"I have always been passionate about helping others and as a person living with von Willebrand disease. I hope to be a healing hand to others with vWD and implement change in my community."



Sarah Blake

Manchester College
Elementary Education and Mild Intervention

"Helping children is something I have always been interested in and I cannot wait for the opportunity to positively impact their lives. Being active within the bleeding disorders community has helped me discover my passion for helping children and it has taught me to always dream big."



Pamela Way

Chattanooga State Community College
Nursing



Ryan Lally

Albany College of Pharmacy
and Health Sciences
Pharmacy



Seth Kelly

University of Alabama History and
Social Science with a concentration
in Secondary Education

"I hope to share my experience of living with hemophilia with others, by demonstrating how I don't let this disorder slow me down. I hope to leave each person within the hemophilia community with a feeling that "you can" live your dreams."



**BREAKING THE VICIOUS CYCLE:
INVESTING PROPHYLACTIC
FACTOR USE IN FUNCTIONAL
BODY MASS.**

By Ian Muir

Note: I have been fortunate to have had extremely supportive parents along with access to prophylaxis since I was 5 years old. I have no doubt that these are the two largest contributing factors to my healthy joints and ability to participate in triathlons, snowboarding, and other high-energy sports. As I have gotten older, I recognize that with hemophilia, and many other conditions, everyone is not dealt the same cards. We may be playing a similar game, but we are on a spectrum of advantage in the game. Circumstances such as insurance, inhibitors, and target joints can have a dramatic effect on the whole family's experience with hemophilia. I acknowledge these disparities between my experience and others, and hope that some of these general thoughts on "using prophylaxis to its full potential" are relevant and could help (even in some small way) you, or a hemophiliac you care about, play the cards you/they have been dealt.

After a large iliopsoas bleed landed me in the hospital for my 5th birthday, we would always do prophylactic infusions on Mondays and Thursdays, because they seemed like the best days to keep my factor levels up while I was at school. Prophylaxis was done because the need for it was there. I was going to play kickball, play on the monkey bars, and practice flying jumps off the swings. Little did I realize at the time that the preventive treatment, coupled with the activity, would keep me out of the vicious cycle of atrophy, injury, being sedentary, and more atrophy. That was also

"A get out of jail free card", a chance to do things with the assurance of significant protection for the next 24 hours, and dwindling protection after that."

long before I realized how valuable each of those \$1,500 vials were that brought me up from 0% factor 8 to 60%. They were a sort of "get out of jail free card," and a chance to do things with the assurance of significant protection for the next 24 hours (and dwindling protection after that).

As I got older, my appetite for pushing my limits remained, and I found myself following in my dad's footsteps to start running cross country and track in high school. Throughout all the miles of running, my parents and I would often regroup about how I was feeling, distinguishing normal fatigue and soreness from precursors of bleeding episodes from the training.

I ran off and on for fitness during college and started swimming more seriously. At 24, I found myself on one of the best collegiate triathlon teams in the country, and I fell in love with the sport. The variety in training for swimming, biking, and running suited my body very well, and I found that the two days of rest between training blocks for one sport were great for recovering. Continuing to discuss any aches and pains with my parents, we reached a consensus that it would be in my best interest to run on days that my factor level was pretty high, in order to quickly contain any micro-bleeds, overly strained muscles, or turned ankles. From these discussions came the concept of using prophylaxis to help keep up my training momentum. I believe this has led to more resilient joints that are constantly getting stimulus to stay coordinated and supported. From then on, I promised myself that I would use each prophylactic dose as an opportunity. Though the factor would have a fleeting presence in my body, its benefit would not.

From my peak of fitness in early 2010, and my now current attempts to sustain it as a twenty-something in the working world, I am humbled by how efficient the body is at eliminating energetically expansive muscle it does not think is needed. It needs a constant reminder that, "Hey! This stuff is important!" and for hemophiliacs, doubly so. Without constant reminders that ankle and leg muscles are important, muscles will atrophy and leave one exposed to more easily turned ankles and vulnerable knees from lack of joint support during flexion and more impact on the skeleton from running and walking.





It may seem like a lot of work to maintain this, but with the increasing awareness of sport specific and functional training, people are enjoying the benefits of their workouts and find the fitness easier to sustain. The general premise of sport specific or functional training is that strength exercises should be designed around a goal. For example, I want the motions of running, walking, swimming, bike riding, basketball, skiing, and playing soccer to be easier. By strengthening with specific weight lifting, rubber bands, pilates, or stretching motions, the body is reminded that



Ian Muir

muscles, nerves, ligaments, and tendons required for these motions are important.

So how does prophylaxis fit into this? Well, as some of us (particularly the severe hemophiliacs among us) can attest to, there is an annoyingly large variety of mundane motions and activities that cause bleeding episodes. By saving for high factor level days, some of these more vigorous “reminders” of exercise stimulate our bodies to hang on to tissue that is quite functional and helpful for living an active life. The vicious cycle is transformed into the fitness investment cycle: infuse, build and maintain functional body mass, protect coordination and strength, live it up, infuse.

