I get some pretty stunned responses when I tell family and friends that I am grateful for hemophilia. They can’t understand how it is possible that I can be thankful that my 9-year-old son, Thomas, has unexpected, ill-timed, and painful bleeds. How could anyone find good in dealing with a nonsensical insurance company? Obviously, I could do without the physical and mental anguish a chronic condition entails, but without hemophilia in my family’s life, we’d be much less blessed. In a season of thankfulness, I’m thankful for hemophilia and the bleeding disorders community it has brought me through the Hemophilia Federation of America.

I clearly remember when my husband and I heard the diagnosis that our newborn son had severe hemophilia A. A few days later, as the shock was wearing off and I cradled Thomas in my arms, I thought to myself, “This will either tear us apart or build us up. The choice is mine.” Our family immediately reached out to both the local and national bleeding disorders community for advice and support. Those contacts became even more vital a few short months later, when Thomas developed an inhibitor.

Because we attended a local chapter event when Thomas was only 6 weeks old, we were able to see children growing and thriving with hemophilia. Experienced parents were there to share their stories, offer advice, and to say, “I understand what you are feeling right now.” One moment stands out — the moment I knew could really handle this: I stood watching a gaggle of 5-6 year old boys run around, chasing each other, laughing and giggling during a fierce game of tag, as their parents watched from a distance—chatting about everything and nothing at all. I won’t lie — I tightened the straps on the Baby Bjorn and tucked Thomas a little closer to me, knowing that one day I’d have to loosen the reins and let him live.
grate•ful  Adjective \ 'grat-fel\ 
thankful, appreciative; indebted, obliged, obligated, in someone's debt, beholden.

Dear HFA Family and Friends,

As 2012 comes to a close, we are pleased to reach out to our community with a message of thankfulness for your ongoing support. We hope that the coming winter months are good to you and your families, and that 2013 is filled with blessings.

At HFA, we are grateful for the support of our local member organizations around the nation. Community members across the country were heard at their local organizations as they asked about HFA, and we welcomed our 36th organizational member this year.

We were also saddened by the loss of a number of individuals connected to the bleeding disorders community in 2012. At times like these, we come together, united by blood, to share our memories and our tears. For every one of those instances, it is the sharing of grief as a community that gives us strength. For that, we are thankful.

As we look to next year, we see a horizon that gives us much to reflect upon: new treatments available, the consideration of genotyping, the potential threats to access and choice, and more.

We are thankful and grateful to be working together as a community of strong, passionate, and committed advocates on these topics. Please stay tuned, stay informed, and stay involved—we are here to support!

Warm regards,

Matthew T. Compton
Board President

Kimberly Haugstad, MBA
Executive Director

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"As we express our gratitude, we must never forget that the highest appreciation is not to utter words, but to live by them."
John Fitzgerald Kennedy
Being a female with a bleeding disorder is not easy. Our symptoms range from being mildly inconvenient to having life-threatening bleeds. Menorrhagia (heavy periods) is the most common symptom of a bleeding disorder, and women with untreated or under-treated disorders, may be at greater risk for serious complications. Unfortunately, thousands of girls and women do not receive a proper diagnosis or the appropriate medical care.

Having a bleeding disorder does not just affect the patient, but often has a direct impact on relationships. Women have reported the need to schedule intimacy as well as other life activities around their menstrual cycles. Issues of partner emotional and physical abuse have been reported due to symptoms, side effects, and cost-of-care.

That’s the bad news. The GOOD news is that while having a bleeding disorder may or may not be central to a woman’s daily life, all women with such disorders have the right to live productive, meaningful and fulfilling lives -- and they are doing it!

Women have the ultimate responsibility for their self-management decisions and the resulting consequences. This includes the decision to be informed about their treatment options and the decision about how to cope. Active coping strategies include making the most out of your condition, looking for alternative ways to achieve goals, being an active participant in your health, and not allowing your condition to define who you are.

On the other hand, some women choose to passively cope with their disorder. Passive coping strategies include doing nothing, denying symptoms, ignoring treatment options, and allowing the disorder to become your primary identity. Such strategies may lead to feelings of anxiety, depression, fatigue, and social withdrawal.

Active coping takes effort. It requires re-evaluating perceptions about yourself and others and is much easier when a woman has the necessary emotional support from family and friends. However, it is ultimately a choice made by each individual. Thankfully, our community is full of women who are examples of active coping.

Empowering Community Voices

Laura Kinison-Curtin was diagnosed with vWD while her children were young. Prior to the diagnosis, Laura did not understand why she was often too tired to take the children to the playground. Receiving the diagnosis along with proper treatment was “good news,” because it provided an explanation for being fatigued and took away her guilt. “It made me feel like a better mother because, I had an explanation for being tired.”

Laura is now empowered to take an active role and encourages others to realize that having a bleeding disorder “is livable.” She stresses the importance of making sure women are getting the proper treatment and urges others to keep things in perspective. “In every aspect of life, there are good times and bad times, but even with a bleeding disorder, we can lead a pretty normal life. “vWD is part of my life, but it doesn’t define who I am.”

