

Symposium '13

DON'T MISS

Gears for Good	10
Informed Consent	14
Your Choice, Your Voice	21
HCV History and Advances	26

Your Voice Has Been Heard.

Dear HFA Family and Friends,

We hope that you enjoy this edition of *Dateline Federation*, as it reflects something we believe deeply in – the power and importance of team. Teamwork is an integral part of our history, our present, and our future which relies on working together as a united, strong, and unified community. HFA works hard to be the community voice for people with bleeding disorders. Our voice comes from actively listening and hearing what you have to say and making sure we support your needs.

HFA recently hosted its 2013 annual Symposium in Frisco, Texas. Over 700 members of the bleeding disorders community attended this important and motivating event. Thank you to all who came and celebrated our theme of TEAM: Together Everyone Achieves More! If you were unable to attend, you'll find many articles and photos in this issue that summarize the experience. Next year, we want you on our team for our 20th anniversary celebration!

We heard many inspiring and wonderful stories during Symposium about the work you're doing locally, how you are spreading awareness, advocating, and making a difference in the lives of those living with a bleeding disorder. We also appreciate the feedback and ideas that we receive from YOU! We have already begun work on putting some of that feedback into action. Just as our Symposium celebrated, we will all achieve more working together!

Enjoy this issue of *Dateline* and have a wonderful summer!

Warm Regards,



Matthew T. Compton

Matthew T. Compton
Board President



Kimberly Haugstad

Kimberly Haugstad, MBA
Executive Director



OFFICERS

Matthew T. Compton, President
Tracy Cleghorn, Vice President
Rocky Williams, Secretary
Douglas Hartsough, Treasurer
Paul Brayshaw, Past President

PUBLICATIONS COMMITTEE

Bob Marks, Chair
Margie Yancey, Vice Chair
Jill Williams
Barbara Chang
Lori Long

MISSION

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

Dateline Federation is published four times a year by the HFA, 210 7th St., Ste. 200B, Washington, DC 20003. Toll Free Number: 800.230.9797; Local Number: 202.675.6984; Fax: 202.675.6983. Requests for permission to translate and/or reprint contents of *Dateline Federation* should be directed to the Editor at info@hemophiliafed.org. *Dateline Federation* is available as a PDF file from the HFA website at www.hemophiliafed.org.

DISCLAIMER

The material provided in *Dateline Federation* is provided for general purposes only. HFA does not give medical advice or engage in the practice of medicine and recommends that you consult with your physician or local treatment center before beginning any form of treatment.

© 2012 Hemophilia Federation of America.
All rights reserved.

CONTRIBUTORS

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

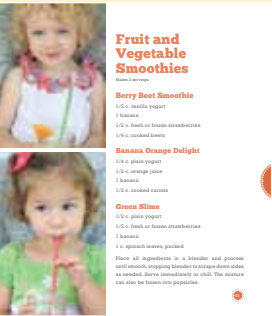
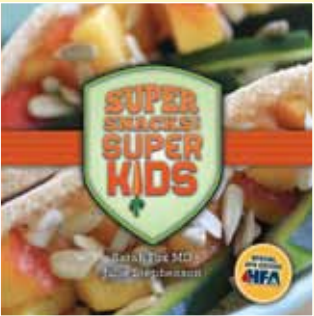
Rich Pezzillo, Communications Manger
Shelly Mattson, Editor
Kristin Mitchell Design, Graphic Design
Justin Levesque, Graphic Design
Michael DeGrandpre, Graphic Design
Gina Sierra, Photographer
Melissa Lathlean, Photographer
Todd Pitman
Vaughn Ripley
Billy Conde Goldman
Linda E. Wyman-Collins
Sadaf Ahmad
Jill Packard
Wendy Owens
Mark Antell

Together We Are Creating a Healthier Community

By Janet Chupka

At 6:30 a.m., the alarm clock went off. Some chose to hit the snooze and opt for more sleep. Many chose to drag themselves out of bed, throw on some sweats, and head down to lobby to awaken their bodies with a refreshing brisk walk, or more gently with some simple yoga. At Symposium 2013, participants were afforded the opportunity to join in wellness activities and gather health information throughout the weekend. The theme of Symposium 2013 was T.E.A.M.: Together Everyone Achieves More. It was with this in mind that the FitFactor activities for Symposium 2013 were planned. Whether it was participating in the morning walks or yoga, moving and dancing with the Nia group, creating a healthy snack, or centering yourself in the meditation and sound session, individuals were offered the opportunity to learn about and experience different wellness practices together.

Wellness is generally defined as a healthy balance of the mind, body, and spirit that results in an overall feeling of well-being. There is not a “one size fits all” approach to wellness. Individuals must find a form of physical activity and healthy practices that fit their needs, ability, and lifestyle. The FitFactor Lounge, located in the Exhibit Hall, exposed the attendees to a wide range of wellness practices. Participants had the opportunity to relax with free, 10 minute chair massages, or listen to and experience the benefits of meditation & sound healing with Randall & Kristin Brooks (www.thebhaktihouseband.com). They also viewed a demonstration and then participated in the martial arts for physical activity, self-defense, and psychological benefits. Jule Aguirre (www.juleintheLOTUS.com) demonstrated the art of Nia dance, which connects the mind, body, and spirit through movement to music, and then encouraged us to join her with her lively music and positive energy. There was also an opportunity to ask questions and learn about holistic medicine from Naturopathic Physician Kimberly Wilson (www.innovationswellness.com).



The quest for wellness should begin at a young age. The FitFactor team encouraged healthy choices for the children at Symposium by providing each child's family with a special HFA edition of the *Super Snacks for Super Kids Cookbook*. Nutritionist and yoga instructor Barbara Capasso joined the children and shared some information on the benefits of eating healthy foods. She shared with them which vitamins and minerals are especially important to people with a bleeding disorder and what types of foods contain these nutrients. Barbara also did a demonstration of one of



the recipes from the cookbook and had the children make their own to eat for their snack. All of the children (ages 5-12) participated, and most of them tried their creations (some of them saved them for mom or dad to try). They were pleasantly surprised at how delicious something so good for them could taste!

Whether you were an early riser joining us on our fitness walks or for morning yoga, a recipient of a wonderfully relaxing massage, a participant in creating your own healthy snack, a mover and shaker on the dance floor, or a participant of any of the FitFactor activities, the FitFactor team applauds you and appreciates the effort you make in accepting responsibility for your own well-being. As an individual, you are creating a healthier you. **TOGETHER we are creating a healthier community. GO TEAM!!!**



Symposium 2013 TEAM Together Everyone Achieves More!

Each year, Symposium brings community together to connect with old friends and the opportunity to make new connections. Beyond social-networking opportunities that creates fundamental relationships within our community, Symposium offers educational sessions that address the health and wellness needs of the bleeding disorders community. We hope you went home armed with a sense of empowerment in your journey of becoming strong self-advocates!

In tandem with our 37 state based member organizations, HFA brought together over 700 moms, dads, caregivers, spouses, siblings, and stakeholders from all across the United States to Frisco, Texas. We already can't wait for our meeting next year that will celebrate our 20th anniversary! ■■



"HFA's 2013 Symposium was like a great big family reunion — food, fun and fellowship with a healthy dose of education! It was great seeing old friends and making new ones, but the knowledge gained from world class speakers was the greatest benefit of all!"
-Brendan Hayes,
Texas Central Executive Director





"As a first time Symposium attendee I was so impressed by the personal feel to the conference. I felt that everything was geared towards the membership and allowed for plenty of interaction with the speakers and other attendees. I can't wait for future meetings."