By traveling “light” and shaping most of the mass we carry into being functional, this helps us do the activities that we love. Hemophiliacs can take a fleeting, yet appreciated, protection, such as factor, and have it pay out more permanently as smarter tissue that helps to protect the body at lower factor levels. ■■

“He who would travel happily must travel light.”

- Antoine de St. Exupery

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- Ride West Virginia to Washington, DC
3 days | 156 miles
- Virtual Rider – Bike in your local area
- Donate – Support a rider or make a donation to the ride

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Register today!

www.GearsForGood.com

Pedal WITH A PURPOSE

September 28-30th ~ Will You Join Us?

Gears for Good 2012 Charity Ride is HFA's second annual bike ride. The inaugural ride in 2011 was a lot of fun and funds raised supported our cause so we decided to do it again!

Energized and exhausted was how the riders described how they felt when they arrived in Washington, DC. Riders said it was an exhilarating experience to remember!

Andy Matthews participated in 2011. "I loved the chance to, at times, race my Blood Brothers and enjoyed the camaraderie we developed."

Riding 155 miles in a weekend is not something Kimberly Haugstad, Director of HFA had ever done before. "Last year, twelve riders bicycled from West Virginia to Washington, DC in three days. It was inspiring!"

Stronger bodies bleed less. Riding 155 miles in a weekend may be a stretch for some, but regular exercise keeps our joints and muscles healthy.

FOR

Gears for Good makes an important statement about what we can do as people with bleeding disorders. HFA encourages every member of our bleeding disorders family to exercise.

One way to support the ride is to participate! We have 35 rider spots this year!

One other way to support the ride is to donate personally or ask others to donate. Funds raised exclusively support the programs HFA offers to the bleeding disorders community.

Do support this cause if you can! Learn more:
www.gearsforgood.com



Photos from the 2011 Gears for Good Ride

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.

Talk with your healthcare provider about your current ABR and how you can set goals to help reduce or eliminate it.

**TAKE
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Wendy Owens, Project Manager for the CHOICE Project.



Prior to joining HFA, Wendy was the Executive Coordinator for *New England Coalition for Affordable Prescription Drugs* (NECAPD). Her initial experience with the hemophilia community was as the Advocacy Coordinator for the New England Hemophilia Association. Wendy began her career in the private sector starting and running several companies, including an advance composite materials engineering firm with technology patented around the world. For the past 11 years, Wendy has been an advisor to US Secretary of Commerce and US Trade Representative on Information and Communications Technologies, Services, and Electronic Commerce as a member of an Industry Trade Advisory Committee (ITAC-8). Wendy lives in the greater Seattle area with her family.

Allie Boutin, Program Coordinator



Allie was born in Mexico and moved to the Boston area in 1988 to earn her college degree. She received her B.S. in Computer Science from Merrimack College in Andover, Massachusetts. Allie has worked in high-tech and marketing industries for 18 years and has experience managing teams and projects of various sizes and complexities. Allie lives in MA with her husband Jim and their

two sons, all who are very involved in local chapter activities and events. Allie is excited to work for HFA as a program coordinator, where she will be able to apply her experience in an area that is near and dear to her heart – hemophilia.

Janel Johnson Momanyi, Program Coordinator



Janel returns to HFA after being on hiatus since 2009. Over the past three years, she has worked as a volunteer coordinator at The American Red Cross and as a Health Educator at Johns Hopkins University. Janel enjoys connecting with people, and she has a special talent of encouraging others. Janel earned a Bachelor's degree in Psychology from Coppin State University in Baltimore, MD and Master's degree in Public Administration from Baruch College in New

York, NY. She is excited to be working with the hemophilia community again. ■■



Continued from page 1

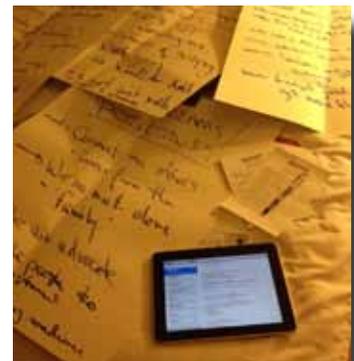
that our conversations had spawned. Those boards were then turned into our script. We had our message.

The effectiveness of a message depends upon not only the substance of that message, but how it is delivered, or, in other words, the vehicle. So I developed a structure for the piece that would (hopefully) engage an audience quickly and only ask for two minutes of their time. We injected (punfully intended) a few moments of levity, and in the end, we had a quick, young, and entertaining advocacy video. And since social networking was the theme for this year's Teen Connection group, we came up with a strategy for blasting our content across the various platforms. With our strategy in place, we quickly accrued hundreds of views and saw a tremendous amount of shares from the online bleeding disorder community. Our teens gave an earnest effort, and, in turn, have a unique advocacy product, specific to their voices, of which they can be proud.

