Factor Nine News

The Coalition for Hemophilia B Winter 2010

Topics in Hemophilia

New York Constituents Ready to Walk the Hill

On Thursday, February 17, 2011, "educated and motivated" participants of NHF Annual Washington Days were ready to advocate.

Members of the bleeding disorders community from across the U.S.A. spent the day on Capital Hill talking with their senators and representatives about the implementation of The Affordable Health Care Act, HTC funding, personal stories and facts about bleeding disorders.

Advocates thanked the supporters of health care reform and highlighted specific cases in how reform has helped members of the community with the extension of dependant coverage up to age 26 and the elimination of pre-existing exclusions for children under the age of 19. The group also explained to their legislators the role of the Hemophilia Treatment center and how proposed cuts to both Maternal & Child Health and CDC funding could significantly impact access to comprehensive care provided by HTCs.

To learn more about the facts and future benefits of the Affordable Care Act, log on to www.HealthCare.gov

My Son Logan

By Tara Baugman

March 24, 2003 was one of the greatest days of my life. After giving birth to my beautiful baby boy I was in awe. March 25, 2003, not so much.

Although I was diagnosed as having a "variation" of vWd at the age of 7 (with no prior family history), I was told that my baby would be fine (my levels were normal during my pregnancy) with minimal chance of him having vWD and most likely he would have symptoms similar to mine. I had never been hospitalized or needed any kind of medication to control bleeding.

The following day, my son was circumcised and there were bleeding issues. After oozing all day, they finally took him to NICU for a unit of cryoprecipitate. The NICU doctor came and spoke with me to let me know that the oozing had stopped and that if it was vWD it was the worst case he had ever seen. On March 26, 2003, a hematologist was called in and ran tests. My son, Logan, was diagnosed with severe hemophilia B. He was put on factor and had to stay in the hospital for a few days to get daily doses while the circumcision healed.
The diagnosis of hemophilia B was a complete shock to me and my family. There was no family history that we knew of. The local HTC was great at educating me about hemophilia

B. Being a single mom I was lucky to have a very supportive family. Whatever came at us, I knew they would be there, and they always were.

Logan didn't really have any problems until he was about 7 months old. That is when the true severity of what hemophilia was really hit me. On October 13, 2003, Logan had a right front temporal subdural hematoma and had to be rushed from home by ambulance to the hospital where he had surgery to relieve the pressure on his brain. He received over 30,000 units of factor during his 14 day stay. During that time he had his first port placed. We started prophy after he was released.

For the most part, things seemed to go very well for the few months that followed. Within a week or two before his first birthday he seemed to have a lot more bruising than usual. Our HTC suggested we switch to another factor product since it had a longer half life and we did. But the bruising continued and actually became worse.

The week following his first birthday, we went back to clinic to run his levels. I remember we dosed him, a little bit later they took blood, and a little bit later it came back with a factor 9 level of less than 2% and that he had a titer level of 0.9. He was admitted that day to the hospital to start ITT with IVIG. It all seemed to happen very fast.

My mind was spinning. I thought only hemophilia A patients got inhibitors, not Bs. Well, at least that is what most of the reading had told me. I was confused, lost and overwhelmed with what this all meant. In all honesty, I had no idea what an inhibitor actually was. Logan failed ITT not once, not twice, but three times over the next few years and anyone, whether factor VIII or factor IX, knows that ITT is tedious, tiring and frustrating, especially when all outcomes point directly to fail. My Pop and I once had a discussion about ITT and possibly trying it a fourth time and he said, "that kid is great at failing." That's probably one of the reasons we have yet to try it again.

As his mom, I drove myself crazy trying to figure out why or what caused him to develop an inhibitor. I read his medical records, looked at his infusion logs and did research on the internet. I thought if I knew the why and what, it would go away. It took me a while to figure out that the why and what really doesn't matter. All that matters is that he has one.

At that time, with so little data regarding factor IX and inhibitors, it was hard to come to a truly educated decision on what is right and wrong when doing ITT. What I can say is every time Logan failed to eradicate his titer, I always felt that I, as his mom, also failed him.