-Aaron Reeves



TEAM
Together Everyone
Achieves More



"Informative sessions and good friends, made for another great Symposium. See you next year!"
-Chad Stevens

HFA Annual Awards

Each year, HFA recognizes the service of special volunteers who have stretched above and beyond with their contributions to make a difference in the bleeding disorders community. Nominations are collected across the country through HFA's board and 36 member organizations. HFA's board of directors has the responsibility of casting the vote for who will receive these awards of distinction.



Charles Stanley Hamilton Legacy Award:

Christopher Walsh, MD

Award for extraordinary lifetime service that encompasses volunteerism, professionalism, and leadership.



TEA (Teach, Empower, and Advocate) Award:

Danielle Nance, MD

An award to an outstanding woman who supports women's bleeding disorders issues.



The Terry Lamb Health and Wellness Award:

Patrick Lynch

Award for exceptional commitment to supporting and encouraging health, nutrition, and wellness behaviors in the bleeding disorders community.



Ron Niederman Humanitarian Award:

Dave Cavanaugh

Award for extraordinary service to the community via one's professional service and work.



Volunteer of the Year Award:

Stanford Murry

President's Award:

Judy Igelman

Michael Davon Community Service Award:

Jim Holmberg

An award for extraordinary service to the community via one's volunteerism and charitable giving.



Symposium 2013: A Dad's Perspective

By Todd Pittman



Fifteen years ago, my life was changed when my second-born son, Christopher Todd, was diagnosed with hemophilia. His blood does not clot properly due to severe factor VIII deficiency. This seemingly invisible disorder has had the greatest impact on my family and involvement in the bleeding disorders community.

I started attending local chapter events with the Northern Ohio Hemophilia Foundation (NOHF) serving as a peer-to-peer counselor. My family and I would speak to and help answer questions from new families who had a child diagnosed with hemophilia. Through the local chapter and support from HFA, we started a Dads in Action (DIA) program in our area. For the last 2 years, I have served with Ray Volney as co-chair for our local

DIA group, and have since expanded my role on the national level by becoming a trained speaker and facilitator.

This past April, I was fortunate enough to attend my second HFA Symposium. The event is filled with educational sessions and fun activities for the entire family. Every day offered a new opportunity to select from a wide variety of issues that addressed relevant topics like medical, psychosocial, and advocacy.

This year in particular started off on a high note when I participated in a roundtable discussion Friday morning with other dads in the bleeding disorders community. Each participant told their story about how a bleeding disorder has impacted their family respectively and shared how personal tales of hardship and struggle brought our families closer together. We all could relate to the tragic stories of late night visits to the ER, as well as the humorous side of raising a child with a chronic illness. The roundtable allowed our stories to be told with the idea of encouraging others to understand that they are not alone.

Following the video shoot, I attended a basketball game that encouraged teenagers to become more active and involved in a physical activity. Sadly, my team ended up losing in the championship, but the event created a winning experience for all that participated. There were no NBA all-stars or first round draft picks. In fact, there were a few players who had never stepped foot on a basketball court before. However, this achieved success by simply getting teens and adults up and active. In the end, everyone walked with great memories, a team photo, and jersey.

On Friday night, Dads in Action hosted Family Game Night in conjunction with the Blood Brotherhood's Poker Night. The event was a major success as it fostered interaction between so many different people and families. Young and old were involved in high-spirited, friendly competition and fun, including two large poker tables set up for those willing to test their skills. Laughter and smiles filled the room and lingered long after the final card was played.

On Saturday afternoon, different tracks offered sessions for specific groups at Symposium: Blood Brotherhood, Blood Sisterhood, and parents. On the parents track, dads and moms were together for a general session, then broke out into separate groups (it was great to see 25+ dads at ours!). Dr. Lauren Mednick from Children's Hospital Boston got us started with a great presentation called, "I've Got This: Helping Our Children Help Themselves." Like many areas of parenting, a lot of the information was common sense, but Dr. Mednick also shared useful new ideas. We learned that encouraging your child to take more responsibility for healthcare tasks starts with understanding adherence.

In general, the prevalence of poor adherence to medical regimens in children with chronic illness is 50% or more. A global hemophilia survey conducted in 2006 identified 7 common factors affecting adherence:

1. Inability to understand potential benefits (75%)
2. Denial (67%)
3. Poor venous access (66%)
4. Lack of parental/family commitment (75%)
5. Interference with lifestyle (62%)
6. Teenage rebellion (48%)
7. Lack of time (42%)

Dr. Mednick shared age-specific barriers to adherence and methods to increase success. She also suggested some age-appropriate tasks that parents might encourage their children to take on. Several strategies were consistent across the ages:



- Address the specific barrier complicating adherence
- Include the child/adolescent in developing strategies
- Start from where the child/adolescent is at, gradually increasing goals, while working towards the ideal
- Develop a consistent, predictable routine around medication taking
- Plans need revision over time
- Provide attention when the child/adolescent is engaging in positive behavior and praise cooperation frequently

As the father of a teen who has hemophilia, I have seen great strides in my son with taking ownership and helping himself. Christopher first started this process by helping to mix his own medicine and later by pushing the factor through the syringe. He is now able to self-infuse his medication and take ownership of his condition. I feel it is important and beneficial to be involved in getting your child active in this process. Positive reinforcement can only lead to bigger achievements later in life.

The conference ended with a trip to a local ballpark for food and fun. Families were able to get autographs from the team before the game started and a photo booth provided the opportunity to pose for your very own baseball card. Despite the home team coming up a little short at the end, it was a great finale to a wonderful weekend at Symposium. I am grateful for the opportunity to attend as well as contribute to such a great event. **I encourage everyone to join us in 2014 as we celebrate HFA's 20th anniversary! ■■**

Todd C. Pittman was born in Canton, Ohio and is a graduate of The University of Akron. Todd is the father of three wonderful young men; Andrew, Christopher, and Trevor. Todd has served as a Peer to Peer Counselor to newly introduced families into the bleeding community through the treatment center. He has been an active board member for the Northern Ohio Hemophilia Foundation (NOHF) for the past four years. Currently he is a facilitator and Head Co-Chair for the NOHF Dad's in Action committee.



What the Gears for Good Bike Ride Means to Me

By Vaughn Ripley

Two years ago, I heard about the HFA's "Gears for Good" bicycle ride along the C&O Canal. Only two years prior to that I had ridden the C&O Canal Towpath trail from Washington, DC to Cumberland, MD (the opposite direction of the GfG ride) and was excited to ride the other way. Hearing about this ride was a fortuitous epiphany for me, as I'm always seeking new fitness adventures. This particular ride is not only challenging, but it is run by HFA and supports hemophilia awareness, which is a win-win in my book! That being said, I plan to pedal this ride every year!

As a hemophiliac, I've long been aware that fitness and overall health were especially beneficial to me and help to curb my bleeds. I have also found which activities improve my joints and which ones have ended up doing more harm than good (like rock climbing). Over the years, I've whittled down the types of physical activity I participate in and, utilizing the limited wisdom I have narrowed this list down to a few powerful exercise types. High on my list is bicycle riding. Gears for Good was a perfect fit!

My primary reason for doing this ride, as I said, is for fitness and improving my body's ability to survive trauma. When

done correctly, I've found fitness to enhance my joint strength, increase lubrication of target joints, improve my flexibility, and help my healing process when faced with a bleed. These benefits add up to create a healthier and relatively bleed-free me!