Shelly Mattson, believes that having a bleeding disorder (vWD), has helped her in the development of positive values and life-long skills. As a child, she attended summer camps for children with bleeding disorders. The counselors became her heroes and instilled in her a desire to help others. As a result of this, Shelly took on...
Eating Smart During the Holidays
By Faith Hunter and Janet Chupka

The holidays are upon us, and staying healthy during this season can be challenging. While this is true for the general population, it is especially important for individuals with hemophilia or other bleeding disorders. We understand the importance that activity and a nutritious diet play in maintaining a healthy weight, and decreasing the number of bleeding episodes and amount of factor needed to prevent or control a bleed.

For many of us food represents comfort, and the various smells of the holidays trigger numerous, joyous memories of childhood. However, studies have shown that a few extra cookies or a slice a pie each day during the holiday season can easily add 4-5 unwanted pounds in only a few short weeks.

How can you enjoy the multitude of desserts at the office holiday party and still fit into those jeans in January? Here a few tips to help you stay healthy and not overeat during the holidays.

1. Eat Small Amounts
of those comfort foods you love. Don't deprive yourself. Enjoy a small piece of pie or one cookie, but not both. Select one item that looks yummy and that you know you will enjoy. Fill your plate with healthy vegetables, fruits, whole grain crackers, cheese and lean meats. Also, split a holiday entrée with a friend or relative when dining out. Portion control is key.

2. Don’t Hang Around
the table or buffet, instead mingle with friends and family. It can be hard to resist the delicious food that is calling your name. Choose your items to eat, and then move to a different part of the room if you can. In most cases, you will think twice before walking back to the table.

3. Eat Light and Fluffy Desserts
Select the angel food or sponge cake with fruit, instead of pound cake. Eat mousse (which is whipped with air) instead of chocolate pudding and egg custard. Keep it light and low in calories.

4. Drink Lots of Water
Mild dehydration can sometimes feel like hunger, so avoid this feeling and drink water. Water can also be used to slow down your eating by taking a sip or two between bites. Also, have a glass or two of water before you start drinking alcoholic beverages, and have one in between drinks to slow down your alcohol consumption as well. Don’t forget that cocktails add calories, so be mindful.

Visit us at http://fitfactor.hemophiliafed.org/ and www.getingeareapp.com
*As with any new activity, or if you are having joint or bleeding problems already, make sure you check with your physician or physical therapist to be sure you are ready to get started.
Don’t Skip Meals
Breakfast is still very important. Don’t save those calories for a big holiday meal. Not only can skipping meals make you feel tired and crabby, but it can also make you overeat when you finally have a meal. For breakfast, have a bowl of cereal or oatmeal, eat raisins and nuts for a snack, and enjoy a light salad for lunch.

Stay Physically Active
Have fun doing holiday-inspired activities. Enjoy, walking around the mall, going to view the holiday lights in your neighborhood, gathering pine cones, playing in the snow, or building a snowman.

Many people will be making resolutions to become physically active in the new year, and FitFactor is here to help you jump start a healthy routine and share tips on how to maintain a healthy lifestyle throughout the year. Here are a few suggestions.

1. Be realistic. Select a safe, attainable goal with a realistic time frame. For example, if your goal is to eat healthier, begin by eliminating one unhealthy food from your diet at a time, not ALL unhealthy foods at once. Do what you like to do consistently. If you want to swim, walk, try boot camp or cycling, and start off doing it 1-2 times a week, then slowly increase your time or distance. Just don’t force yourself into doing something you don’t like.

2. Wear a pedometer. Research has shown that wearing a pedometer encourages people to walk about an extra mile each day, lose weight, and lower their blood pressure. Aim for 10 minutes to start, then amp it up to 30 minutes of brisk walking and a total of 10,000 steps per day. Start slowly. Have a smart phone? Download HFA’s Get in Gear app and log your miles while listening to your favorite music. The app keeps track of your workouts and progress and even rewards you for your efforts!

3. Work out with a friend. Working out alone can be difficult, so find a partner in health. This person will help to motivate you to stay active, boost your confidence, challenge your weaknesses, and make fitness fun. You can do the same for them. Your workout partner can even be your spouse or your child.

The benefits of exercise far outweigh the risks of inactivity. For those in the bleeding disorders community, it means healthier muscles and joints and fewer bleeds and treatments of factor. What activities are you going to choose to get you on your feet, on your way to better health, and a better life? Make 2013 your year!

The Henderson Family
The Henderson Family from Nebraska are the final winners of the 3rd FitFactor Super Grain quarterly raffle drawing and will receive a gift prize package from Untied Natural Foods, Inc. Valued at over $250!

Lane & Paisley Henderson are pictured holding their mother Sarah’s recipe for Apple Cinnamon Quinoa Cereal. They say it tastes like warm apple pie, for breakfast!
A Father’s Commitment To Family

By Jane Cavanaugh-Smith

As 2012 winds down, we look back upon the past year and find much for which we are thankful. We’d like to share some of that with you.