It can be easy to think of advocacy as daunting: something that takes tremendous effort and is best done by older, more experienced individuals. Nothing could be further from the truth. Advocacy can be as simple as having a frank conversation with a classmate before gym class, or encouraging a disgruntled coworker with joint pain to try jogging on an elliptical as a means to fitness. I do not think most people realize how great an impact they have on others during life's more understated moments, and as influential as I would like to think our video is, perhaps the most valuable takeaway from the experience was witnessing our teens realize their power. Each individual's honesty and enthusiasm inspired the next. They found commonalities in their struggles and life experiences. They empowered one another. Without realizing it, their advocacy began before the video was released, and hopefully the experience will encourage it for a long time to come.

You can watch the teen video by going to: voices.hemophiliafed.org

Patrick is a severe hemophiliac as well as a professional actor, writer, and producer living in Brooklyn, NY. He is currently developing a comedic web series about a hemophiliac called STOP THE BLEEDING!, which will be released this Fall. ■■



**GET HEALTHY, GIVE SUPPORT,
GET IN GEAR!**

By: Janet Chupka

In June, we officially launched our Get in Gear fitness app!

The Get in Gear mobile application is designed to encourage the bleeding disorders community and community at large to improve overall health wellness by tracking their fitness efforts.

Get in Gear is a free mobile app, available for download and use on both Apple and Android mobile devices. This app allows the user to raise awareness for people in the bleeding disorders community: those affected by Hemophilia or von Willebrand disease. You do this by simply choosing from any of the seven activity categories, and tracking your time and/or distance performing these activities. It is that simple! There is something for everyone on this app and all levels of fitness are included. You can choose from activities such as:



Running, jogging, walking, hiking



Swimming, water aerobics, water activity



Bicycling, spinning



Weight training, strength training, resistance training



Cardiovascular activities such as: aerobics & dancing, Zumba - a Latin inspired combination of dance and aerobics and even motion controlled fitness video games-such as Wii Fit & Xbox Kinect



Martial arts, karate, Taekwondo, Tai Chi, yoga, and Pilates - a physical fitness system that builds strength, endurance and flexibility by focusing on concentration, control, breathing and the flow of movements



Organized, team and other sports: baseball, basketball, soccer, golf, bowling

This list is not meant to be all-inclusive, but rather a guide to see how your own fitness activities can fit into one of these categories. The activities listed, in general, are safe activities for those with a bleeding disorder.*

The app even allows you to listen to your own music and playlists from your device while tracking your exercise.

It is a win-win app for you and the community of people you are helping. You get healthy and physically fit and money and awareness is raised for people with a bleeding disorder.

Get started today. Visit www.getingearapp.com for more information or visit the iTunes or Google Play to download the app.

Get healthy, Give support, Get in Gear!

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

"I'm a 46 year old male, 195 lbs, smoker. I love the Get in Gear app because it has motivated me to exercise after many years of being out of shape and having high cholesterol. Thanks to your app, I have been exercising consistently for 2 months."

-Ben



***“The pen is mightier than the sword,
provided the words written
are persuasive.”***

Many of the tips are based on the research of the Herndon Alliance (herndonalliance.org). For more tips and talking points tailored to our community, visit HFA's page of messaging: hemophiliafed.org/what-we-do/advocacy/advocacy-tools/

MIGHTY WORDS

By Jonathan VanderBrug

“The pen is mightier than the sword.” Is this adage true? In advocacy, yes, as long as we add a caveat: “The pen is mightier than the sword, provided the words written are persuasive.” No matter which advocacy actions you take – writing a letter to the editor, talking with a neighbor about the importance of a hemophilia assistance program, or meeting with a public official to express support for a bill – success often hinges on word choice. People can react differently to the same statement based on how it's phrased.

In the political frenzy leading up to this November's elections, a myriad of interests will bombard the public with TV, radio, print, and online messages. To win others to your cause in this competitive environment, you must choose our words carefully. Here are seven tips on how to make your case convincingly

USE WORDS THAT WORK

Words to Use:

- Prevention
- Individual
- Responsibility
- Fairness
- Quality, affordable care
- Peace of mind, giving security
- Smart investments, invest in the future
- Competition, accountability
- American solutions
- Choice, control

Words to Avoid:

- Universal
- Regulated
- Required, mandated
- Government health care
- Inexpensive
- Free
- Avoid complex terms such as prophylaxis, recombinant, or expenditures

The views of men can only be known, or guessed at, by their words or actions.

- George Washington

1. Who is it? – While certain words and phrases (such as “fairness,” “choice,” “peace of mind,” “prevention,” and “investment in the future”) have positive connotations across the demographic spectrum, you cannot rely on the same message to persuade everyone. Instead, know your audience. Listen first, understand their experiences and concerns, and then tailor your message accordingly.

