

Healthier Bodies,



BLEED LESS

Honestly, I didn't blame them, because that's what I felt like: a young, fragile, broken child, who everyone was constantly worried about. I started to resent that I had hemophilia and began hating my life.

Not participating in physical activities as a child caused me to become isolated. I fell into a depression as deep as an abyss, for I honestly did not know how to accept hemophilia as a part of my life. It wasn't until I ventured off to college, when I realized, "The fact is I hemophiliac." The question became, "How do I deal with this? And "What do I do now?"

Even though, I didn't play contact sports when I was a child, there were still so many

things that I could have done like swimming or hiking. Instead, I chose to focus on what I couldn't do, rather than what I could do. When it comes to sports and exercise, there are so many things that you CAN DO with a bleeding disorder. I've learned that I can be active and take risks; I just have to be responsible when doing so.

For example, I work with my doctor to develop a regimen that fits my activity level. If I am more active in the evening, I will take my dose right before I begin the activity so my factor levels are at their peak. If I find myself having breakthrough bleeds, I will discuss with my physician the possibility of increasing my dose.

I have hemophilia.

When I was a child, my parents told me that I couldn't play football, baseball, soccer, or other contact sports, because I was a "bleeder." I always wondered growing up, what does being a bleeder ever mean? All I knew was that I bruised easily and that I wasn't going to die from a paper cut.

During gym class in school, while my friends played basketball, I walked around the track and thought about why this condition was stopping me from doing things that I wanted to do. My classmates in school started calling me, "bubble boy."

DON'T
MISS

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EXECUTIVE CORNER

well•ness Noun \, wel-nes\

the quality or state of being in good health, especially as an actively sought goal

Dear HFA Family and Friends,

Welcome to the fall edition of Dateline Federation. We hope you enjoy this publication and share what you learn with others around you!

This issue of Dateline is dedicated to the topic of wellness. It has been both demonstrated and documented that stronger muscles and joints will bleed less frequently. At HFA, we continue to devote energy to encouraging and supporting people with bleeding disorders and their families in their efforts to build healthy bodies. See this issue and our website for further information on our Fit Factor Program and HFA's Get In Gear mobile app that can assist you in your own efforts!

Good health requires commitment from anyone who pursues it. For our bleeding disorders community, we live in a reality filled with additional challenges. For anyone with joint or muscle damage, it can be a painful road, requiring fierce determination and strength of will just to keep moving. For a family with young children, it can be a battle between knowing that it is good to build strength, and worrying about having a bleed.

We continue to live in a health care world that threatens access to clotting factor at many turns, and the reality is that access will continue to be a battle we fight both nationally and locally in the states. It can be an intimidating feeling knowing that your insurance provider is looking at every avenue to cut covered costs.

Incorporating good, healthy decisions is a choice we can make though! Engaging in exercise, even a little at a time, and making healthy, nutritious food choices are within our control.

It is a message that has merit! Consider a future conversation you will have with a legislator or insurance company. You are hearing references that these are tough times and everyone has to pitch in and do their part and work together. Having dedicated yourself to wellness, you have an excellent response to them. Warm Regards and Good Health,



Matthew T. Compton
Board President



Kimberly Haugstad, MBA
Executive Director

"I am doing everything in my control to be as strong and healthy as possible to protect my joints from expensive bleeding episodes. I am doing my part."

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What Does Lyonization Mean for Carriers?

by Dr. Danielle Nance

Lyonization is a term given to the process of X chromosome inactivation, and was named after the geneticist who described how genes are expressed when they are on the X chromosome, Mary Lyon. She noticed this through studying the color of the coats of mice of females and males (coat color is carried on the X chromosome). She saw that male mice could be brown or white, but females could be splotchy brown and white but never light brown. She predicted that the same patterns should be seen for all of the genes that are on the X chromosome, and she was right. The mechanism that produces the separate but mixed coat color is also responsible for the reason why women can have widely different factor levels, and why women with mutations on the X chromosome often have mild disease or no symptoms at all, even if they carry the disease mutation.

The X chromosome is one of a special pair of chromosomes that determine the sex of humans. The other half of the pair is called the Y chromosome. The chromosomes are named based on their shape when seen under a microscope right



before the cell divides. There are many genes on the X chromosome that have nothing to do with sex development but are critical to the growing human, like certain muscle proteins, the gene for color blindness, a severe combined immunodeficiency disease, and the classic hemophilia genes.

Preetha, is a 27 year old woman who has mild hemophilia (also known as a symptomatic carrier) with factor VIII activity of 22%. She wants to know why she has low factor levels, but conversely, her sister, Sara, who also has the same gene mutation, has factor levels of 65%. Preetha has had trouble with nosebleeds since she was a child, periods that lasted for a full 7 days, which caused her to become anemic, and has had a blood transfusion after she had her tonsils out due to excessive bleeding. She recently got married and is worried about passing the hemophilia gene to her children.