We are grateful for our collaboration with our member organizations for helping to sponsor 26 Dads in Action local events, attended by over 300 adults and 100 children. Thank you to our partners who are bringing Dads in Action to their local communities:

Virginia Hemophilia Foundation
Northern Ohio Hemophilia Foundation
Hemophilia Outreach of El Paso
Arizona Hemophilia Association
New York City Hemophilia Chapter
Tennessee Hemophilia and Bleeding Disorder Foundation
Hemophilia Foundation of Southern California
Hemophilia Foundation of Maryland
Connecticut Hemophilia Society
Florida Hemophilia Association
Hemophilia Foundation of Northern California
Louisiana Hemophilia Foundation
Hemophilia Foundation of Arkansas

“Our Dad’s come from many different states and varied backgrounds. They are older and younger. Some are quite gregarious, and others are more reserved. But, they have one very important thing in common—the commitment shown to their families and each other.”

Dads in Action is designed to be a program by Dads, for Dads. Our eight facilitators are fathers from the community who have gone through training and now graciously volunteer their time to travel and host local events. Our sincere thanks go to Lance Cleghorn, Doug Hartshough, Stanford Murry, Jim Boutin, Felix Garcia, Josh Hemann, Todd Pittman, and Chris Smith for their commitment to educating and building support amongst the dads in our community.

We are grateful for the professionals and community members who have developed and presented our webinar series. Topics were chosen based on feedback from community surveys and cover a variety of issues related to bleeding disorders and general parenting. Thank you to our webinar presenters for sharing your insights and expertise.

Most of all, we are thankful for the opportunity to meet and work with an amazing community of Dads.

2012 Webinar Series:

Pain Issues – Michelle L. Witkop, DNP, FNP-BC / Northern Regional Bleeding Disorder Center, Munson Medical Center

Anger Awareness – Mark J. Borowski, M.S.

Back to School – Cathy M. Tigg-Johnson, MSSA, LISW / UH Case Medical Center

Joint Health - Patricia Tobase, PT, DPT, OCS / USCF School of Medicine

Bullying – Diane Horbacz, Med

Inhibitors – Sonji Wilkes

They come from many different states and varied backgrounds. They are older and younger. Some are quite gregarious, and others are more reserved. But, they have one very important thing in common—the commitment shown to their families and each other, which is very inspiring. We asked a few Dads to share their thoughts on family, community and what makes them feel grateful.
What Family and Community Mean To Us:

“When my son was born with hemophilia almost 20 years ago, I had no idea that this diagnosis would lead me to meeting some of the best friends I will ever have. We were fortunate to connect with an active local chapter early on, and when they started doing Dads in Action programs, I really found my place. No offense to all of the wonderful moms, but it’s different when we get together with just the Dads. I have learned as much about living with hemophilia from these guys as I have from any medical professional. We have helped each other through tough times, we have celebrated triumphs and milestones, and we have had a lot of fun. A LOT of fun. I will be forever grateful to this community, and especially to the other Dads, for making me a better father and a better man.”

~ Chris, Massachusetts

“One of my scariest moments as a Dad, and also one of my most thankful, comes from the same experience. My son Owen, who has hemophilia, needed an emergency appendectomy, and watching his eyes close as the anesthesia was administered was one of the hardest things I have ever faced. I prayed that there was enough factor in him to keep my precious son with us. He made it through the surgery like a champ and, brimming with gratitude, I decided that regardless of time constraints, I would grow my commitment to the bleeding disorders community. Today, I am very involved in my chapter, where I co-chair the Dads in Action group. I am also proud to be on the Board of Directors of HFA. Like most fathers, I juggle the needs of all my busy children, my lovely wife, and the high demands of a job. But I’ve learned I can always make time for what is truly important in my family’s life. I am humbled and grateful to be part of a community of supporters who never tire of figuring out how to get it right.”

~ Ray, Ohio

“One of the biggest lessons I’ve learned as a father is that you never know what you or your family can do until you try. My wife and I have seven wonderful children, including two sons who have hemophilia. All but one of our kids came to us via adoption or the foster care system. I never imagined myself able to raise someone else’s children, but I’ve now helped to raise dozens. I never imagined having so many children living in the same home, but now I can’t imagine it any other way. And I certainly never imagined myself to be able to stick a needle into my child’s veins, but now we’re encouraging them to do it themselves. Because of our experiences with hemophilia, we were encouraged to foster other highly special needs children, and it has opened our eyes to a whole new world of parenting.”

~ Matt, Indiana
leadership roles in the bleeding disorders community and learned the art of public speaking and communication skills; both of which are utilized in her work today. Shelly adapted life to still do what she loves to do, and like Laura, not let her disorder define her. She focuses on the things she can do, while understanding and respecting her limitations. Shelly has also made life-long friends within the bleeding disorders community and is an advocate for support groups.

Kimberly Philo was diagnosed with hemophilia as a child. One of the greatest lessons she learned is that everyone deals with something. “It’s true — having a bleeding disorder can get in the way at times, but people have much greater challenges,” she said. As an athlete with knee problems due to bleeds, Kimberly has adapted her exercise regime by wearing a knee brace and became pro-active with her treatment. An avid bike rider, Kimberly now rides without a brace and recently completed a 7-day, 461-mile ride! She urges other women to “be smart about what they are doing” but to find an outlet they enjoy.