2. Bleeding Disorders 101 – Don’t assume the other person knows what a bleeding disorder is. Begin the conversation with a few sentences that describe the basics. For example, you can simply say, “My body has a shortage of a protein – called factor – that is necessary for bleeding to stop. As a result, I can bleed a lot and for a long time when I’m injured or even for no apparent reason at all.”

3. Common speak – Avoid jargon when explaining bleeding disorders and making your case. Many of the words our community uses everyday seem like a foreign language to people who have never heard of Hemophilia or von Willebrand Disease. To them, “prophylaxis” sounds like an alien planet on Star Trek. Better instead to say “use regularly” or “preventative.” Medical accuracy is important, of course, but teaching others about bleeding disorders often requires us to dispense with technicalities, at least at first. For example, most people without a bleeding disorder cannot define “infusion, but they know what “injection” means; so, use that word instead. Clarity opens the door to convincing others; confusion shuts it.

4. Heart, not head – Emotion, not logic, moves people to support a cause. Therefore, seek to win the person and not the argument. Without a doubt, the best way to accomplish this is by sharing your personal health care story and making it the centerpiece of your case. Your own experiences are the most convincing illustrations you can give in support of your cause because they are genuinely yours. Almost anyone can cite facts and figures, but you alone own your story. Statistics come and go; but the relevance and uniqueness of your story make it memorable to those who hear it.

5. Always keep the goal in mind – Memorable does not necessarily mean convincing, and the goal in advocacy is not just to tell your story for the story’s sake. The goal is to win or protect policies vital to our community. Therefore, always connect your health care story to the policies at hand. Explain how they directly affect you and your family and then end with a clear, specific call for support. “Because my family cannot afford the \$250,000 annual cost of John’s factor, I urge you to vote yes on Senate Bill 233, which will save the State Hemophilia Assistance Program.”

6. “Brevity is the soul of wit” – The first adage we discussed might need a caveat, but this one does not. In an age of tweets, attention spans are short, and the person you’re trying to convince – especially a legislator – probably has a busy schedule. Brief is better. Boil down your case, including your story, to 2-3 minutes at the most. This certainly isn’t easy, but it is possible with time and effort. Put your personal health care story down on paper (a good exercise even outside advocacy), list all the reasons to support your cause, and then identify and combine the 5-6 points you deem most important and persuasive.

7. Practice, practice, practice – Read and repeat what you wrote. Try it out on family members and friends and get their feedback. The more you practice, the more prepared you will be when a neighborly conversation across the fence turns to politics or you run into your state senator at a local parade.

Keeping these seven tips in mind, you’ll be a confident, persuasive advocate. You will be ready to say the right words, at the right time, to the right person. In advocacy, that is more than powerful – “That’s Mighty.”

was any way we could help. One friend lives in Canada, and I myself and my other friend live here in the U.S. After getting some more background information from the friend in India, the three of us sprang into action immediately, making phone calls and sending emails to our contacts in the Canadian and United States hemophilia communities.

By the next day, we had not received much response to our calls for help. We thought, "What can we do to help this guy? No one should have to suffer like he is, no matter where they live!"

I told my friends that I had an idea. I messaged another hemophiliac friend of mine on Facebook, who happens to also live in India. He immediately responded, and I put him in touch with the person in India who needed the help. They spoke with one another on the phone immediately.

As it turned out, the friend in need of assistance had some great treatment resources and assistance that were possibly available to him that either he and his family didn't know about or hadn't taken advantage of. My Facebook friend from India worked with the gentleman's father to get some treatment in place. He is in a much better place now and doing much better.

It just goes to show you how powerful the Internet and social media can be. After just 2 or 3 140-character messages, 4 guys from 3 different countries, all hemophiliacs, were able to help out a fellow blood brother and hopefully get him on the road to recovery and wellness!

A Word of Caution

When using social media, be cautious and selective of the information shared online. Anything posted online should be considered public information, so it is important to be aware of that. Privacy settings on Face-

book should be updated to only allow your friends to view posted information. Screen friend requests carefully. Not everyone you may get a request from may have your best interests in mind.

A lot of advice and information is posted on social media regarding treatment, doctors, etc. Many in the bleeding disorders community share experiences. That information and advice should not take the place of your doctor. Use what you learn online as a guide, but always check with your doctor! ■■

Ryan is 43 years old and has moderate-severe hemophilia A. He became a Licensed Practical Nurse after working in the corporate world for 20 years. Ryan retired from nursing in 2010 due to health issues related to hemophilia. He is very active in the hemophilia community through social media and locally and nationally through various events in the bleeding disorders community.

In 2011, his Hemo Hijinks blog attracted nearly 10,000 readers and he also currently authors Infuzed for HemAware, a national bleeding disorders magazine. Ryan is also a contributor to the website "Infuzr"



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“NO MATTER WHERE YOU GET YOUR CARE; YOUR VOICE SHOULD BE HEARD.”