There are two pieces of advice I can give to any inhibitor patient or their families is to talk to other inhibitor families. Regardless of the type of hemophilia they have, they are your best allies and can give you advice that I believe only they can give because they live with inhibitors too. The other piece is to make sure you have the support you need whether it is through other inhibitor families, HTC, private hematologist, organizations and, of course, your family. I am very lucky to have an HTC here with a hematologist who truly cares and takes her time in making decisions. I value her opinion due to her straightforwardness. Our nurse coordinator is the best (Logan has even given him a nick-name) along with all the other nurses there. I have met some great people who have inhibitors or are the parents of children with inhibitors. My family may not always understand what goes on, but the encouragement and devotion is something I treasure.

Regardless of hard times, my son is still my greatest accomplishment. He brings me laughter and joy every day. He makes me proud of his ability to tolerate all the doctors, hospital stays, and even me when I have to dose him multiple times in a day. I believe I have truly learned more from him about dealing with the obstacles in life than I learned in the 28 years before I had him. I no longer live by "what ifs." I live by "what is" and that too is something I learned from a little boy who wants to grow up and find dinosaur bones!

Life as a Young Woman with a Bleeding Disorder

By Danielle Schwager

My name is Danielle Schwager and I am a 23-year-old graduate student living in Cleveland, Ohio. I am studying to earn my Master's Degree in Higher Education Administration and Student Personnel at Kent State University. I love music, football, my family, and the city of Cleveland. I love going home, not only to grab a home-cooked meal and see my parents, but also to see our family dog, Maggie (who is always the most excited to see me!). These are all things that are obvious just by interacting with me. Something else that you may notice is my medic alert bracelet. On it you will find the words *"Hemophilia B. Treat with Benefix."* After having four teeth extracted and bleeding afterwards for ten days, I was diagnosed with hemophilia B at the age of eleven.

Initially, this was a huge shock to me. I didn't know what hemophilia was and had never heard of it before. I remember my parents, my Mom in particular, being extremely upset and angry – upset as this bleeding disorder would pose an incredible challenge to me at times throughout my life, and angry that my pediatrician didn't diagnose it sooner. She asked him multiple times while my twin sister, Heather, and I were growing up if we could be females with hemophilia, as her father was a diagnosed hemophiliac and I was constantly bruised as a child. My pediatrician told her time and time again that I was a female and therefore could not have hemophilia B.

In the years that followed my diagnosis, I learned a lot about hemophilia and bleeding disorders. I did several class projects, which helped me feel more comfortable in sharing my story with others. As an adult, I have become more involved with the bleeding disorders community, including attending local and national annual meetings, receiving a scholarship to attend this past year's World Hemophilia Congress, and joining the Northern Ohio Hemophilia Foundation's Women's Task Force.

I feel that through my volunteer efforts I have become an advocate for women with bleeding disorders and try to educate others about women and bleeding disorders any way that I can – through pamphlets, conversations, or sharing my story in articles (like this one!). It is a personal goal to spread awareness about women and bleeding disorders to the medical community and to eradicate the misconception that women cannot have bleeding disorders.

I think that some women in my situation would be angry and upset with what has happened to them. I will admit, there are times that I do get scared. As a recent college graduate, I was concerned about maintaining health insurance in case I didn't get into graduate school. While I am not planning on having children anytime in the near future, there is the reality that I could pass on this disorder to my children. Additionally, pregnancy is something I need to be concerned about, as the process of childbirth can be very dangerous for someone like me.

However, I do not see my hemophilia as a handicap. My Mom feels guilty for passing this onto my sister and me, but I understand that it is a genetic condition that is out of her control. I reassure her that while I recognize that I have limitations due to my hemophilia, I refuse to let life pass me by just because my bleeding disorder makes things difficult. I embrace my bleeding disorder and have become a stronger woman for it. I have received opportunities to travel the country and experience the world, along with meeting different people in the Northern Ohio region. I have made great friends and colleagues who support my endeavors and encourage me to keep working with those in the bleeding disorders community.

I truly strive to make a difference, and I hope that by sharing my story I can help just one person, whether it's helping someone cope with their diagnosis, encouraging someone to get more involved, or helping someone realize that they are not alone.