The genes that make women become female instead of male reside on the X chromosome. In fact, in the absence of the Y chromosome, a fetus will always be female, even if she is missing one of her X chromosomes. Women have a pair of Xs, but only really need the amount or dose of genes present on a single X chromosome. What happens in women shortly after the egg and the sperm meet is one X is saved and condensed until it is needed again to produce new and perfect eggs when the

"All women who are carriers of a hemophilia mutation should have their factor levels checked to assess the risk of bleeding."

"Women with factor levels that are low may require treatment to prevent bleeding during surgery, or in the case of trauma or injury."

woman is old enough to reproduce. The other X is continually set to work, producing the vital proteins to ensure a healthy individual.

The developing female embryo inherits one X from her mother and one from her father and one or the other in each cell of her developing body will choose, by a complex set of chemical reactions, to coat and condense itself. It happens very early after fertilization. The decision to inactivate the X that was inherited from the mother or the father is random, like flipping a coin, but once the choice has been made, the cell and all of its daughter cells as the embryo grows into a recognizable fetus will express only the genes from the X that is active. Women can have very different bleeding symptoms depending on how their genes were inactivated very early in development. For Preetha, as she grew into a fetus, about 80% of her active X had the hemophilia mutation and 20% of the active X was normal. In her sister, the random X inactivation event produced a different effect. Around 65% of Sara's active X does not have the hemophilia mutation, so therefore, she produces a normal amount of factor VIII.

Although the X inactivation is permanent for a woman during her lifetime, X inactivation is reversed when a woman produces eggs. During the final stages of nurturing an

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BULLYING IN TODAY'S WORLD:

A SERIOUS PROBLEM FOR KIDS WITH A CHRONIC CONDITION

By Diane Horbacz, Med

Children with special health needs such as a bleeding disorder can be at an increased risk of being bullied because of issues like physical vulnerability, social skill challenges, and intolerant environments.

Bullying means that kids with bleeding disorders may become a target when they use crutches one day and the next day they do not, are limited to certain activities during recess and gym class, have a visible PICC line/port, or miss several days of school.

Bullying is aggressive, intentional behavior that hurts or harms another person physically or emotionally, which involves an imbalance of power. Most often, bullying is repeated over time and has been around for many years. Thankfully, we now have laws and policies that promote awareness, educate school staff and encourage advocacy.

Many people do not realize that bullying comes in different forms that include physical (hurting a person's body or possessions), verbal (saying or writing mean things), and social (hurting someone's reputation, embarrassing someone, or spreading rumors).

These days, kids not only socialize in the physical world, but also in the virtual world. This has created what is now known as cyber-bullying. Most of us – including most kids – do all kinds of things online, like socializing via email, posting and sharing pictures and videos, having profiles on social networks, and sharing information with friends and family. These ways of socializing and communicating can be fulfilling, but yet they can also come with certain risks.

55%

of students report
having given out personal
information to someone
they have only met online

As a parent, educating your kids about cyberbullying is the first step to creating awareness around this important issue. Talk to your kids about the risk when being online. Start early and create an honest, open environment. Initiate conversations and make sure to communicate your values. Ask them to tell you if an online message makes them feel threatened or hurt. Keep an open channel of communication with your child, and hopefully he or she will come to you ■■

58%

of students admit
to using the
Internet unsafely,
inappropriately,
or illegally



DO YOUR PART TO HELP STOP BULLYING

HFA RECOGNIZES OCTOBER AS
NATIONAL BULLYING PREVENTION MONTH



For younger or school age kids:

1. Starting with very young kids, it is a good idea to supervise them while they are online – maybe even choosing the sites they can visit. As they are ready to explore a little more, consider limiting their exploration to sites you've already checked out and that you think are OK for their educational and entertainment value.
2. Be patient: Most kids need small bits of information repeated – and often – for it to really sink in. Keep talking; chances are it will pay off.
3. Kids need different levels of attention and guidance at different ages – and it is really up to you to decide where your own kids fit.
4. Communicate your values – and how they apply online: You are the only one in a position to guide your kids this way. Be very clear with kids about this. It will help them make smarter decisions when they are faced with tricky situations.

For teens: – By the time kids are teenagers, many are ready for more independence from their parents. They are starting to form their own values and reflecting those of their friends. But that does not mean there is no point in talking with them.