By: Wendy Owens

In life, there are so many choices. Leave it to HFA to come up with a new one. This one involves the entire bleeding disorders community and deals with the quality of care it receives. Through a cooperative agreement with the Centers for Disease Control and Prevention (CDC), HFA is running the CHOICE (Community Having Opportunity to Influence Care Equity) Project. The focus of the CHOICE Project is to collect information regarding health experiences of people who have a doctor-diagnosed bleeding disorder and do not receive care at a federally-funded hemophilia treatment center (HTC).

Since 1998, the CDC has collected information on the health status of people with bleeding disorders who receive care at HTCs. Much has been learned from this information. However, a study from the mid-1990s showed that a third of people with bleeding disorders received care outside of the HTC network. Little is known about the health experiences of people who do not receive care at HTCs. So HFA and the CDC have decided to learn more through the CHOICE Project.



more information gathered. With more information, there is a better chance of learning what can be done to improve the health of people with bleeding disorders. This includes possibly identifying medical and social issues that require further study.

HFA member organizations are a key component to the CHOICE Project's success. HFA has teamed up with six of its member organizations in Texas, Arizona, New Mexico, and Louisiana to help it identify people to take the CHOICE survey. The survey itself is available in English and Spanish and takes roughly 20 minutes to complete. People can take the survey online or in paper format.

The CHOICE survey asks questions about diagnosis, bleeding history, treatment, insurance coverage, quality of life, and quality of care. The information collected from the survey will be used to understand the health of people with bleeding disorders who do not receive care at HTCs. It will also be used to identify issues that need further understanding, such as where care is being obtained, what complications are being experienced, and what treatment is being used.

Personal privacy of the survey-takers is of the utmost importance to HFA. HFA will collect all survey information. Personal information will not leave HFA's secure, password-protected database. HFA will compile paper-based surveys into this database and will shred and recycle

the paper documents. HFA will share de-identified data with the CDC. Data shared with the CDC will include a unique identifier code but will not contain personal identifiers, such as name or address. Information from this project may be published. However, no information will be published that could identify a survey-taker.

If you have a bleeding disorder, your voice should be heard – no matter where you get your care. You matter, and it is your choice whether you want to participate in the CHOICE Project. To find out how to take part in the CHOICE project, call 800-230-9797 or go to choice.hemophiliafed.org. ■■

“A study from the mid-1990's showed that a third of people with bleeding disorders received care outside of the HTC network.”

Together, HFA and the CDC hope what will be learned will help assure equity in the care received by all members of the bleeding disorders community. The more participants enrolled in this project, the

CHOICE PROJECT
Community Having Opportunity to Influence Care Equity

A photograph of a family smiling together. A man is carrying a young child on his shoulders, and a woman is standing next to him, also smiling. They are outdoors in a natural setting.

WHAT IS THE CHOICE PROJECT?
CHOICE is a new project driven by the Hemophilia Federation of America (HFA) and supported by the Centers for Disease Control and Prevention (CDC). CHOICE collects information through an online or paper-based survey. This survey collects information regarding health experiences of people who have a doctor-diagnosed bleeding disorder and do not get care at a federally funded hemophilia treatment center (HTC). De-identified information will be shared with the CDC to help understand the health status of people with bleeding disorders who do not get care at HTCs.

The logo for the Hemophilia Federation of America (HFA), featuring a stylized red and blue 'HFA' with a small graphic of people below it.

ACCESS TO CARE HIGH ON HFA'S ADVOCACY AGENDA

By Eboni Morris

During the last few years, the health care reform debate has brought the condition of America's health care system to the forefront. Politicians, doctors, hospital staff, and insurers began to publicly re-examine the health care provided to Americans, and everyday citizens began heavy advocacy for better care.