Laura Kinson-Curtin encourages women to reach out to others in the bleeding disorder community. She feels participation in face-to-face meetings “takes the mystery out of the bleeding and makes it easier to handle.” Shelly Mattson has also benefited from informal support groups and networking. She suggests other women seek someone with similar symptoms to serve as a mentor, even if the only communication is by phone or online. Kimberly Philo believes women need to find a positive outlet for their feelings, because when you do you forget about your disorder for a while.

Coping and Acceptance
Everyone has bad days. Days where we want to give up and give in to our health issues. When my bleeding disorder prolonged healing from mastectomies, I chose passive coping. I didn’t want to change my attitude—I wanted to feel sorry for myself. Unfortunately, such an attitude hurt my family and myself. I recently had major heart surgery and deliberately chose to focus on active coping. It has been difficult, and I have not done it perfectly, but it has made a tremendous difference in my healing, my view of myself, and in my relationships.

Are women who chose to actively cope with their disorder any “better” or “smarter” than those who do not? Absolutely not. Each one of us has had times of frustration and depression. It is natural and part of life. While none of us choose to have a bleeding disorder, we can still embrace life and all it has to offer. When we focus on the positive, adapt our behaviors to meet our goals without compromising our health, seek out support from others, and open our minds to new attitudes, we can have hope that our disorders will become a part of who we are instead of defining who we are. It is possible, and it is happening within our community. **

“WWD is part of my life, but it doesn’t define who I am.”
— Laura Kinson-Curtin

Active Coping Strategies:

**Find someone to trust.**
Everyone needs to express their feelings.

**Educate yourself about the disorder and treatment.**
While doctors may be the medical experts, you are the expert of your body. Don’t be afraid to be assertive about your care.

**Make a thoughtful list of things you can do.**
Focus on things that provide meaning and purpose to your life.

**Allow yourself to be less than perfect!**
Try to do away with the self-judgment and guilt.

**Network with other people in similar situations.**
Support helps women realize they are not alone.

**Make time for fun!**

Susan Fletcher, PhD, MSW
Susan earned her MSW and PhD from the University of North Carolina. She is the Principal Investigator of a research study investigating the health-quality of life of men over the age of 50 with hemophilia, and is studying quality of life among females with bleeding disorders. She is also writing a book about courageous individuals positively coping with life-altering conditions. Susan lives with her husband, Gregory, in Chapel Hill, North Carolina.
WHAT IS YOUR ABR?
ANNUAL BLEED RATE

Minimize the impact of bleeds on your life.
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Talk with your healthcare provider about your current ABR and how you can set goals to help reduce or eliminate it.

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Thank You for your Generosity

Often times we give thanks for things we’ve received and for people who have helped us. But thankfulness can also be given for circumstances avoided. Some families who receive Helping Hands assistance are able to avoid home loss, utility disconnection, or car repossession. These families are thankful that programs like Helping Hands exist. Sometimes, they even express interest in volunteering and/or being a financial contributor to the program after they get back on their feet.

Thank you to our sponsors of the Helping Hands Program. Our corporate sponsors include: Novo Nordisk, Grifols, Walgreens, and CVS Caremark. Helping Hands requests have grown in recent years and struggles to remain funded. HFA especially acknowledges Novo Nordisk for providing additional support earlier this year when Helping Hands had utilized all existing funding and was in danger of closing.

The Helping Hands Program is a promise. Anyone in the bleeding disorders could find themselves in a difficult financial situation and HFA raises more than $120,000 each year to assist the bleeding disorders community with emergency needs. Our promise is to support our vulnerable population.

You can help! In 2013, all individual memberships received will be directed to the Helping Hands program. Please join HFA as an individual $25 or family $50 member. Membership and donations at: www.hemophiliafed.org.

We are so Grateful

To donate, visit www.hemophiliafed.org.
"Thank you for all that you do."

"This means so much to my family in this time of need."

"I greatly appreciate your care in helping with my struggle."

"I am truly thankful that you approved my application."

"I greatly appreciate the assistance. Thank you for helping my family and I out with the deposit."

"Thank you, again with your help, I will not lose my house for my son and I. Thank you, again."

"We sincerely appreciate the financial help that is being provided through the Hemophilia Federation of America’s Helping Hands program."

"We are so grateful that we have been approved to receive assistance with our utility bill. It is a huge burden that has been relieved for us."

"Thank you for helping me in this time of need. I hope one day I can help others as you helped me."
Tis the Season: Preparing for Policy Changes in 2013

By Eboni Morris

For the past few years, HFA has educated the bleeding disorders community about provisions within the Affordable Care Act (ACA) that have potential benefits for them. As we enter 2013, state governments are now faced with the decision of if and how they will implement the ACA in their state; and in particular, whether to set up a health insurance exchange or expand their Medicaid program.

As you may already know, states have a few options in health insurance exchange implementation: a State-Based Exchange (SBE), a Federal-State Partnership Exchange (Partnership), or Federally Facilitated Exchange (FFE). Since there is only a year left before exchanges must be operational, at this point, states that have not already begun implementation and plan on having an exchange will most likely have a partnership exchange or a federal exchange.