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One Mom's View On Having Her Daughters Tested for Hemophilia

By Victoria Schwager

My father never talked much about his hemophilia, especially to me. He never wanted me to worry. He was in his 30s when he was diagnosed with Factor IX deficiency or "Christmas Disease." He is one of the lucky ones who received factor concentrate in the 80s, but he escaped the ravages of HIV/AIDS and Hepatitis C. I was aware of his hemophilia B but never understood the implications it would pose as I started to have children of my own. When I became pregnant with twins in 1986, I understood that if I had boys they would need to be tested and if I had girls, we were "in the clear." I had girls, but that perception was wrong.

As a toddler, my daughter Danielle always had bumps and bruises that were painful and slow to heal. At age six, she fell on her head and developed a forehead bulge that slowly evolved into a facial bruise: moving from a bruise across her entire forehead to two black eyes, and eventually bruises down to her chin. I began questioning her pediatrician about the possibility of her and her sister, Heather, having hemophilia (she had bruises too), but was told, "Girls cannot have hemophilia." I should have questioned harder: not only was my maternal instinct telling me something was wrong, but I was also a nurse. She continued with more painful bruises, more testing that included a rule out for leukemia, but never any testing for hemophilia or referral to a hematologist, even with my father's history.

The Schwager family, (from left): Heather, Danielle, Kurt and Victoria

This all changed when Danielle was eleven and had four teeth pulled to make room for braces. She hemorrhaged! Not immediately, but eight hours later. Clots were forming in her mouth, but they would not hold. Her oral surgeon recognized she had a problem and he referred us to a pediatric hematologist and Hemophilia Treatment Center. After much pain, bleeding and bruising, Danielle and her twin sister, Heather, were diagnosed as symptomatic carriers of mild hemophilia B. All of these years we questioned their pediatrician, all with the same answer; *"Girls cannot have hemophilia."* He was wrong, and my daughters are not alone.

It is believed that over 3 million girls and women in the United States may have a bleeding disorder with fewer than 10,000 being diagnosed (NHF Website 2010-2011 Victory for Women with Blood Disorders Women to Women Outreach Program). Women can have von Willebrand Disease and factor deficiency problems, as well as platelet disorders. Many girls and women go through years of menorrhagia, soft tissue bleeds and needless hysterectomies. Most boys and men are diagnosed with hemophilia by age three, while girls and women are diagnosed on average within 16 years of the onset of symptoms. I also take issue with girls and women being labeled as symptomatic carriers, even though they may have the same factor level as a man who is labeled as having hemophilia. I believe this adds to the misconception in the medical community "girls cannot have hemophilia."

I feel guilty that I did not either change pediatricians or argue harder to get my daughters diagnosed earlier. I did not trust my "gut instinct" that told me they had a bleeding disorder and that their pediatrician was wrong. I now belong to my local hemophilia foundation and I am chair of our local Women's Task Force to spread awareness of women's bleeding disorders. If the boys and men in your life have been diagnosed with hemophilia and you have heavy periods, nose bleeds, bleeding after mouth surgery, or have hemorrhaged after childbirth, please talk with your physician about the possibility of YOU having a bleeding disorder. You may be one of those girls or women who have yet to be diagnosed.

A Note: From the Coalition for Hemophilia B: we have noticed from our years of survey's that there are at least 2 percent of woman with factor IX with bleeding disorders.

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CSL Behring is a proud supporter of the Coalition for its many years of service and dedication to the community.

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Product Safety – When is Clotting Factor Safe Enough?

By Chris Healey, Vice President, Public Affairs, Grifols, Inc.

The truth is, the definition of safety continues to change. In the 1980s and 1990s safety meant free of HIV, hepatitis and other viruses. In the late 1990s it meant making sure there was adequate supply during times of recombinant product shortages. More recently, Jay Epstein MD, Director of the Office of Blood Research and Review at the Food and Drug Administration (FDA) has said:
"Today, with HIV and other viral contaminants under control, inhibitor formation presents itself as the chief adverse event associated with the use of antihemophilic factor..." (November 2003 FDA Inhibitor Workshop).

Of course, the fact that HIV and other viral contaminants may be "under control" doesn't mean that manufacturers, healthcare providers or consumers can ignore the "old" safety concerns. To the contrary, as the focus on safety continues to evolve and morph, we must broaden our view and somehow maintain vigilance across all aspects of safety. This is no small feat.