Healthy lifestyles have been proven scientifically to lengthen your life, improve your mental capabilities, lessen stress and depression, decrease your chance for heart disease, and give you more energy. As a hemophiliac, I have found a plethora of additional benefits related to my bleeding disorder. Strengthening joints not only helps to stabilize them and prevent injuries, but it also helps with repair during and after a bleeding episode. Bicycle riding is a fantastic exercise option for people with a bleeding disorder because it is low impact and builds muscle and joint strength by incorporating some of the biggest problem areas like ankles, knees, and hips.

Bicycle riding targets the glutes (your butt), quads, hamstrings, and calves. Yet this exceptionally good exercise doesn't stop there. Many stabilizers and assisting muscles come into play during a ride. Your lower back, abs, and triceps are worked during the ride as well. Even

TOP TEN REASONS to join us on the Gears for Good Ride:

- 10 Meditative effect and fresh air (instead of being cooped up in a stinky gym)
- 9 Strength and aerobic improvement (plus it builds stamina)
- 8 Boost your overall mood and self-esteem
- 7 Longevity
- 6 Burns calories (and, most importantly, fat!)
- 5 Improves coordination and balance
- 4 Low impact exercise
- 3 Strengthen joints (knees, ankles, and hips)
- 2 Raising money and awareness for an amazing cause
- 1 Meet and hang out with some incredible people who are living with a bleeding disorder, just like you

the forearms, shoulders, upper back, and chest come into play while riding your bike. Suffice to say that bicycle training targets the legs and works the entire body out. On top of the muscle gains, it is also a wonderful cardiovascular workout that helps the respiratory system too. Riding builds muscle, burns fat, increases your cardio and respiratory capacity, and adds years to your life to boot!

As you can see, I'm a huge fan of riding. And, I think it is one of the primary reasons I experience fewer bleeds and problems related to my hemophilia.

In addition to the obvious anatomical improvements, the ride has also helped me to build several lifelong relationships with other "bleeders" and their parents from around the country. These connections have fostered a healthier lifestyle and improved knowledge for me. The

amount of friends that I have from the bleeding disorder community is growing each and every year. Gears for Good is a big part of that growth.

As you guys and gals know, the overall theme of this summer's issue of *Dateline* is T.E.A.M (Together Everyone Achieves More). I believe that the relationships and benefits that you will receive from the Gears for Good ride is a perfect example of what T.E.A.M. stands for. As individuals, we can only go so far, but when we team up with like-minded folks who are having similar experiences, we increase our ability to learn and grow exponentially! It is imperative that we do things on a daily basis to improve ourselves, and this is a wonderful avenue to do just that with a group of amazing people.

If you are (or someone you know is) living with a bleeding disorder, I would highly

recommend this extraordinary ride as a way to improve your overall fitness abilities, create new friendships, enjoy some of the most stunning scenery you will ever experience, and to glean abundant information, experience, and knowledge from a fantastic collection of diverse, caring people!

Come join my "easy bleeding" friends and me this September on this momentous ride to raise awareness and help our brothers and sisters in the bleeding community!

For more information, check out the website: www.GearsForGood.com ■ ■

Vaughn Ripley is a certified personal trainer with the NSPA. He's also the author of "Survivor: One Man's Battle with HIV, Hemophilia, and Hepatitis C". You can read more fun-filled information at his blog: www.hivlongevity.com

3rd ANNUAL **Gears for Good**

Pedal With a purpose

CHARITY BICYCLE RIDE

SEPT. 27-29, 2013

Register Today!

www.GearsForGood.com

3 DAYS – 156 MILES
West Virginia to Washington, DC

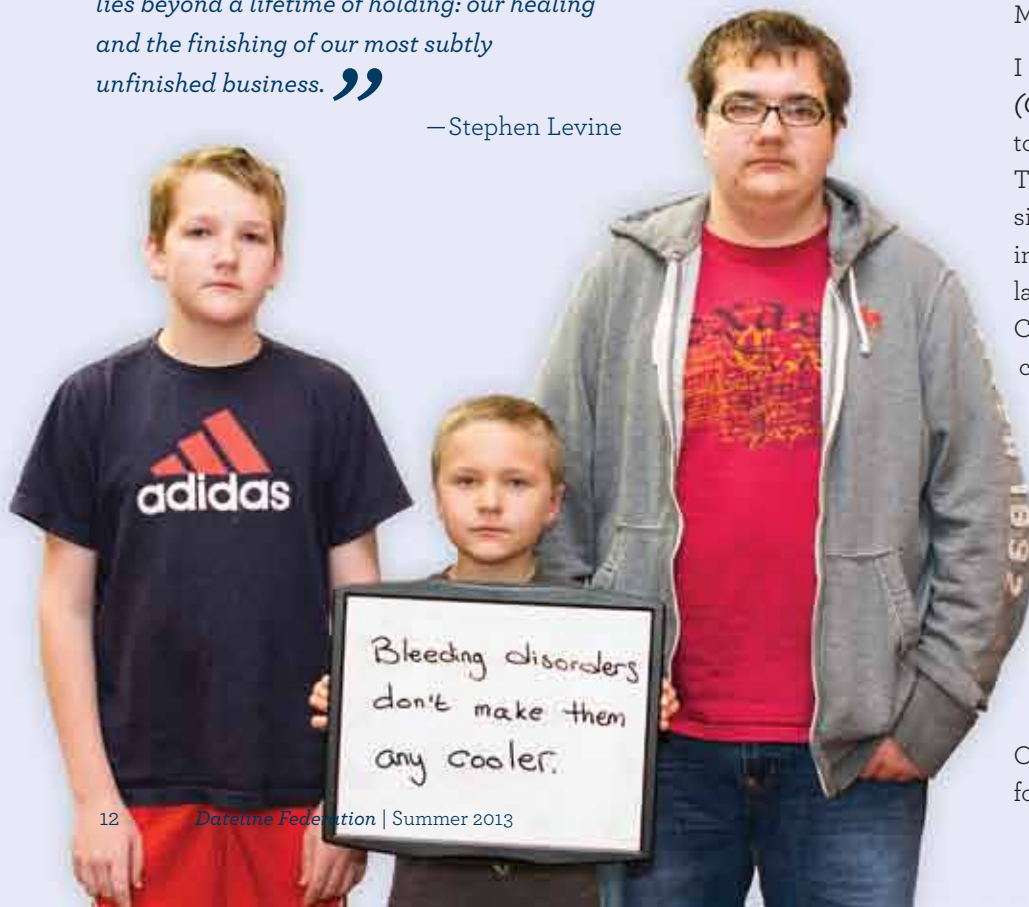
An Experience I'll Remember for the Rest of My Life

By Billy Conde Goldman

HFA's Blood Brotherhood is a national program for adult men living with hemophilia or von Willebrand Disease (vWD) that provides social support, promotes health and wellness, and establishes a sense of community. HFA has partnered with thirteen member organizations across the country to deliver local Blood Brotherhood groups. HFA sponsored scholarships for thirteen Blood Brothers to attend Symposium 2013 in Dallas, Texas. Oregon Blood Brother Billy Conde Goldman shares his experience below as a first-time attendee of Symposium.

“Grief is the binding alloy of the armoring about the heart... Opening the heart to the mind's pain, we find space to explore mercifully... We enter directly into our grief, encouraging it to reveal its deepest nature. So we discover what lies beyond a lifetime of holding: our healing and the finishing of our most subtly unfinished business.”

—Stephen Levine



This was my first time attending HFA's annual Symposium.