Below are some advocacy tips to help you approach health insurance exchange advocacy in 2013 and a timeline for a few relevant provisions in 2013. Check out our website for talking points and issue briefs on health insurance exchanges and other provisions in the ACA.

If your state is implementing an exchange:
- Make sure the bleeding disorders community in your state is an active partner in the planning process. States must have open and public meetings. If you need assistance in identifying the entity in your state that is overseeing exchange implementation, please contact us.

If your state is implementing a Partnership exchange:
- In addition to what is stated above, make sure your state has a clear plan toward preparing to take over the exchange at some point in the future, and that this plan ensures affordable and quality coverage for the bleeding disorders community.

If your state is not implementing an exchange:
- It is important to note that although your state has chosen not to operate its own Exchange, the Affordable Care Act guarantees access to coverage through an exchange overseen by the U.S. Department of Health and Human Services. Your state still has to select a benchmark plan, which is a baseline model for the minimal coverage plans you will have to offer. If they do not, the default plan is the largest small group plan in the state.

If your state is deciding on Medicaid expansion:
Educate state officials on the necessity of health insurance for the bleeding disorders community.

- Without expansion, many working adults would have incomes too high to qualify for Medicaid, but too low to qualify for subsidies to buy coverage in the exchanges. They would likely remain uninsured and go without needed care, ultimately leading to increased costs due to uncompensated care, which is a disastrous combination for a person with a bleeding disorder.

- The Medicaid expansion will reduce the number of uninsured adult residents, especially those with chronic and disabling conditions like bleeding disorders. Childless adults in the bleeding disorders community, especially young adults, are having great difficulty in obtaining quality and affordable health insurance.

- The expansion will provide coverage for community members who are disabled and are in Medicare’s 2 year disability wait period.

Continued on page 14
RGI: Rapid Gratitude Inventory

By Jonathan VanderBrug

Each year, scientists from the Field Museum conduct RBIs. This doesn’t mean they play baseball and swing for “Runs Batted In.” It refers to Rapid Biological Inventories. Teams of biologists visit remote natural areas and spend three weeks inventorying species in order to learn about the local ecosystems. A 2011 RBI in the Amazon, for example, recorded over 1,800 different species of plants and animals. This included rare creatures like the yellow-footed tortoise and the pink river dolphin.

During this holiday season, a time for reflection and giving thanks, I recently conducted my own Rapid Gratitude Inventory (RGI), focusing on my work with you, the bleeding disorders community—one of the most amazing communities I have ever known. Below are a few of my many reasons for gratitude.

I am grateful for the sense of family in the bleeding disorders community, not just that the community has caring families within it, but that the community is itself a caring and welcoming family. Bleeding disorders do not discriminate based on ethnicity, geography, or social status, and neither do HFA’s activities. In a world where diversity usually leads to division, I am grateful for the model of unity-in-diversity that the bleeding disorders community shows.

I am also grateful — and solemnly so — to those with hemophilia who contracted HIV and/or hepatitis in the 1970s and 1980s due to contaminated blood. They did not ask for this role, but they lived it with courage and grace, and many still do. They are some of the strongest, most steadfast people I know—vigilant leaders in calling on our nation to protect its blood supply. John F. Kennedy once said, “The highest appreciation is not to utter words, but to live by them.” Because of these advocates, any person who has ever received or may someday receive a blood transfusion — that’s everyone — owes gratitude to them. To fully show our thanks, we must continue to advocate for a safe blood supply, as well as for development and access to better therapies for Hepatitis C.

This leads me to another reason I am grateful to the bleeding disorders community: the overall commitment to advocacy. From meeting with agency officials, to testifying at public hearings, to writing to state legislators — the bleeding disorders community is filled with passionate, articulate advocates who take policy change seriously, who invest energy in learning the issues and improving their advocacy skills, and who won’t take “no” for an answer. The community has been a leader recently in achieving key policy victories such as the elimination of lifetime caps and the end to denying coverage to children due to pre-existing conditions. I am thankful for this leadership that continues to work for health care justice.

Perhaps this holiday season, you’ll have time to conduct your own RGI. If so, may you be joyfully surprised by the diversity and sheer abundance of reasons for thanks in your life.

Thank You!

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Pain and You
By Angie Lambing

Anyone who has ever experienced pain knows that it has an effect on all aspects of your life. It can affect your sleep, your ability to work, or your ability to attend school. Daily pain can affect you emotionally, to the point where you feel bad all the time and don’t want to hang out with friends. It can also affect your mood negatively, leading to depression or anxiety.

In order to treat pain, you should explore your own concerns about adequate pain management. There are several potential barriers that should be explored within yourself as you navigate through healthcare to obtain pain management. Your own previous personal experiences of pain can “color” your current beliefs about pain management. Frequently in U.S. culture, boys are encouraged to “be tough,” and that “big boys don’t cry,” which can be the beginning of how you show your pain from a bleed. Many people worry about the potential harmful effects of any oral pain medications, and would rather “tough it out.”