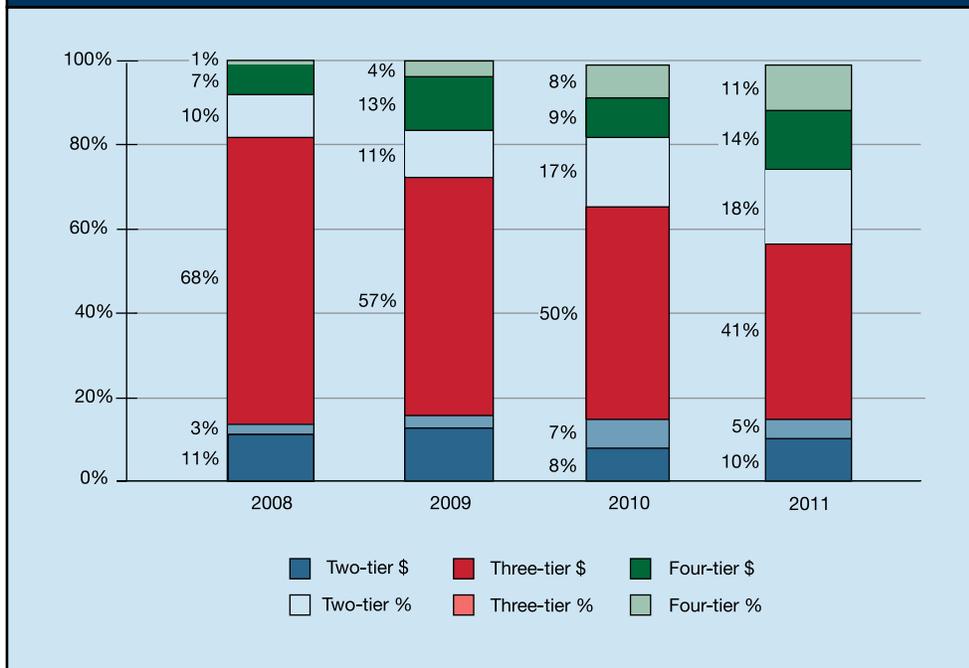
The Affordable Care Act became law and the Supreme Court has upheld its constitutionality, but we must keep the pressure on our state and national leaders to continue to develop solutions to the inadequacies of the system. The bleeding disorder community experiences all too often the effects of a system that most all have agreed is fragmented, expensive, and does not ensure all Americans with access to the care they deserve and desperately need.

In general, access to care refers to the ability to obtain health care services. You usually safeguard this access by having some type of health insurance. Even with insurance, for the bleeding disorders community, access to care can come with many barriers including:

- Cost- especially the cost of medication(s)
- Access to physicians (specialists) and qualified specialty pharmacy
- Insurance company restrictions: prior authorization, step therapy, and other utilization management techniques
- Excessive cost sharing (coinsurance)
- Claim denials
- Pre-existing condition exclusions

Research has shown that these barriers and many others undermine access to care and have negative effects on health outcomes. Nonetheless, this has not deterred insurance companies, or state governments, through programs like Medicaid, from applying these tactics to patients. Even with the best insurance policy, it is almost impossible to avoid having high costs associated with care.

Figure 1. Prescription Cost-Sharing Tiers 2008-2011



This chart shows employers increase use of four tier plans and co-insurance (%)

Access can also be limited by other factors, including geography – where we live vs. the location of the nearest hospital, doctor's office, or Hemophilia Treatment Center (HTC), as-well-as which pharmacies operate in a particular area. Access can also be affected by our own ability to make informed decisions about our care or communicate effectively with our health care providers.

Currently, there are some big changes happening in the health care system that will affect your access. We will briefly discuss two: excessive cost sharing in commercial health insurance plans, and the movement of state Medicaid programs to a managed care system.

Medicaid

Medicaid is a national program for low-income individuals, and due to the failing economy, more Americans find themselves dependent on this program. According to the Kaiser Family Foundation, Medicaid covers approximately 60 million Americans. According to a recent survey they conducted, in FY 2012, 50 states implemented at least one new policy to control Medicaid costs. Most states have used managed care insurance plans as a tool for cost savings. Managed care plans receive a set dollar payment (capitated payment) that the

state pays to the company regardless of how much your care costs. Approximately two out of three people on Medicaid are currently enrolled in a managed care plan.

After this description, you may be able tell that using this set payment formula for covering services, treatments, and medications for a person with a bleeding disorder is extremely problematic. However, states are moving fast to find ways to cover all services, including clotting factor, under a capitated or managed care system.

This is troublesome in numerous ways:

- Clotting factor is extremely expensive and usage can be unpredictable will these plans be able to cover its costs with a set payment regardless of usage?
- How will states set capitated rates for high cost patients that encourages companies and providers to participate in the network?
- How are states monitoring the managed care companies they use to cover the chronically ill in order to guarantee patient access is maintained?

Excessive cost sharing

Many health insurance companies are moving away from the system of a patient paying a

co-payment or fixed dollar amount for a specific drug to a co-insurance structure, where the individual pays a percentage of the cost of a drug. These two systems are very different. With a co-payment, a patient is covered for the drug and pays their set dollar amount for access to that drug. With a co-insurance, you are paying toward the actual cost of the drug. For example, when you have a plan with a specialty tier, you may be paying anywhere from 20% to 50% of the cost of your prescription, essentially co-insuring with the insurance company instead of the company directly insuring your needs. People who are taking highly expensive drugs, including clotting factor, are potentially exposed to this practice.

Typically drugs are classified in 3 tiers: (1) generic; (2) preferred brand name; (3) brand name. Now, more often we see insurance plans with a

fourth tier (4) brand name and specialty drugs. Clotting factor is considered a biologic medication (there is no generic alternative) and is almost always relegated to the specialty tier.