Teens have access to the Internet through their mobile devices, phones, computers, and their friends computers, so it is really hard to watch what they do. It does not hurt to reinforce 'good citizenship' messages with teens, along with three important messages that many need to hear:

1. Not all information is credible; just because it is posted, does not mean it is so.
2. Once they post something, there is no taking it back. It is out there in the world.
3. No matter how impersonal it seems, screen names, profiles and avatars belong to people with real feelings. Treat them the way you'd like to be treated.

Diane has her Masters in Special Education and spent many years teaching; her specialty was working with children who have Emotional & Behavioral Disorders. For the past ten years, Diane has been developing and presenting educational programs specifically for the bleeding disorders community. She is the mother of three children; her two sons have hemophilia.

**HOW TO WIN THE
BATTLE OF THE BUGS**

By Janet Chupka

For most of us, fall and winter means less time outdoors in the fresh air, and more time spent in close quarters with those that we work, play, learn, and live with. It is a great opportunity for cold and flu viruses to work their way from one person to the next. While we all try to stay healthy, it is especially important for individuals with chronic conditions and compromised immune systems to take extra measures to avoid illness. For individuals with hemophilia or other bleeding disorders who infuse, it is especially important to pay special attention to hygiene. The infusion site presents an additional portal of entry or exit of viruses and bacteria. To help prevent the spread of germs to and from those around you, here are some simple things you can do to stay well:



4

1

Wash your hands

The single most important thing you can do to help stop the spread of germs is good hand washing. Hand hygiene is critical to interrupting the spread of infectious diseases.

If soap and water are not available, alcohol-based hand sanitizers that are at least 60% alcohol can be effective.

2

Do not touch!

Avoid touching your eyes, nose and mouth. These are the most common places for viruses to enter the body.

6

3

Lay low

If you are feeling ill, stay home and limit your contact with others.

Incorporating these simple measures into your life will help keep you on the path to wellness and will make you victorious in the “battle of the bugs!” Visit: <http://fitfactor.hemophilafed.org/> for more great information on physical activity, nutrition, health & wellness.

Flu shots

Sudden fever, body aches, sore throat and a dry cough are all symptoms of the flu. Yearly vaccinations offer protection against the flu, and are now available in a nasal spray. See your healthcare provider to discuss if a flu vaccine is recommended for you.

Exercise

20 to 30 minutes of moderate exercise daily (such as brisk walking) increases blood flow which helps to boost the immune system and ward off illness.

8

Be happy

The hormones the body releases when stressed can lower the body's resistance to fight off germs. Identify the sources of stress in your life and find ways to reduce them.

7

Go to bed

Adults need at least 7 hours of sleep each night and children need 8 or more. The body re-energizes and repairs itself while sleeping. Getting enough rest is a vital part of staying well.

5

Eat well

Maintain a healthy diet. Fruits and vegetables are packed with vitamins and antioxidants that provide the body and the immune system with the power it needs to fight off germs and keep you well.



is

DISHING IT OUT!

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Congratulations!



The Long-Holderried Family

from New Mexico, are the winners
of the 2nd FitFactor Super Grain
quarterly raffle drawing.



All prior non-winning entries
will be entered into the
next drawing as well.

ACUPUNCTURE:

NEEDLES & HEMOPHILIA? DOES THIS MAKE SENSE?

By Angela Lambing, MSN, NP-C

Hemophilia pain

It is well known that persons with hemophilia have episodes of painful experiences. Pain results after an acute joint bleed, where the synovial capsule fills with blood and expands with nowhere to go. Once the bleeding is treated with factor, with time the blood in the joint is reabsorbed and the swelling and pain resolve. But we also know about those daily aches and pains, and difficulty moving the joints, especially in the morning, where the pain is there waxing and waning on a daily basis. These symptoms are most likely related to the end stage joint dysfunction resulting in daily arthritic pain. Most persons with hemophilia know how to treat a bleeding joint and minimize joint bleeding with prophylaxis. But what about the joints that have already been affected and "talk to us" daily?

What is acupuncture?

Pain management should involve a "multimodal" therapy. What does that mean? Not just treating pain with pain pills, but using other types of therapy that may work best for you.

The basis of acupuncture is that the energy called "chi" flows through and around your body along pathways called meridians. Along these meridians are target "energy points" that correlate to different parts or functions of the body. By targeting these energy points through the insertion of needles, we are able to alter the flow of energy, thus improving the health of the person.



How is acupuncture performed?

A certified acupuncturist will ask about health history and do a physical exam, using key points on your body (muscles and bones) in order to place needles in the appropriate places. Very thin needles are tapped into the skin, some deeper than others. Most often, you do not feel anything when the needles are inserted, but sometimes, you may feel a slight pressure, tingling sensation, or ache. This provides the sign that the "chi" has been accessed. After the needle has been placed, the provider may roll the needle slightly or may use heat or an electrical current on it. Most treatments can take between 15-60 minutes, depending on the area of need. Acupuncture has been around for thousands of years, and used frequently for the management of arthritic pain with reported benefit.