These effects could include feeling drowsy when starting a new medication, possible nausea, constipation, and feeling like the medication could make you feel cloudy and hard to function. Often these side effects can be managed by communicating with your provider, so that dosage adjustments or timing of medications can be made. Many people don’t like to take any pain medication for fear of addiction. Addiction is a neurobiological condition where someone craves the drug and continues to take it for reasons other than for pain, despite knowing that it may cause harm. Understanding addiction can better help you understand how to take your medication responsibly. Talk to your pain provider about these concerns. Many people may “tough it out” and save their pain medication for when they really need it, or feel that having hemophilia is just part of having to endure pain. And many people fear taking any pain medication, and worry about what others may think of them. Some people may have pressure from family telling them they should not be taking pain medication because that makes them a ‘drug addict.’ This is not true.

Pain is a physical response to an actual injury or change within your body. It is the body’s signal, telling us that something is wrong. Your job as the person experiencing pain, is to talk with your provider and share your issues of pain and your concerns about treating it, so that you can work together as a team to improve your health.

Principles of Pain Management:

1. Have a comprehensive plan
2. Explore the emotional and cognitive aspects of pain and pain management
3. Listen to your body
4. Pain is frequently undertreated so explore those issues
5. Individualize treatment for pain
6. Set realistic and functional goals to reduce and manage pain
7. Anticipate pain and treat it

Angie Lambing, NP
Angela is a nurse practitioner for the past 21 years, working as the hemophilia nurse coordinator at Henry Ford Health system for the past 11 years. Her passions in hemophilia care are focusing on the aging issues in hemophilia and pain. She has participated in research, lectured and authored many articles related to the hemophilia pain experience.

In addition, here are some important dates for ACA implementation in 2013:

Children’s Health Insurance Program (CHIP):
- Re-authorizes the program through 2015

Health Insurance Exchanges:
- States need to indicate whether or not they will operate a health insurance exchange
- Exchanges need to start open enrollment October 1, 2013

Medicare Part D:
- The phasing in of federal subsidies for brand-name prescriptions for those in the coverage gap by reducing beneficiaries’ co-insurance

Medicare:
- Increases the Medicare Part A tax by 0.9% on earnings over $200,000 for individual taxpayers, and $250,000 for married couples filing jointly and imposes a 3.8% assessment on unearned income for higher-income taxpayers

Medicaid:
- Increases Medicaid payments for primary care services provided by primary care doctors to 100% of the Medicare payment rate for 2013, and 2014, with 100% federal matching funding

Flexible Spending Account Limits:
- Limits the amount of contributions to $2,500 per year for medical expenses

Financial Disclosure:
- Requires the disclosure of financial relationships between physicians, hospitals, pharmacists, other providers, and manufacturers and distributors of covered drugs, devices, biologics, and medical supplies

During this important time of health policy changes, HFA encourages state advocates to look at joining or forming coalitions with other stakeholders, where appropriate, to make sure consumer needs are met. We are here to support your advocacy. Please contact us with questions or for assistance!
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Innovation leads the way
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As the industry leader in coagulation therapies, CSL Behring offers the most extensive portfolio of coagulation products for patients with factor deficiencies, including FIX, FVIII, FIX, FXIII, and von Willebrand factor. And we continue to broaden our efforts with a number of recombinant factor therapies in development, including rFVIII, rFVIIa, and rFIX.
Hemophilia: A Suit That Fosters Empathy
By Thomas Ford

I remember visiting my cousin Leland's house from a very young age. Spending time with family has and always will be one of the most important things to me, but spending time with Leland was always different. My first memories of my cousin were of his little blue hat—a padded helmet he would wear whenever the cousins were over. Leland wore this hat because he was born with hemophilia, as were two of my other cousins, and he needed to take preventative measures to make sure that if he did have an accident, there was some "padding for his noggin." I was blessed to not have had to endure the hardships of being born with hemophilia, but at the same time, I was put into a situation that has given me what I consider to be a unique perspective.

"He's not special because he has hemophilia—it's just part of who he is, and in no way does it define who he is as a person."

For the entirety of Leland's life, he's been nothing but a cousin and friend to me, and I to him. He wasn't my sickly cousin that I felt bad for, he wasn't the fragile first-born that he was to his mother, nor someone I felt like I had to take care of or that needed my help. In retrospect, that probably would have been the smart, not to mention, helpful, way to approach things. But now, as both of us are young adults, I feel it was all for the best. When I think of my cousin, I think of great taste in movies, video games that I will never be good at (much to his dismay), and how he laughed at literally everything I said up until he was 13 years old. I do not think of hemophilia when I think of him. He's my cousin, not my cousin with hemophilia.

The challenges and hardships faced by those with bleeding disorders are something that I will never fully understand or relate to. But the best thing that I can do as Leland's friend and cousin is treat him exactly the same way I do all my other cousins and friends. He's not special because he has hemophilia—it's just part of who he is, and in no way does it define who he is as a person. Like anything is one's life, it has shaped him into the person he is today, and he's one of the strongest people I've ever met because of that. I respect him for what he has to put up with, but still expect him to have convictions, treat people with the same respect that he would want to be treated with, and stay true to himself and where he comes from. If you're reading this, chances are you are either have hemophilia or are close to someone who does, so remember that no matter how big of a part hemophilia plays in your own life or your loved one's life, it does not define you. You are better and stronger than your condition, and don't you ever forget that.