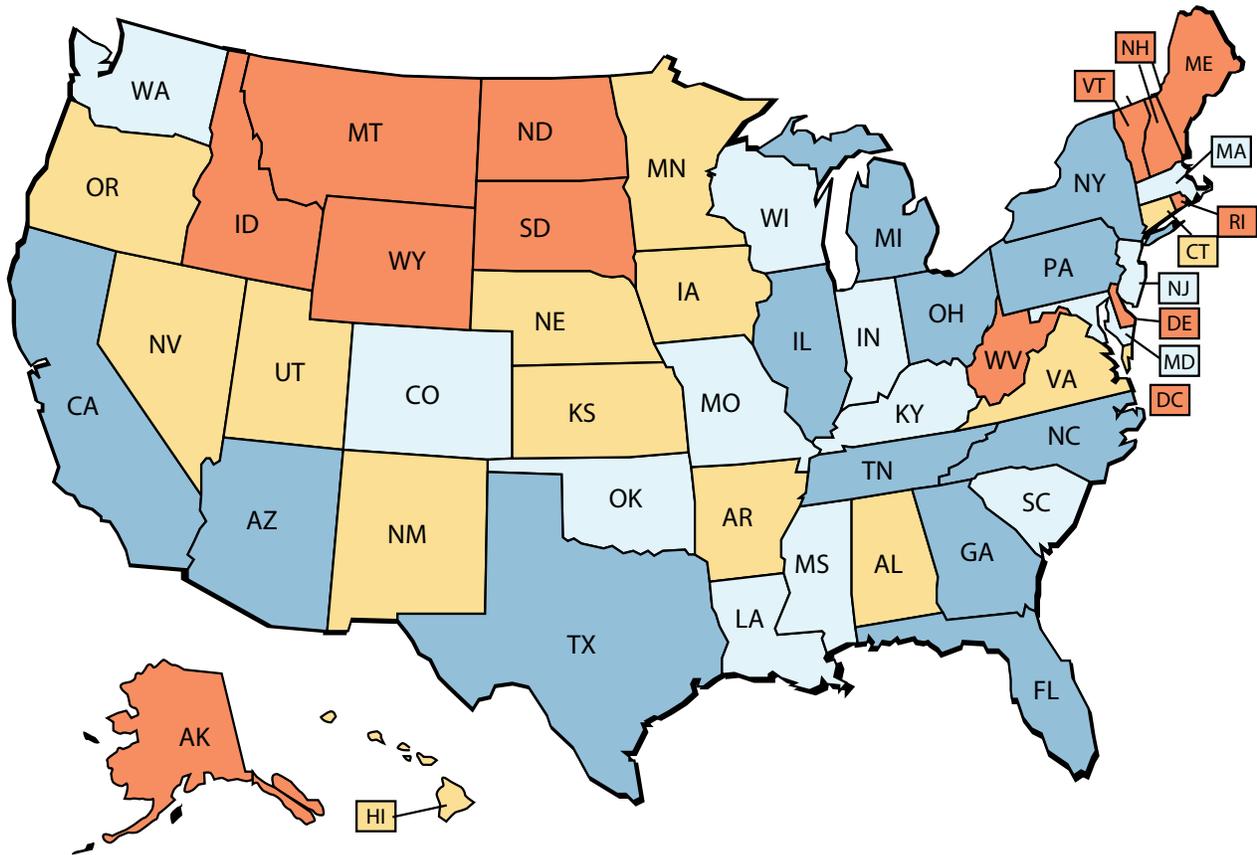
This four tier system puts an increased burden on patients to pay out of pocket for the cost of their medication, many times in addition to the out-of-pocket costs for doctor and hospital visits. It is important to note that the Affordable Care Act does not address this issue for commercial plans, and there are limited regulations for preventing increased cost sharing, co-insurance and the development of specialty tiers in plans that will operate in the health insurance exchange starting in 2014.

Many states have active advocacy coalitions around this issue. Several state hemophilia foundations are involved in these coalitions.

In the last two years, approximately 19 states have been involved in some activity regarding this issue, either through introducing legislation or establishing state-funded studies to evaluate the problem. HFA has also been involved, as always supporting state efforts, and we have recently joined a national effort called the Coalition for Accessible Treatments to advocate against this process.

Stay involved and updated about the issues described in the article by:

- Receiving updates from HFA or your local hemophilia foundation
- Research state organizations that may be working on this issue
- Join in the advocacy by participating in a coalition or sharing your story with HFA!



Source: Kaiser Family Foundation



BLOOD BROTHERS IN ACTION

By Mark Antell and Paul Brayshaw

People with Bleeding Disorders and HCV is a non-funded and informal volunteer group of patients and supporters affected by the HCV crisis among people with bleeding disorders. We organize and lobby for development and availability of new and far better HCV therapies for our community.