IS ACUPUNCTURE FOR YOU?

1. TALK TO YOUR HEMOPHILIA TREATMENT CENTER FIRST TO DISCUSS WHAT IS BEST FOR YOU. YOU MAY BE ENCOURAGED TO DO PROPHYLAXIS.
2. CHOOSE AN ACUPUNCTURIST WHO IS CERTIFIED BY AN APPROPRIATE AGENCY. REFERRALS BY OTHERS YOU TRUST CAN BE HELPFUL.
3. DO YOUR HOMEWORK, LEARN ABOUT THE PROCESS, AND LEARN ABOUT THE ACUPUNCTURIST. YOU CAN CHECK FOR CERTIFICATIONS ON THE WEB.
4. SUCCESS WITH ACUPUNCTURE MAY REQUIRE SEVERAL TREATMENTS BEFORE AN IMPROVEMENT IS NOTED, AND MAY REQUIRE OCCASIONAL REPEAT TREATMENTS TO MAINTAIN OPTIMAL RELIEF.
5. TALK TO THE ACUPUNCTURIST TO KNOW WHAT TO EXPECT, WHAT IS A 'NORMAL' RESPONSE, AND WHAT MAY BE DIFFERENT.
6. REMEMBER THAT PAIN MANAGEMENT REQUIRES A MULTIMODAL APPROACH. WHAT MAY WORK FOR YOU MAY NOT WORK FOR OTHERS. YOU HAVE TO DETERMINE WHAT STRATEGIES WILL WORK BEST FOR YOU.
7. KEEP AN OPEN MIND!

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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 CHARGE
Today. Tomorrow. Together.

Visit us at www.thereforyou.com

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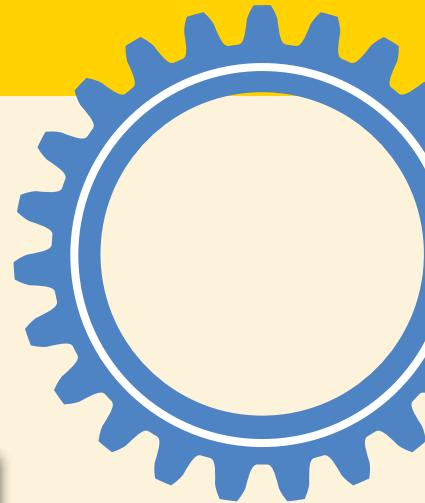


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Gears *for* Good



2012



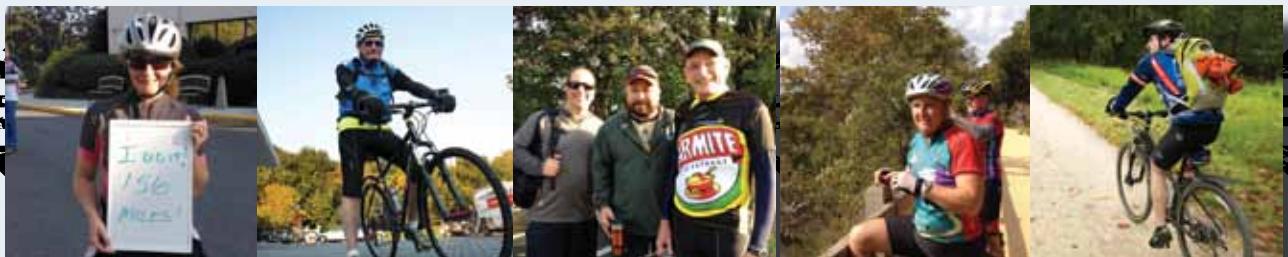
2012 Riders:

Barry Haarde, Vaughn Ripley, Ryder Haske, Keith Councill, Jarod Cady, Dan McKinley, Kimberly Haugstad, Nick Cady, Andrew Cady, Tricia Cady, John Scofield, Gino Cadete, Paul Brayshaw, William Brayshaw, Shaun Pensoneau, Allie Boutin, Tom Knoerzer, Cindy Knoerzer, Kathy Temple and Matt Stinger



Pedal WITH A PURPOSE

Gears for Good Bike 2012 Ride raised over \$38,000 for critical programs and services HFA provides for the bleeding disorders community!



"Thank you to the riders, corporate donors, family, and friends for making this possible!"



YOUR VOTE Matters!

Election Day is just around the corner. As an advocacy organization, HFA wants all community members to exercise their right to vote and participate in our democracy. We all have seen in the media a lot of information about the presidential candidates: President Barack Obama (D-IL), and his Republican challenger, Gov. Mitt Romney (R-MA).