I was born in 1964, a Gemini Dragon with severe hemophilia A. Even though I've had hemophilia for years, I've only recently begun meeting others with hemophilia. I am navigating with curiosity, resistance, and excitement.

Symposium began for me with the *Remembrance Ceremony*. Given my past isolation from the community, I do not know anyone with hemophilia who has died. However, I was moved by the words of loving affirmation. It got me thinking/feeling about my mother, Myrna Colton-Gillette, who died in 2007. The next day, I awakened early in the morning with tears and smiles of gratitude for her advocacy for my care and on behalf of the hemophilia community when I was a child in Watertown, Massachusetts.

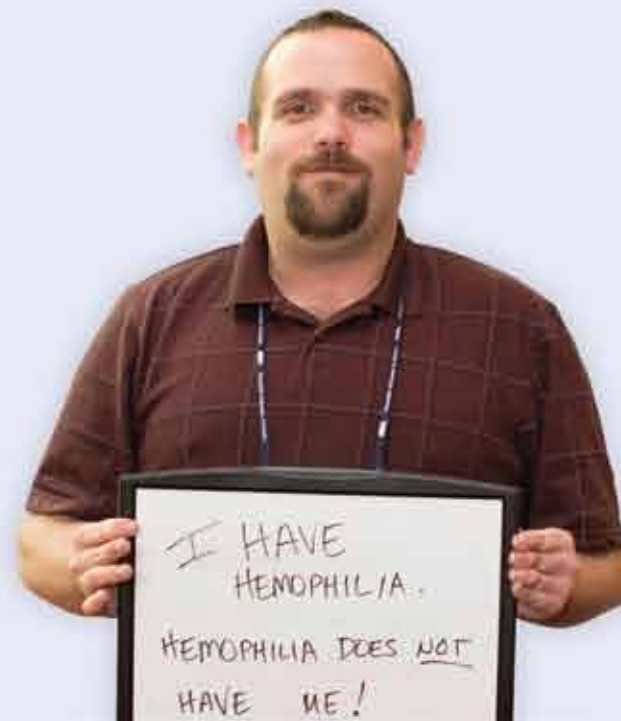
I attended the Committee of Ten Thousand (COTT) Town Meeting—an inspiring participatory forum for communication and discussion. There, I saw passion, commitment, and responsibility in action. Changes in health care and insurance were discussed. A dedicated vigilance is needed to monitor these issues, and COTT is doing that work. Also discussed was creating a national living memorial for people with hemophilia who have died of HIV/AIDS and Hepatitis C. This is important for the hemophilia community and for the country as such a memorial acknowledges those who have died and serves as a potent reminder for the ongoing importance of the safety of the blood supply for one and all. Being especially moved by this presentation, all I have to say is, “Long live COTT!”

On one of the breaks between programs, I was fortunate to meet Gary and Karen Cross. Gary

wrote Vial 023, a book that documents the life and death of his son, Brad, who had hemophilia, and the involvement of Gary and his family and colleagues in the hemophilia/pharmaceutical company settlement. Vial 023 is a powerful and moving memoir and history of the tainted blood tragedy.

Symposium concluded for me with the Blood Brotherhood Rap Session. This was the largest gathering of people with hemophilia I have experienced. Everyone in the room had hemophilia. It was an incredible feeling to be among people like me and be part of this convergence of blood friends. Knowing that each person had their own story about their triumphs and trials from hemophilia provided a sense of community and family like atmosphere. There was much to share and learn from each other. I was reminded about the challenges presented by having just hemophilia and no co-infections. While there have been significant advancements in hemophilia treatment since I was child, improved care, physical, psychological and spiritual challenges remain. Hemophilia impacts the whole being, and attention needs to be given to this full spectrum of needs. The Blood Brotherhood program is a gift and a valuable resource. May it continue to thrive!

The HFA symposium was an awe-inspiring and awareness-raising experience for me. Many thanks to the Hemophilia Foundation of Oregon and the Hemophilia Federation of America for financially supporting my presence and allowing me to be part of an experience that I will remember for the rest of my life. ■■



“The Blood Brotherhood program is the best pill in my bag, the best friends I could have, the healthiest thing to come my way in a while.”

—Blood Brother



Informed Consent Toolkit

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

As a patient or a parent of a child with a bleeding disorder, you may, at some point in time, have the opportunity to make a decision to participate in a clinical trial for a new factor product, a research project, or the genotyping project. This decision should not be taken lightly. All your questions should be addressed and you should thoroughly understand what you are signing. You should research the study or clinical trial on your own, as well. Don't ever feel rushed into signing anything. Consult the three national organizations (HFA, NHF, & COTT) for guidance and more information. You can research any clinical trial online. Go to www.clinicaltrials.gov. Check with your local hemophilia chapter and see what information they have or questions they can answer. Investigate the clinical researchers involved in the studies or projects.

ClinicalTrials.gov is a website that provides patients, family members, health-care professionals, and other members of the public easy access to information on clinical studies. The information is provided and updated by the sponsor or principal investigator of the clinical study, and the website is maintained by the U. S. National Library of Medicine at the National Institutes of Health.

Informed consent, the foundation of ethical research, includes four major ele-



ments: disclosure of essential information to the subject, comprehension, competency, and volunteerism¹. According to the Nuremberg Code, the subject should have sufficient knowledge and comprehension of the elements of the subject matter involved to enable him to make an understanding and enlightened decision. Informed consent implies not only the imparting of information by the researcher, but also assessing the subject's comprehension of the benefits and risks of and alternatives to participating in the research. The U. S. Department of Health and Human Services regulations relating to research of human subjects² state that the information that is given to the subject should be written at a reading level understandable to the subject, use lay terminology (not professional jargon) and be worded without loaded terms that might coerce a subject into participating in the study without understanding its terms.

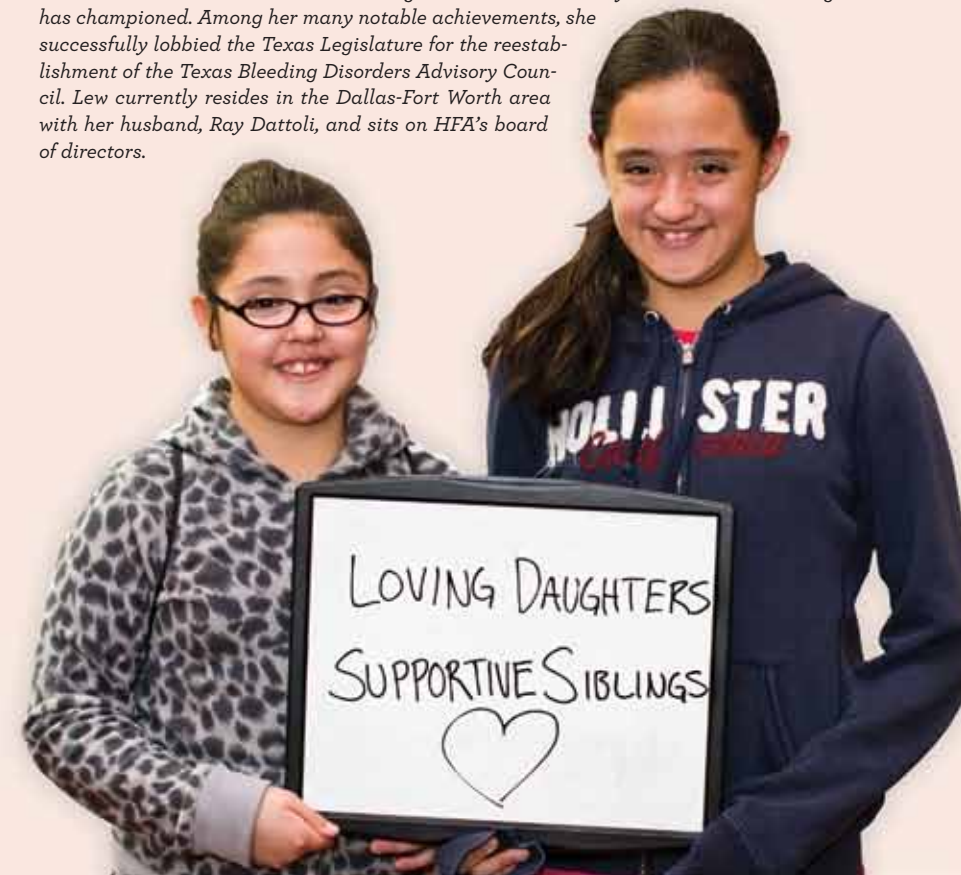
In the United States, the average reading level is no higher than the eighth grade. The average reading level of Medicaid enrollees is about the fifth grade. A 7-year old, in some cases, can sign a consent form. Despite this fact, research consent forms are often written at a college or graduate school level.