"Having hemophilia has shaped my cousin into the person he is today, and he's one of the strongest people I've ever met because of that."
LINK educational programs provide an interactive forum for patients and caregivers to provide feedback while learning about the latest in the community. Program topics range from health insurance to treatments to lifestyles. So, if you're seeking the latest on real-life issues — connect, learn and make the LINK.

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

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We're laying the foundation for Deeper Connections

We are Biogen Idec Hemophilia, and we're developing long-lasting factors

But that's only the beginning...

› From the community. For the community
Our CoRe Managers are currently out in the community working to improve the lives of people with hemophilia

› BiogenidecHemophilia.com
Connect with our CoRe team, watch videos about Biogen Idec Hemophilia, and more!

› Biogen Idec Hemophilia
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Stay informed on the most recent developments from Biogen Idec Hemophilia and the issues that affect you most

Biogen Idec Hemophilia
Community Connections
Join our community today!
www.BiogenidecHemophilia.com/CommunityConnections

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"It can be what puts problems in to perspective, or it can be the hand that you extend to someone else that makes the difference in their life."

Worth It All!

By Axel Freese

Being a member of a group has advantages, as well as disadvantages. But I’m a member of a group that has no downside that I’m aware of - I’m a Blood Brother!

The Blood Brotherhood magic is one that is hard to describe to a non-Blood Brother, but it is something that each Blood Brotherhood member gets instantly. It’s like being connected to someone in a fundamental way, even if you have never spoken with them before. It is almost elemental, and so rewarding in lots of ways, both big and small.

Before joining the Blood Brotherhood program, I felt I had a pretty good support system for myself – family, friends and a few bleeder friends. Then I heard about the Blood Brotherhood Online Community – www.hemophiliefed.net - and wow, did my world ever open up!

There is a whole community of bleeders that are on that site and they share so much with each other. For instance, I shared with them about my recent total knee replacement and how I prepared for the surgery, how I got through rehab, as well as where I am now that it’s been over a year since the procedure. I’ve had several Blood Brothers thank me for sharing that information, as they felt they could only really accurately get that from a bleeder that had actually been through the procedure. The same holds true for the Blood Brother that shared his experience of an elbow replacement, or the one that shared his experience of his ankle fusion. And there is a lot more content where that came from.

The only other way to get that kind of information exchange happens when Blood Brothers get together at meetings. Sadly, meetings can be tough to get to, and making a connection when you are having a bleed is really hard. But the online BB site is always there! We have well over 500+ topics, and we are heading toward nearly 8,000 individual posts very soon.

These days, the social media sites seem to be magnetic to nearly everyone, but there are some topics that simply don’t lend themselves to open discussion on the World Wide Web. But having that discussion with a group you know and that knows you, is terrific. It can be what puts your problems into perspective, or it can be the hand that you extend to someone else that makes the difference in their life. It is wonderfully fulfilling!

I’m thankful every single day to be a member of the Blood Brotherhood! Come

In Memoriam

On October 6, 2012 the bleeding disorders community lost a national champion and advocate, Arthur Philip Zerbe. Art was born on July 24, 1961 in Wantagh, NY and was a long time resident of Deerfield Beach, FL. Art dedicated his life to volunteering for the hemophilia community. For many years, he was a camp counselor at Little Running Brave and pioneered health care by owning his own highly successful health care company. Art had a love for life that was infectious and always found humor in everything even though he was dealt an unfair hand. He will be greatly missed by those whose lives he touched.
"Every day I count my blessings- while I walk, while I drive, while I shower... that I am still able to do all this independently. My friends and my family’s support from near and far make this happen. There is no joy greater than knowing that you have people you can count on. For this I am thankful."

"Personally, and this sounds like something that is not correct to our community, but "I’m thankful for my hemophilia!“ Why, you ask? Because it has made me self-reliant (self-infusion), made me know that the world isn’t fair (getting a bleed when I had something planned), and because it has put me in touch with the best group of the people on the planet - the hemophilia community!"

"I am truly thankful for my friends here on the forum. I am thankful for the opportunity to share stories with one another, to support one another, to laugh with each other and to cry with each other."

“There is simply no better "up-side" to having Hemophilia than to have access to the Community. They are my Brothers! They know what I know, and there is no need to discuss it, or even mention it. It is known by both of us. It’s that simple, and yet it isn’t that simple. There are H’s issues that make each Brother’s issue each his own, but yet; there is a commonality that binds us all. That commonality is what I’m thankful for!"

“In a way I too am thankful for hemophilia. I have always thought that having a chronic illness from birth, with all the limitations, doctors, hospitals, have better prepared me for HIV, hepatitis and all of the other “later in life” issues that have come our way."

“I am truly thankful for my friends here on the forum. I am thankful for the opportunity to share stories with one another, to support one another, to laugh with each other and to cry with each other."

HFA Welcomes The Hemophilia Association of New York to the BloodBrotherhood!

HFA welcomed a new Blood Brotherhood site this fall with the addition of The Hemophilia Association of New York (HANY). This marks the 13th HFA Member Organization to join the Blood Brotherhood program. HANY will provide local face-to-face meetings for adult men with bleeding disorders located in the New York City area. HANY Program Director, Annie Sukhnanan, will serve as the site coordinator.