However, many of your members of Congress, state legislators, and local government officials are up for re-election too! Here are some helpful hints before you enter the voting booth on November 4th.

Logistics

✓ Make sure you are registered

In most states, you must register before you can vote. Some states allow Election Day Registration (EDR) that allows individuals to register and then vote same-day. Policies vary among the states that allow EDR.

✓ Know your polling location

✓ Find out about any identification you need to bring

✓ Be prepared for long waits, or, as an alternative, see if your state allows early voting

A majority of states now permit "no-fault" or "no excuse" absentee voting, early in-person voting, and vote-by-mail (VBM).

✓ Ask your board of elections or your polling location for a sample ballot and information about the candidates and issues so you can prepare yourself right before you cast your vote

Learn about the candidates and the issues impacting the bleeding disorders community

✓ Visit HFA's website to learn more:

<http://hemophiliafed.org/what-we-do/advocacy/>

FLEXING YOUR ONLINE ADVOCACY MUSCLE

By Jonathan VanderBrug

In the early 1980s, when universities and the government were working together to expand the Advanced Research Projects Agency Network (ARPANet), an early version of the Internet, the Massachusetts Institute of Technology issued this warning to users: "Sending electronic mail over the ARPANet for ... political purposes is both anti-social and illegal. By sending such messages, you can offend many people, and ... get MIT in serious trouble."

Wow, times have changed. On the Internet today, especially in social media, political discussions are as common and accepted as sharing baby photos with relatives or critiquing movies. In the last presidential campaign, for example, 1.5 billion online videos mentioned one or both of the presidential candidates in the title, and nine out of ten of those videos were produced by citizens trying to reach each other. Quantity does not necessarily mean quality of course, but advocates are finding that the strategic use of online networks such as Facebook and Twitter can spread advocacy messages to new audiences and build political support for key public policies. Here are six tips for successfully advancing your advocacy agenda online.

In an amazingly short time, the Internet has moved from a limited, non-political forum to what it is today: a vast, social, blink-of-the-eye venue for robust political discussion and advocacy action. It can give political muscle to even the smallest cause. With the above tips in mind, you and your organization can flex that muscle and move your advocacy agenda forward with strength.





1. Is it really for you? – When deciding if, or how much, to incorporate social media into your advocacy, beware of the “everyone is doing it” pressure. Yes, social media can be a powerful advocacy tool, but it is not for everyone. It requires time, discipline, and commitment. It can give you and your organization political muscle, but like any muscle, it must be regularly exercised to stay strong. If you are not certain that you will have the energy to keep a Facebook page active with regular posts and lively discussion, then do not create one. Not having a page is better than having a stale one.

2. Be intentional and organized – As with other forms of advocacy, working “off the cuff” usually does not cut it. Start with defining your goals for being online and tailor your messages to match the interests of your intended online audience. Use tools such as HootSuite to schedule posts, but also dedicate time each day to respond to what is happening on your wall and to be informed by the political conversations on other groups’ pages. Also, consider assigning a point person to coordinate your organization’s social media activities.

3. Dialogue, not monologue – Ever had a friend who always talked but never listened, or who was quick to explain their political opinion but never asked about yours? Well, that friendship probably did not last long. No one likes to be “talked at,” and that is as true online as it is offline. Ask questions on your Facebook page about the political and policy issues facing our community, thereby giving others the opportunity to express themselves. Respond quickly to comments and thank people for them, even if you do not agree with their stance. In addition, share posts and resources from ally organizations; it builds your partnership with those organizations and brings variety to your wall.

4. Show. Do not just tell – Attract people to your cause by giving your online presence life. Avoid the boring, text-only rut by regularly displaying videos and photos. When you or other members of your organization meet with elected officials or their staff, take a photo of the meeting and post it on your website or Facebook page.

5. Avatars are lousy advocates – It is tempting to use social media as an advocacy crutch, thinking that your comments on a state legislator’s Facebook page can take the place of calling that legislator. Your online advocacy should complement your on-the-ground efforts, not replace them. According to Anita Jackson, Director of Social Media and Blogging for MomsRising, an advocacy group that reaches over 3.5 million people online, “Social media organizing doesn’t happen in a vacuum; it has to happen in the context of a whole, old-fashioned organizing plan.” Online petitions work best when accompanied by a call campaign and vice versa, while emailing a legislator is a great follow-up to a personal visit.

6. Protect your privacy – In the thick of an intense online political debate, it is often easy to forget that the words you are typing into the comment box might very well go public after you click “Post.” Given this, be aware of the forum’s privacy settings and do not post personal medical information. ■■

For more tips, watch HFA’s recent webinar on online advocacy: vimeo.com/49806017
www.hemophilafed.org | Facebook.com/hemophilafed
Twitter.com/hemophilafed



A stronger and healthier body means less bleeding.