Also, make sure you know who has access to the information collected and the results. You should know who ultimately will own the information. Consider if the data will affect not only your generation but future generations. Will the information collected or the results make an impact on your future employment or access to insurance coverage? Once you opt into a study, you can opt out, but they get to keep the information you have already given them. You do not get it back, if so stated in the consent. If you are signing your minor child into a study, consider how it will affect them in the future. Don't be afraid to ask questions. Take all the time you need to truly give informed consent! ■■

¹ Elizabeth Winslow, PhD, RN, FAAN

² 21. C.F.R. Section 50.20

Linda "Lew" Collins is a clinician, lobbyist, educator, community activist and volunteer that has dedicated herself to improving the lives of those living with hemophilia. Her passion and commitment to education and awareness about bleeding disorders is evident by state and national legislation she has championed. Among her many notable achievements, she successfully lobbied the Texas Legislature for the reestablishment of the Texas Bleeding Disorders Advisory Council. Lew currently resides in the Dallas-Fort Worth area with her husband, Ray Dattoli, and sits on HFA's board of directors.



Thank You!

Your support makes it possible to serve our community nationwide!

2013 HFA FUNDERS AND SPONSORS

**\$500,000+
VISIONARIES**

CDC Collaborative Partners

**Supports:*
Blood Brotherhood
Fit Factor
CHOICE Project

**\$300,000+
CHAMPIONS**

Baxter
Novo Nordisk, Inc.

**\$75,000+
BENEFACTORS**

Bayer Healthcare
Pharmaceuticals
Biogen Idec Hemophilia
CSL Behring
Grifols USA
Pfizer Pharmaceuticals

**\$50,000 +
Grifols USA**

**\$10,000+
FANS**

AHF, Inc.
ARJ Infusion Services
National Cornerstone
Healthcare Services
Hemophilia Alliance

Responding to Challenging Circumstances

By Sadaf Ahmad



HFA's Helping Hands Program is an urgent financial assistance program that provides aid to individuals and families to assist in crisis situations with expenses such as housing, transportation, and utility bills.

HFA conducted a survey of Helping Hands (HH) applicants to understand the program's impact and assess the experiences of the most vulnerable members of the bleeding disorders community. Through phone and email outreach to over 250 households, HFA maintained its connection to those who benefitted from the HH

program's emergency assistance funds from 2011-2012. Over 70 households responded to the survey. By listening to the suggestions of HH survey respondents, we hope to improve the program and make further developments to address the needs of the bleeding disorders community.

A final report will be published later this summer. Our preliminary findings showed that the Helping Hands program was crucial to keeping families afloat during a financial crisis. A total of \$246,449.04 was distributed to approximately 470 households from January 1, 2011 through December 21, 2012 towards rent, mortgage, utility bills, and car payments. Overwhelmingly, HH survey respondents continually mentioned how much they appreciated the financial assistance they received in their time of need, with 91% rating the HH program as very valuable. Overall, most HH respondents found the guidance and resources provided useful during their time of crisis.

Respondents faced the precarious situation of maintaining both physical and financial health when grappling with a chronic condition affecting themselves or a family member. As suspected, in this economy, job loss was a significant factor contribut-

ing to challenging financial circumstances. Medical bills and being behind on other bill payments were the other factors leading to difficult or similar financial circumstances.

OTHER REASONS SPECIFIED INCLUDED:

- Lost wages with reduction in hours and bonuses
- Poor health/disability preventing steady income
- Lack of financial aid for college with lack of steady income
- Single parent income supporting multiple family members with bleeding disorders
- Unemployment due to caregiving responsibilities for a family member
- Family members with other diseases requiring expensive treatment
- Change in household (e.g. birth of new child or parents/children moving back in)

HFA would like to sincerely thank all of the respondents of this survey for their time and participation. HFA remains committed to serving the bleeding disorders community facing financial difficulties and looks forward to how we can meet the community needs. ■■



Follow HFA on Social Media!



LIKE US
on FACEBOOK

keyword: Hemophilia Federation of America



FOLLOW US
on TWITTER

@hemophiliafed

The Homecare That Cares!

AHF's® homecare pharmacy works exclusively with bleeding disorders.

We operate on **two principles...**

Superior Service
100% Client Satisfaction

Community Involvement
Donating a Large Percentage of Proceeds Back to the Community with Countless Volunteer Hours

Independently Owned Family Operated

800-243-4621
AHF@AHFinfo.com
www.AHFinfo.com



One of HFA's Largest Homecare Donors!

You can help keep our community's safety net intact! Become a member of HFA. In 2013, 100% of membership dues will support the Helping Hands Program to assist families in crisis. www.hemophiliafed.org/donate/become-a-member

Come On In, the Water is Fine

A Moms First Time Experience at Symposium

By Jill Packard

At Symposium, I wore the same socks for two days in a row, I stayed up four hours past my normal bedtime every night, and I finally realized that I needed to brush my teeth at exactly 7:21 a.m. on Friday.

I was like a young child at Symposium: so completely engrossed in everything going on around me, that I simply forgot about proper oral hygiene. I had such an engaging, meaningful and amazing time at Symposium; my inner being was being nurtured and cared for — just not my self-hygiene!

Previous Symposium attendees might understand that sense of camaraderie and jubilation, but if you’ve never attended Symposium before, the feeling is one of pure acceptance and belonging. Symposium is like the community candy store; lollipops varying in shades of cardinal red, ebony black, and super hero blue. In choosing a lollipop, I knew that whatever lollipop I chose, each session (each lick) was going to change me both as a mom and as a person. By the end, I could tell each session was created with considerate thought and loving reflection.