We have had some successes including:

- An increased sense of urgency about the HCV epidemic among the largest bleeding disorder organizations (HFA, COTT, NHF).
- A Citizen Petition to FDA that led to the following:
 1. An FDA policy statement recognizing that existing medical solutions for our population are mediocre
 2. A commitment from the FDA that they will encourage drug firms to include us in clinical trials and expanded access protocols
 3. Agreement that biopsies should not be required for our participation in early access protocols, and
- A MASAC position statement withholding positive review of certain therapies because they have not yet been assessed in people with bleeding disorders.

Until very recently, we had excellent hopes that far better therapy for HCV would be available in the near future. Reports through early spring indicated that one drug, GS7977, owned by Gilead Pharmaceutical, had shown some success in monotherapy. More importantly, in a couple of small trials, GS7977 combined with a Bristol Myers Squibb drug (BMS 790052, also known as Daclatasvir) resulted in 91% to 100% cure rates with short duration, low side-effect therapy.

We were, therefore, enormously disappointed when we read a NY Times article* stating that

Gilead has broken the collaborative effort in order to pursue in-house drug combinations. The decision appears to be entirely business-driven. Gilead does not seem to want to 'split the swag' for a cure.

On the positive side, the marketplace is not waiting for Gilead. BMS is experimenting with a combination of Daclatasvir plus their in-house equivalent to GS 7977. Furthermore, the search for a cure remains an active pursuit by several pharmaceutical firms.

Nevertheless, the barrier is disappointing. We have talked a bit to Gilead, but they are not responding seriously. We have talked to FDA, but they do not see that they can force Gilead to change its policy. Some HCV advocates are upset about this. Others are silent, remaining focused on testing and encouraging patients to try approved (albeit mediocre) drugs. We are

now consulting with our friends and supporters about an appropriate response from the bleeding disorder community. Should we try to affect the Gilead decision? Would it help to obtain a consensus position among all the major bleeding disorder organizations?

[*www.nytimes.com/2012/04/20/health/drug-collaboration-lags-on-hepatitis-treatment.html](http://www.nytimes.com/2012/04/20/health/drug-collaboration-lags-on-hepatitis-treatment.html)

For more information on People with Bleeding Disorders and HCV, visit: <http://sites.google.com/site/accesshcvtherapy/start> and talk with other men with bleeding disorders on the Blood Brotherhood Online Private Group: <http://www.hemophiliafed.net/>

Blood Brothers Mark Antell and Paul Brayshaw are taking advocacy for improvements to Hepatitis C treatments into their own hands with the group People with Bleeding Disorders and HCV.

In Memoriam

On May 29, 2012, Terry A. Lamb, passed away in Lynchburg, VA of a cerebral hemorrhage. A son, Austin Tyler Collins-Smith; sister-in-law, Kitty Lamb both of Lynchburg; and numerous relatives along with many, many friends survive Terry. Terry simply never met a stranger.

Terry was an HFA Board member and a person with severe hemophilia. He was a true gentleman filled with positive energy, a cowboy with that sweet, southern, charm and charisma who attracted friends like a magnet. A fitness enthusiast, Terry volunteered with HFA's Fit-Factor and actively role modeled healthy living and exercise. Terry, you are remembered with love.

"They don't make them like you anymore."





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LEND A HELPING HAND

By Janel Johnson Momanyi

Thankfulness, Gratefulness and Appreciation are common terms expressed by recipients of Helping Hands funds.

The outpouring of emotions is overwhelming at times because persons are so heartened that such a program exists.

Due to the current financial crisis, there have been a record number of applicants this year. The Helping Hands program is on track to receive well over 300 applications by the end of December 2012.



“Thank you for helping us with the bill. It has lifted a large burden off of our shoulders. The past three years have been a financial mess and I simply don’t have proper words to express our gratitude. We are so fortunate to have people like yourselves to assist us in desperate times.”

-Helping Hands Recipient

Many American families are struggling these days, but families affected by hemophilia have the added stressors of unexpected bleeds, hospital visits, expensive medical bills, missed time from work and sometimes a lack of health insurance.

Not being able to pay the electricity bill means a family affected by hemophilia not only has to find a place to cool off in the summer months, but they also have to find a place to store their life-saving medication. Not being able to afford a car payment means a family affected by hemophilia may not be able to take a loved one to a treatment facility during an unexpected bleed.

To say the least, the additional stressors of financial hardship can be challenging for families affected by hemophilia. And unfortunately not every Helping Hands application can be approved, because the funds are limited. Every effort, however, is made to assist as many families as possible.

In an ideal world, a program like Helping Hands would not need to exist, but many persons are so glad it does:

We thank our many Helping Hands supporters. In particular, we recognize Grifols, Novo Nordisk and Walgreens for their key support of this program. To donate to this program visit www.hemophiliafed.org ■■



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We are Biogen Idec Hemophilia, and we're exploring ways to make clotting factors last longer.

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- A team that includes leaders from the community, such as Dr Glenn Pierce, former President of the National Hemophilia Foundation, and 20-year veteran of biotechnology development
- 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



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