Starting a regular exercise program is the key to staying healthy, protecting your joints, and even decreasing bleeding. Getting physically fit doesn't have to take a lot of time or cost a lot of money, and it can make a big difference in how you feel with your overall health. General wellness means striking a balance between eating healthy, staying physically fit, and managing your stress levels. These practical tips can help you jump-start any exercise program.

Tip #1: Stretching

A quality exercise program involves stretching before and after your primary activity. This gives you time to slowly warm up and cool down the body. Stretching can be as simple as breathing deeply as you hold poses, touching your toes (standing or seated), or doing deep lunges. Stretching and deep breathing can improve your flexibility, circulation, reduce stress, relieve soreness, and increase the strength of the muscles around joints.

Tip #2: Cardio Exercise

Moderate aerobic exercise is the heart of staying healthy (no pun intended!) Simple cardio exercises can include walking, swimming, bicycling, jogging, or dancing. It is recommended that adults aged 18-64 get at least 2 hours and 30 minutes of moderate intensity physical exercise each week. That's just over 20 minutes a day. Life gets busy, but it's possible to find 20 minutes a day for your health. It can be as simple as taking the stairs instead of using the elevator, parking further away at the grocery store, or going for a walk during your lunch break. Be creative and incorporate exercise into your daily routine.

Remember: Pain is a warning sign, and could be the early indication of a bleed.



Maintaining a Healthy Lifestyle

The key to starting an exercise routine is to find something you enjoy doing. If it is spending time with your children, start a game of tag or shoot some hoops together. If you crave a little quiet time, take a hike, work in the garden, or take a brisk walk with the dog. Feeling social? Take a water aerobics class, or bike or jog with a friend. Choose activities that cause an increase in breathing and heart rate. All of these activities count toward your goal of 150 minutes a week.





The key to sticking with it is to schedule activity time into your day. You are much more likely to exercise if it is a planned activity in your schedule. Remember, 20 to 25 minutes a day is all it takes to reach the 150-minute per week goal.

GET STARTED TODAY

1 Set simple, attainable goals.

Write these goals down and put them somewhere that you will see them every day.

2 Find someone to work out with.

Having an exercise partner will keep you accountable, and is a great way to give and get support.

3 Log your activity.

Keep track of the days you exercise and for how long. You will see how quickly the minutes add up and how attainable 150 minutes a week really is.



*As with any new activity, and especially if you are having joint or bleeding problems, make sure you check with your physician or physical therapist to be sure the activity you are planning to do is right for you. ■■



Rich Pezzillo is the communications manager for HFA. Rich has hemophilia and over 12 years of leadership experience working with the bleeding disorders community. Rich Pezzillo earned his B.S. at Western Connecticut State University and currently resides in Washington, D.C.

"I will never let what I cannot do, stand in the way of what I can do."



In June, HFA launched an exciting new fitness campaign called Get in Gear --a free app that will track your fitness and workouts, which is available for download and use on Apple and Android mobile devices. This app raises awareness about bleeding disorders while helping to improve your overall health. Simply choose from the seven activity categories, and the app will track your time and/or distance performing that activity. It is that simple! There is something for everyone on this app, and all levels of fitness are included. Join the more than 6,000 people that have downloaded it, and start your own path toward a healthier body and life today!

6,213

**number of people who've
downloaded Get in Gear
since June 1, 2012**

SCAN AND DOWNLOAD



GETINGEARAPP.COM



Continued from page 8

How safe/useful is it with hemophilia?

There are both possibilities and risks of acupuncture use for persons with bleeding disorders. In theory, the needles are very small, and only enter through the first few layers of the skin, so bruising and/or bleeding should not be a problem. There have been several studies performed with acupuncture use on persons with hemophilia.

In 2002, Rosted and Jorgensen reported a successful trial of acupuncture in one person after his factor level was increased to greater than 15% prior to each acupuncture treatment. After five acupuncture treatments, he reported a significant improvement in his knee pain. In 2006, Wallny studied acupuncture use on 10-12 hemophilia patients for arthritic pain and found that pain scores were improved without any bleeding episodes reported from the procedures. And most recently (reported January 2012), Henry Ford Health System performed an acupuncture study with their twinning partner in India, where 9 persons with varying levels of hemophilia participated. Some received factor prior to acupuncture treatments and some did not.

There was no bleeding or bruising reported by any of the patients in the study. More than 50% of the patients identified a decrease in painful joints after acupuncture treatments, and a decrease in oral pain medication usage, and an improvement in quality of life.

Remember, there are multiple ways to manage pain. You have to seek what therapies will work best for you. ■■

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.