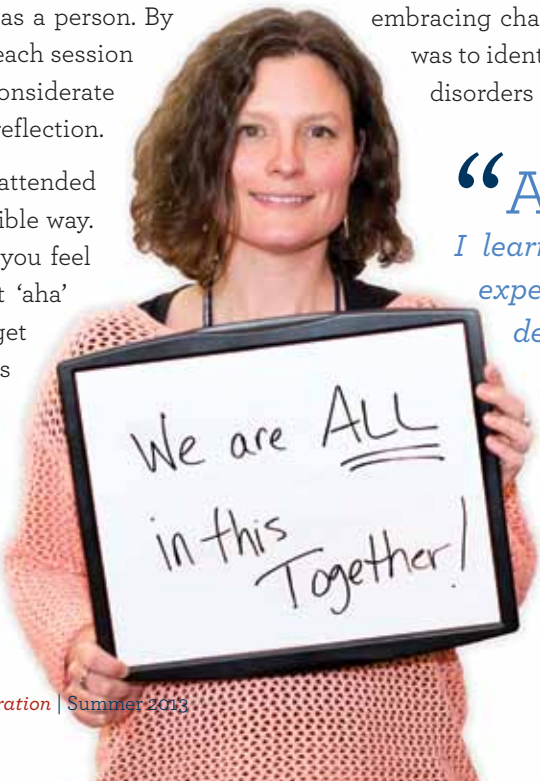
Every session I attended moved me in a tangible way. You know—the way you feel when you have that ‘aha’ moment, where you get the feeling that wells up in your chest and your body tingles a little? Each education track had a class that spoke to me and said,



“Come and learn, there is something for you here.”

My first deeply memorable experience was attending the Remembrance Ceremony. What I realized at its conclusion was how important it is for us all to remember the history of this community. It’s that history that has created the spark that ignited the fire and the passion that continues to exist in the bleeding disorders community. That fire is a part of all of us.

My next memorable experience was attending the session about women and bleeding disorders. It’s so exciting to know that the community is remaining current and embracing change. As a mother and a carrier, I learned how important it was to identify my own experience and understand how have a bleeding disorders affects both the emotional and physical.



“As a mother and a carrier, I learned how important it was to identify my own experience and understand how have a bleeding disorders affects both the emotional and physical.”

One of the most meaningful experiences for me was the mom’s rap session. It was in that space that I met with other moms who experience the same flavor of “normal” as I do. It was, with those other mothers and caregivers, that I could reflect on how important it is to hear each other’s stories and create space for the new voices that needed to be

heard. Moms, along with everyone else in this community, are in a constant state of change with new information they receive every day. We can support each other indefinitely as long we trust that we all have purpose.

Symposium was wonderful and it’s my own fault that I did not make time until Friday to brush my teeth. The days at Symposium can be as busy or relaxed as you like. There is plenty to do, but no one is judging you or forcing you to go to every session or activity. Everyone there knows, in some way, the load you carry and how important flexibility is.

“If you have never been to Symposium, I hope you will consider taking the plunge. There are many other moms in the water ready to catch you! Come on in, the water is ready for you!”

In my mom’s world of tight budgets and busy calendars, I finally felt like I was being taken care of. Every meal was taken care of, if I wanted it to be. My bed was made daily. And if my children had been there, I would have known that they were always engaged. There was always something for the children to do that gave them time to connect with other people who live in their state of normal.

All around the country, especially in rural areas, you meet people who aren’t aware that a local, let alone national community exists. I can personally say that until a few years ago, I did not know that the HFA held an annual Symposium since 1999 that I could attend, as a first-timer, for a low cost. There is a community out there and it is for moms, sons, dads, daughters, young adults, tweens, teens, twenty and thirty something’s, and all of our elders. We support each other! We are all in this together!

I’m from rural Maine. Reflecting back, I realized how daunting this trip was. I had only crossed the Mississippi one other time in my life. This was the first time that attended a national bleeding disorders event. I had to let go of anything that was holding me back. For this new adventure, I had to hold my breath and take a plunge into the unknown. If you have never been to Symposium, I hope you will consider taking the plunge. There are many other moms, many other people in the water ready to catch you! Come on in, the water is ready for you! ■■

Jill Packard is the mother of two sons, ages 5 and 9, who have hemophilia A. From rural Maine, Jill is passionate about her family, connecting people, and building sustainable communities. Co-founder and interim president of the Hemophilia Alliance of Maine, Jill is also passionate about supporting the rural bleeding disorders community.

It's your life. It's our passion.

We are Biogen Idec Hemophilia and we're dedicated to you—today and looking toward the future. Through our Community Connections program, we're pleased to bring you an inspiring selection of empowering opportunities, programs, resources, and support to help make that future the best it can be. Here are just a few of the programs and resources offered through Community Connections:

- **Our passionate CoRe Team.**
To build a powerful community, we look to the people most dedicated to it—and that includes patients, parents, and outspoken community advocates. Because they've been involved for decades, this CoRe Team believes in bringing you inspiring programs, including their spirited new Webinar series, CoRe Conversations.
- **Our Motivated, Vibrant, Powerful LIFE-SKILLS SERIES.**
We're committed to helping you live life to the fullest. That's why we've created a wide range of educational opportunities to help you make the most of it.
Sign up for Biogen Idec Hemophilia's Community Connections program now. It's our way of staying connected to the community—and helping you stay connected too.

Join today.

www.BiogenidecHemophilia.com/CommunityConnections

Receive a cooler bag and more information when you register now.

© 2013 Biogen Idec Inc. All rights reserved. HEM-1000946

Blog for Mom’s Launched!

IN February we launched, “Infusing Love: A Mom’s View,” a blog dedicated to mothers in the bleeding disorder community. We are excited to introduce a group of incredible moms who will share their stories and experiences with you! We have moms from all over the United States, who are single, married, have one child, have many children who range in ages, and who are coping and managing multiple diagnoses. Visit hemophiliafed.org every Wednesday for a new posting! ■■



YOUR CHOICE, Your Voice.

By Wendy Owens

What if, in 20 minutes, you could help improve the lives of everyone in the bleeding disorders community? It is possible—if you let your voice be heard. The time is now: The CHOICE Project survey is ready! Take it online or on paper in English or Spanish. Make the CHOICE and use your voice!

Through a cooperative agreement with the Centers for Disease Control and Prevention (CDC), HFA is running the CHOICE (Community Having Opportunity to Influence Care Equity) Project. The focus of the CHOICE Project is to collect information regarding health experiences of people who have a doctor-diagnosed bleeding disorder and do not receive care at a federally-funded hemophilia treatment center (HTC). HFA is asking everyone in the bleeding disorders community to participate in this project by taking the CHOICE survey.

Together, HFA and the CDC hope that what is learned will help assure equity in the care received by all members of the bleeding disorders community. The more participants there are enrolled in this project, the more information HFA can gather. With more information, HFA has a better chance of learning what can be done to improve the health of people with bleeding disorders. This includes possibly identifying medical and social issues that require further study. There is power in this knowledge: power to change lives, improve medical care, and help assure access to the services people with bleeding disorders need.

CHOICE will provide information on what can be done to improve the health of people with bleeding disorders.

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

HFA member organizations are a key component to the CHOICE Project’s success. HFA has teamed up with seven of its member organizations in Texas, Illinois, Arizona, New Mexico, and New York to help identify people to take the CHOICE survey. The survey itself is available in English and Spanish and takes roughly 30 minutes to complete. People can take the survey online or in paper format.

The CHOICE survey asks questions about diagnosis, bleeding history, treatment, insurance coverage, quality of life, and quality of care.

The information collected from the survey will be used to understand the health of people with bleeding disorders who do not receive care at federally-funded HTCs. It will also be used to identify issues that need further understanding, such as where care is being obtained, what complications are being experienced, and what treatment is being used.

Personal privacy of the survey-takers is of the utmost importance to HFA. HFA will collect all survey information. Personal information will not leave HFA’s secure, pass-

word-protected database. HFA will compile paper-based surveys into this database and will shred and recycle the paper documents. HFA will share de-identified data with the CDC. Data shared with the CDC will include a unique identifier

33%
OF THE HEMOPHILIA COMMUNITY DOES NOT RECEIVE CARE AT HEMOPHILIA TREATMENT CENTERS.

code, but will not contain personal identifiers, such as name or address. Information from this project may be published. However, no information will be published that could identify a survey-taker.