The HANY Blood Brothers kicked off their first event on December 5th, with dinner and a presentation on understanding healthcare reform. To find an upcoming HANY Blood Brotherhood event, please visit: http://hemophiliafed.org/resources/calendar/
Over the years, we have experienced many highs and lows due to hemophilia, but even in our darkest days, we still try to take a minute to be grateful for all that we have. We remind ourselves that there are educational programs like Dads in Action, and that HFA keeps us well informed about what to keep an eye on legislatively through alerts and webinars. We thank our lucky stars for Helping Hands and other patient assistance programs. We see our peers bond through Blood Brotherhood and Blood Sisterhood. We know that as a community, our voice is heard. And what a community this is! The relationships I have come to depend on have been nurtured by attending HFA's Symposiums and local chapter events. These connections and networking opportunities are instrumental in both mine and my son's acceptance of his lifelong disorder. At the 2012 Symposium, Ben Turpen started off the meeting as the keynote speaker, and reminded us that you can conquer whatever adversities life throws at you - and that you can do it with grace, a smile and gratefulness. I sat among most powerful mom's group. In that room, we all shared a common, yet not-so-simple bond of mothering a child with a bleeding disorder. We immediately had a connection that could never be severed. The previous session had featured Jeanne White-Ginder, mother to Ryan White. She spoke of love and dignity, and as I waited to speak with her afterwards, I was filled with gratitude. Her willingness to share her son, in life and death, paved the way for a brighter future for my son. At the HFA symposium, the atmosphere was electric and the sparks flew! Just as an electric current gets its power from a conductor, HFA is a conductor—providing energy and power to families through its programs and services. But in this day and age, we don't have to wait for the annual Symposium to network with one another. The use of social media, such as Facebook and Twitter, have given me instant access to my friends. These sites are a place to vent and find support, and I've found them to also be an effective platform to raise awareness and educate the general public about bleeding disorders. When I'm feeling down, I can always visit HFA's website (http://hemophiliafed.org/) and view the "Voices and Stories" to see others share their inspirational histories and their promising futures. Sometimes you need to see and hear the voices of those people most precious to you, and having instant access to them helps tremendously. It's a constant battle to be on the winning side of the positives of a bleeding disorder, but when you look around and see the benefits—love, acceptance, understanding and kindness—you can't help but feel appreciative that hemophilia is what led to such a wonderful place of strength. Don't flip the switch and be led into darkness. Choose to actively engage with HFA and be filled with gratitude and light. My family's advocacy work and participation in the community has led to powerful friendships and an endless stream of knowledge and information. The enrichment you gain is far more than you can ever give. I can honestly say that if we had chosen the path of darkness, our family would be struggling. I would have no clue how to help my son at school when he needs an Individual Education Plan (IEP)
or 504, and I certainly couldn’t have taught him self-infusion on my own. Without my involvement in the community, I wouldn’t know how to cope with the sibling issues that arise for my girls, and no one would be gently reminding me to take care of myself—the caregiver and the carrier. I learned these techniques at Symposia and other events and from the community that HFA helped to create.

The Hemophilia Federation of America is family. There is great empowerment in family and my appreciation for HFA, hemophilia, and my “bleeding” family. They are much more powerful than any physical and mental nuisance that the condition of hemophilia can throw at us. By applying a little gratitude to every infusion, physical therapy appointment, and connection I make, we as a family become stronger and brighter.

“Over the years, we have experienced many highs and many lows due to hemophilia, but even in our darkest days, We still try to take a minute to be grateful for what we have.”

Sonji Wilkes was born and raised in North Carolina, where during high school, she developed an appreciation for volunteerism and community service. She graduated Magna Cum Laude with a BA in Behavioral Science from the Metropolitan State College of Denver in 2001. Sonji volunteers extensively in the bleeding disorders community and was selected as the 2006 National Hemophilia Foundation’s Volunteer of the Year. Sonji also has led her children’s school auction, raising over $225,000 in the last 3 years. Sonji, her husband Nathan, and three children: Nora (11), Thomas (9), and Natalie (6), currently reside in Colorado.
Get Healthy, Give Support, Get in Gear!

By Janet Chupka

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.
The CHOICE Project survey is close to going live, but we need your help. If you or someone you know has a bleeding disorder and does not receive care at a hemophilia treatment center, please consider taking the CHOICE survey before anyone else, as part of our Pilot Program.

All you need to do is take the CHOICE Project survey online or in print, in English or Spanish, and tell us what you think about the survey on a short phone call.

If you want to participate in the CHOICE Project Pilot Program, please contact Wendy Owens via email: choice@hemophiliafed.org or via phone: 800-230-9797.

HFA is conducting the CHOICE (Community Having Opportunity to Influence Care Equity) Project through a cooperative agreement with the Centers for Disease Control and Prevention (CDC). 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).

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

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

Now, that family is a lot bigger. Eric connects with others at The Changing Possibilities Coalition—a unique hemophilia community created by Novo Nordisk.

Join The Coalition today at JointheCPcoalition.com.