Continued from page 3

egg, a woman has an equal chance of passing on either the X she got from her mother or the X from her father. The cycle repeats itself, giving the next generation a new set of chances for combining into something unique. Therefore, if Preetha was to pass the X chromosome with the hemophilia mutation to a daughter, the daughter would have all of the possibilities: no bleeding, mild symptoms or, in very rare cases, severe symptoms.

All women who are carriers of a hemophilia mutation should have their factor levels checked to assess the risk for bleeding. This includes daughters of men with hemophilia and mothers who have sons with hemophilia. Women with factor levels that are low may require treatment to prevent bleeding during surgery, or in the case of trauma or injury. A list of hemophilia treatment centers can be found on the Centers for Disease Control website: <http://www.cdc.gov/ncbddd/hemophilia/HTC.html>. ■■

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HEMOPHILIA

IMPETUS TO MOVE

By Ray Stanhope

SIn 2011 while attending a Blood Brotherhood event hosted by the Lone Star Chapter, I discovered just how far my being out of shape was causing some problems in my life and that taking control of how I treated my body is solely my responsibility. The Blood Brotherhood event brought in two male fitness trainers (James Loomis & Geoff Carr) to work with us on what I will refer to as the three S's: Stretching, Strength and Stamina. In this short little workout it became abundantly clear that some of the health problems were all related to diet and the lack of a physical activity program on my part. This event opened my eyes to the fact that I was approaching sixty even as my mind keeps thinking that I can do what I did at thirty. So changes needed to be made.

The diet part has been the hardest part in some ways because I have always loved cooking and baking as a way of showing loved ones how much I care for them by using quality ingredients in great tasting recipes that I had developed over a lifetime. My failure was not looking at how to create healthy combinations of ingredients and that not all fats are equal in a diet. And that salt in all of its forms may be necessary for life but not controlling the amount of salt looking at the total daily intake lead to completely preventable health problems like high blood pressure which in turns lead to yet other health issues. So I have spent the last seven months changing my diet by watching the types of fats I use and strictly watching the amount of salt added to any recipe while adding a lot more fiber to all meals. This does not mean that I have given up our favorite fast food burger but rather we look at this as a reward every once in a while instead of one of the first option on those hectic days we all have to deal with in our lives.

Facing the fact that the extra weight I had been carrying around has been compounding other health issues and although I have always considered myself active in many ways more was needed. It was ending that short workout out of breath, sweating and tried which crystallized for me just how little the activities I was doing were not enough to keep my body healthy. After my left knee replacement and right ankle fusion many years ago, I gave up riding my bike as exercise because of the difficulties with the stroke and position of

**"I discovered just how far
my being out of shape was
causing some problems in my
life and that taking control
of how I treated my body is
solely my responsibility."**

the pedals. At the time I was spending most of my energy just learning to walk with the limitation that these two surgeries presented so moving for exercise was not a priority. Now however most but not all of the pain and problems have been dealt with so I have started to riding for exercise several times a week again, somewhat inspired by my friend Barry Haarde but certainly not to the distances that he rides.

The results of all of these change are that I have now lost more than thirty pounds, my blood pressure is back down to normal levels with minimal medication and my back pain, although chronic, is somewhat lessened. All of this was caused by one program at a Blood Brotherhood event opening my eyes to just how far I had allowed myself to deteriorate over the years. For this impetus to get moving I am appreciative to Blood Brotherhood and everyone who works to support the program. ■■

In Memoriam

On August 9, 2012, the bleeding disorders community lost a national champion and advocate, Todd Smith. Todd was the President of the Disabled Adventure Outfitters (DAO) in Northern California -- an outdoor challenging and educational program for people with bleeding disorders. Todd's positive energy and charisma will be deeply missed.





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The importance of Wearing a Medical Alert Bracelet with a Bleeding Disorder

Medical ID's are a critical component to your overall health and safety plan - especially for individuals and families living with bleeding disorders. MedicAlert ID's are linked to 24/7 emergency medical information and identification services, relaying critical information to emergency responders about your medical needs.

Emergency department personnel use medical alert bracelets to rapidly identify people with a bleeding disorder. On arrival to an emergency department, one of the routine parts of the evaluation of the critically ill, unconscious, or disoriented patients is to remove their clothing to inspect the body for a cause of their sudden alteration. In these situations, medical alert bracelets can be invaluable as a time saver.



"Medical Alert ID's are linked to 24/7 emergency medical information and identification services, relaying critical information to emergency responders about your medical needs."