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



Health Care Reform Update: Mandate — Schmandate

What Does It All Mean? Let’s Get Practical!

By HFA Policy Team

The final stage of changes to health insurance coverage made by the Affordable Care Act (ACA) are coming in 2014. Are you ready for these changes? Time to learn what changes are coming and how they will affect the bleeding disorders community. The next several issues of *Dateline* will offer some basics that you can use to navigate these changes.

What is the individual mandate?

The Affordable Care Act (ACA) mandates that, beginning on January 1, 2014, you **must** have health insurance. You can fulfill this “individual mandate” by having an acceptable form of health insurance. Acceptable forms of health insurance include buying a health plan from the Health Insurance Marketplace or having employer sponsored insurance, as well as having coverage under Medicaid, Children’s Health Insurance Program (CHIP), Medicare coverage, Tricare, and Veteran’s Health Program.

See the chart on the page 24 for a brief description of each type of acceptable health insurance.

Exceptions to the Mandate

There are exceptions to who is required to meet the individual mandate. These include people with a religious exemption, US citizens not living in the States, non-US citizens living in the States and any US possession, people who are incarcerated, members of Native American tribes, people without coverage for less than three months, people unable to afford coverage, people whose income falls below the federal income tax filing threshold, and people who receive a hardship waiver from the HHS secretary.

There will be a penalty for failing to have health insurance

If you and your dependents do not have an acceptable form of health insurance and do not meet one of the exemptions, from January 1, 2014 forward, you will be required to pay a penalty. This penalty is taken directly out of your annual income tax return or added to the amount of income tax you owe. The penalty for failing to have health insurance is the greater of a flat dollar amount assessed on a taxpayer and any dependents or a percentage of an individual’s or couple’s (if filing jointly) income. As people work to find health insurance in 2014, there is a phasing in of flat dol-

lar penalty amounts: in 2014 the penalty is \$95 per taxpayer, \$325 in 2015, \$695 in 2016, and adjusted annually for inflation from 2017 forward. The annual penalty amount is reduced by half for any dependents under age 18. The percentage of income penalty is calculated based on the amount of an individual’s household income that exceeds an applicable filing threshold each tax year. ACA includes caps on penalty amounts.

You now have the basic information you need to identify which way you can best meet the individual mandate. We will continue to provide practical tips and information in future issues, and you can learn more by visiting HFA’s website at: www.hemophiliafed.org or email us at: advocacy@hemophiliafed.org. ■ ■



WHAT IT IS CALLED	WHAT IT IS	WHAT TO KNOW
Employer-sponsored insurance	Insurance coverage provided to employees, and, in some cases, their spouses and children, through an employer.	If you currently have this type of insurance and expect that to continue in 2014, you are all set. You will fulfill the individual mandate.
Health Insurance Marketplace	Formerly known as the “Exchange,” this is the newest option available. This is a web-based service where consumers and small businesses in every state (including DC) can compare and ultimately buy qualified health insurance plans.	This is the newest option available and provides group insurance to individuals who previously may not have had access.
Medicaid	A federal program that provides health and long-term care coverage to certain categories of low-income Americans.	States design their own Medicaid programs within broad federal guidelines.
Children’s Health Insurance Program (CHIP)	A federal-state program that provides health care coverage for uninsured low-income children who are not eligible for Medicaid.	States have the option of administering CHIP through their Medicaid programs or through a separate program (or a combination of both).
Medicare	A federal program that provides health insurance coverage to people aged 65 and older, and younger people with permanent disabilities, such as end-stage renal disease and Lou Gehrig’s disease.	If you currently have this type of insurance and expect that to continue in 2014, you are all set. You will fulfill the individual mandate..
Tricare	Provides civilian health benefits for military personnel, military retirees, and their dependents.	If you currently have this type of insurance and expect that to continue in 2014, you are all set. You will fulfill the individual mandate.
Veteran’s Health Program	Provides hospital care and outpatient care services to eligible veterans and eligible dependents.	If you currently have this type of insurance and expect that to continue in 2014, you are all set. You will fulfill the individual mandate.

Having issues with co-pays or gaps in coverage for your hemophilia A treatment???



We may be able to help.

Bayer offers a range of programs that can help you navigate insurance questions about your hemophilia A treatment. If you're having issues with co-pays or gaps in coverage, we may be able to offer assistance. Speak with one of our case specialists to find out more.

Call 1-800-288-8374 and press 1 to speak to a trained insurance specialist!

Bayer and the Bayer Cross are registered trademarks of Bayer.
© 2013 Bayer HealthCare Pharmaceuticals Inc. All rights reserved. 04/13 KN10000213B

The impact of healthcare innovation is measured in lives.

Baxter employees around the world apply their expertise in biotechnology, medical devices and specialty pharmaceuticals to develop innovative treatments and therapies that make a difference in patients' lives.

baxter.com

Baxter



HFA Member Spotlight: Hemophilia Alliance of Maine

By Justin Levesque



Of all seemingly innocuous topics, I was recently surprised to find hiking caught in the middle of a most pernickety online debate. In one thread, athletic enthusiasts hastily poured their auto correct failing hearts out over how "The Hike" should be categorized: a recreation or a sport?

While the comments proved a riveting form of entertainment, sports fans decreed that without a sense competition, hiking is but only an outdoor activity. Empathetic Sports Fans (see: athletes who hike, sometimes), were slightly more open-minded but would ultimately find comfort in pop-song referential statements such as, "No longer a recreation, not yet a sport."

But what do hikers think of their undecided position within traditional sports canon? For the most part, people who like to hike were... well... probably off hiking and unavailable for comment. Their response to such claims most closely resembles the chirping of crickets one might hear as

they stare into the night's sky after a day's long trek. Fresh air, tall pines, spring water & camp fire. These are what fill the hiker's mind. The regard for the outdoors, self-determination and a connection to nature transcends the world's perception for these outdoor explorers.

In many ways, folks with bleeding disorders and their caregivers, our community, have learned to live similarly to the hiker's manifesto. As individuals and household members, there is a cacophony of voices that aim to guide, inform and label people who bleed. While these forces are without question necessary and important to managing our disorders, we must, like the hiker, transcend our diagnoses, seek truth, and find empowerment through the choices we make and remain confident that these choices need only be justified to ourselves.

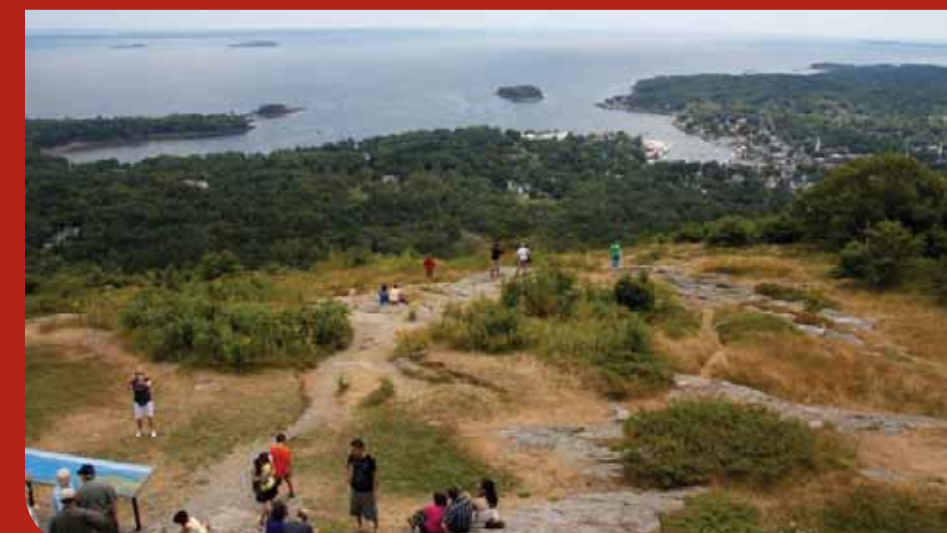
It's with these considerations (and a Thoreauvian respect for the Maine woods) that The Hemophilia Alliance of Maine has chosen the HIKE4HAM as our flagship event. On Sunday, September 22, 2013, our second annual hike will take place on the Mt. Battie Trail, Camden Hills National Park in Camden, Maine. We'll have plenty of water and lunch will be provided, in kind, by Famous Dave's BBQ. Registration and the ability to fundraise your own pledges are available online at our new website: www.mainehemophilia.org. Transportation will be provided so

that all who hit the trails can participate in strengthening the bleeding disorders community.

Can't make it to the official event? HAM invites you to hike anytime and anywhere. Like our Facebook page and share your hiking photos. You can also tag your hike on Twitter (@mainehemophilia) or Instagram using #HIKE4HAM.

We hope to see you in Maine!! The Way A Bleeder's Life Should Be. ■■

Justin Levesque specializes in the critical analysis of images and their impact on social norms & community expectations. He currently lives in Portland, Maine and runs his own design studio, Shop Geometry. He's volunteered at the New England Hemophilia Association (NEHA) Family Camp, serves as the Creative Director for The Hemophilia Alliance of Maine, and graphic designer for HFA. Justin is also a co-director of a project called "FOLX" which provides education and resources for LGBTQ bleeders.



Hepatitis C: Our History, and Advances on the Horizon

By Mark Antell

Recognizing National Hepatitis Awareness Month

The month of May is recognized to bring awareness around those living with viral hepatitis. The awareness effort encourages people to get tested for hepatitis and to evaluate treatment options. According to the Centers for Disease Control and Prevention (CDC), an estimated 3.2 million people in the U.S. with chronic Hepatitis C (HCV) are unaware of their condition. But for the bleeding disorders community, the call for increased awareness and rapid treatment is not entirely ‘on target.’

We Know Our HCV Status

Our community is unusual in the very high level of knowledge about HCV status, liver disease progression, and treatment options. That’s because the problem is both well-recognized and pervasive. From its first availability around 1968 through the early 1980s, clotting factor products were contaminated with HCV through the blood supply. An estimated 20% of those exposed beat the virus off (just like how we fight off colds). The remaining 80%, many of whom have died, are affected by symptoms that often start fairly modestly with GI disturbance, but progress toward serious, even grim, problems due to an increasingly clogged and dysfunctional liver.

Hepatitis C is a pressing issue and the leading cause of death for adults with hemophilia.

Symptoms of HCV

Health effects of particular importance to the bleeding disorders community have to do with bleeding and co-infection. Advanced liver disease clogs blood flow through the liver, causing hypertension in the portal system (which drains the blood supply to the GI tract). In turn, portal hypertension may cause stomach and esophageal bleeding, and it may cause swelling of the spleen and a consequent decline in platelets. In more advanced stages of liver disease, production of clotting factors may be reduced.

HCV is often more virulent in persons who have other health issues. Co-infection with HIV (common in our community) increases the virulence of HCV infection. On average, HCV disease progression among co-infected patients is more rapid and treatment is less effective.

What Treatments are Available Now?

The current Standard of Care (SOC) for HCV is Pegylated Interferon (p-IFN) and Ribavirin (RBV). Cure rates, particularly for people with long-standing disease and co-morbidities, are mediocre. Side effects are frequently nasty, including flu symptoms, anemia, and depression. Treatment time frames are 6 to 11 months, depending on the HCV genotype.

Neither p-IFN nor Ribavirin directly target the HCV virus. The first is an immune modulator, and the second is a broad spectrum antimetabolite. The first generation of drugs that do target the HCV virus include Telaprevir (Incevik) and Bo-

ceprevir (Victrelis). Both were approved in 2011. Disappointingly, the drugs cannot produce a cure by themselves, so they must be added to the SOC cocktail. The enhanced SOC cocktail does improve the cure rates, but it also is associated with sharply increased side effects.

Maybe Rapid Treatment Isn’t Always the Best Idea

The current therapies for chronic HCV involve taking up to a year of a powerful drug cocktail. Some do very well on this therapy, and many are cured, a wonderful outcome. However, for the most common variety of HCV most are not. The U.S. Food and Drug Administration (FDA) is aware of this and supports the development of improved therapies.

“Patients with hemophilia who acquired HCV via the blood supply before effective screening for the virus and others with prolonged HCV are more likely to have poor prognostic factors that may limit use of, or decrease the response rate to, interferon-based therapy.” — The U.S. Food and Drug Administration

The current interferon-based therapies are not only mediocre in terms of cure rate, but many find therapy a very debilitating experience. Some literally cannot tolerate these therapies due to the physical and mental side effects. The technical literature contains many claims that current therapies are “well tolerated,” but this is a misleading statement.

A minority, but growing, expert opinion has it that the current treatments for chronic HCV may often be worse for many patients than no treatment at all.

If Not Immediate Therapy, Then What?

Hopeful waiting. Three years ago, advanced curative therapies for HCV was an unproven concept. That’s no longer the case. We are not far from commercial availability of much better curative therapies. For those who have lived fairly well for decades with HCV, at least one reasonable option is to do this is simply to take care of yourself. Avoid stressing your liver with a lot of alcohol or Tylenol. A lot of people take alternative treatments such as milk-thistle. Help is coming. Over a dozen agents are in clinical testing for new therapies. ■■

Mark Antell is an HFA board member representing the Hemophilia Association of the Capital Area (HACA). Mark

is an educated layperson who is affected by hemophilia and chronic HCV. He advocates with anyone involved in HCV drug development, approval and availability, for the earliest possible access to advanced therapy for our community.

**This is an abbreviated version of a fully referenced article available at www.hemophiliafed.org.*

“Current
Hepatitis C
treatments
are difficult and often
ineffective.”

– Patient with Hemophilia and Hepatitis C



HEPATITIS C With Mild to Moderate HEMOPHILIA?

CONSIDER THIS CLINICAL RESEARCH STUDY.

AI452-030

WE ARE NOW
ENROLLING
ELIGIBLE MALES
18 AND OVER
WHO HAVE:

- hepatitis C
- mild to moderate hemophilia
- never been treated for hepatitis C or are still infected after treatment with peginterferon alfa-2a and ribavirin

Participants may receive, at no cost, study-required:

- Doctor visits
- Study drugs
- Laboratory work and procedures

Find a study site near you at
HepCHemoStudy.com



For instant access on your mobile device scan here

Medical insurance is not needed to participate. Study-related time and travel reimbursement may be provided.

To learn more about how you may be eligible to participate, visit HepCHemoStudy.com

 Bristol-Myers Squibb

137631 07/2013



210 7th St. SE Suite 200 B
Washington DC 20003
www.hemophiliafed.org

NON PROFIT ORG
US POSTAGE PAID
LAFAYETTE, LA
Permit No. 735

Thanks for being part of our family!



Check out our website
for more details!
www.hemophiliafed.org