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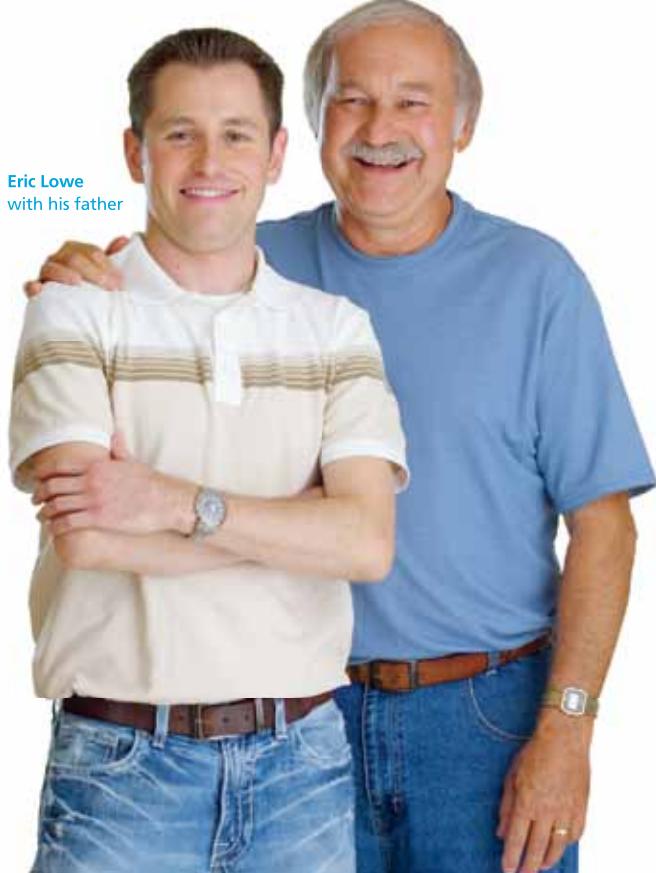
*To our many individual and corporate sponsors of the Helping Hands and Items Program. In particular, HFA recognizes Novo Nordisk, Grifols, Walgreens and CVS Caremark.
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Not wearing a medical ID? HFA can help!

HFA's Items Program assists individuals in the bleeding disorders community with the cost of medically necessary items. HFA understands the enormous financial impact of managing a bleeding disorder and provides this assistance to the community in addition to our Helping Hands program. The Items Program reimburses community members for durable medical equipment and items including:

If you are not utilizing a medical alert bracelet or necklace and are in need of help to obtain one, HFA's Helping Hands – Items Reimbursement Program can assist. Order your medical alert today at: <http://items.hemophilafed.org/>

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YOUR CHOICE,

YOUR VOICE

By: Wendy Owens

It's been documented that 33% of the bleeding disorders community does not receive care at Hemophilia Treatment Centers (HTC). Information about the health and wellness of this 33% is not readily known. HFA started the CHOICE Project to give this 33% a national voice in improving their care, their lives, and their future.

HFA invites you to support this very important initiative. If you, or someone you know, has a bleeding disorder and does not receive care at an HTC, we invite you to be a part of CHOICE. With your input, we will learn more about the needs of the bleeding disorders community and how we can help to meet these needs. Anyone in with a doctor diagnosed bleeding disorder can take the CHOICE survey.

What is HFA's goal for the CHOICE Project?

HFA's goal for the CHOICE Project is to put the survey results to work to improve the lives of those in the bleeding disorders community. The more information we have the better chance of learning what we can do to improve the health of people with bleeding disorders. The CHOICE Project is a way to obtain this information.

Is the purpose of CHOICE to convince people to go to HTCs?

Not at all. A patient's right to choose where they receive care is a core belief of HFA. HFA's purpose in taking on this project is to give patients who don't go to an HTC, the chance to be heard. The intent of this project is to identify if there is a health status variance between HTC and non-HTC patients.

33 %

of the bleeding disorders community does NOT receive care at Hemophilia Treatment Centers

CHOICE PROJECT
Community Having Opportunity to Influence Care Equity

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.

HFA
Hemophilia Federation of America



How will the information collected by the CHOICE survey be used?

The information 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. Potentially these include things such as where care is being obtained, what complications are being experienced, and what treatment is being used.

What efforts is HFA making to assure the security of the data collected by the CHOICE survey?

HFA has engaged a national recognized data security firm to help us put in place the best practices for securely collecting and storing the CHOICE data. Data collected will not leave HFA's secure, password protected database. Data shared with the CDC will include a unique identifier code but will not contain personal identifiers such as a survey taker's name or address. Information from this project may be published. However, no information will be published that could identify anyone who took the survey.

HFA expects to launch the CHOICE survey in late 2012. If you would like more information on the CHOICE Project, please contact us at choice@hemophilafed.org. We hope you will consider participating in CHOICE to let your voice be heard. ■■



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