What this means is that the safety of clotting factor is a shared responsibility. *"How can that be, consumers don't make the products,"* you may ask. That is true, but consumers play a huge role in the safety of clotting factor.

Many of the safeguards in place today for plasma-derived clotting factor are part of the International Quality Plasma Program (IQPP). This is a set of industry standards, different from FDA requirements, that add additional layers of product safety. Some of the standards included in IQPP are:

- Only plasma from repeat or "qualified" donors is accepted, plasma from someone who donates only once is never used.
- Every donation must be held in inventory for a minimum of 60 days so if the donor is disqualified, prior donations can be destroyed.
- Every donation must be tested using special DNA techniques called nucleic acid testing (NAT), for HIV, HBV, HCV.
- Every donor center must meet strict criteria for the health and safety of the people they attract as donors.

Although many of these standards have been in place since the mid-1990s, they too continue to evolve, change and improve. And consumer advocates have been at the forefront of many of these discussions.

More recent concerns have been the identification of viruses like H1N1 and XMRV. When manufacturers learn of such possible threats, they immediately begin challenging and checking their processes and methods to assure the safety of the products. This safety work is often done in collaboration with other companies and regulatory authorities, like FDA, so that there is a common level of understanding and knowledge. One critical element of this work is outreach to the consumer community – even as the work is progressing and not all the answers are known.

For consumers, the first step to maintaining product safety, is to understand product safety. Direct communication with manufacturers and regulators about safety concerns is an essential part of this understanding.

So, when is clotting factor safe enough? I don't think there will ever be an answer to that question. But one thing is for sure, the more educated consumers become and the more questions they ask, the safer their products will be.

The Importance of Adherence for Prophylaxis

Prophylaxis, regular routine infusion of clotting factor, has repeatedly been shown to preserve joint function for hemophilia patients. However, adherence to the treatment is equally important. Just being on a prophylactic treatment regimen doesn't do any good, if you don't take your medicine, that is, if you don't keep up with the infusion schedule. You can't make up later for the infusion you skip today.

In a 2009 article in Haemophilia, Dr. Eric Berntorp of Malmö University Hospital in Sweden explores adherence to prophylactic treatment regimens. The hospital in Malmö was a pioneer in introducing prophylactic treatment. Dr. Berntorp compares their experience with that in the U.S., where less than half of all hemophilia patients receive prophylactic treatment, and even in those, adherence to treatment regimens is low in many age groups.

Barriers to prophylactic treatment and adherence include cost, difficulties associated with venous access and the time required for infusions. Concerns around adherence play an important role in the willingness of physicians to prescribe prophylaxis, and Dr. Berntorp suggests that individualized prophylactic regimens may help increase patient adherence.

With good adherence to prophylactic treatment regimens, patients should be able to preserve their joint function, because once a joint has degraded significantly, it almost never returns to normal.

Note: According to The Coalition's survey in 2006 30% of patients were being treated on a prophylactic basis. In 2008 the percentage went up to 40%. It will be interesting to see the results for 2011. We will keep you posted.

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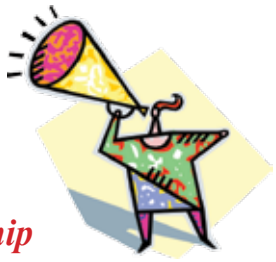
Industry News



New York City Hemophilia Chapter Announces New Leadership Glenn Mones Named Executive Director

The New York City Hemophilia Chapter (NYCHC) has announced important changes in chapter leadership, including the appointment of Glenn Mones as the organizations full-time Executive Director. Melissa Penn, who previously served as volunteer Executive Director, was named chapter President. She assumes the role from Shari Bender, who has served on the chapter Board since its inception. Although Bender recently rotated off the Board, she will continue her involvement with the chapter working on new media projects.

Mr. Mones has more than twenty years of experience at major nonprofit organizations, including senior positions at Planned Parenthood Federation of America, UJA-Federation of New York, and at the National Hemophilia Foundation where he served as Director of Communications and later as Vice President for Public Policy. While at NHF, Mones played a key role in getting the elimination of lifetime health insurance caps into healthcare reform. More recently, he has served as Director of Communications for NYCHC where he introduced many innovations to the chapters communications program and authored a successful PACT Grant application in support of expanding access to care in New York State. *"I am extremely gratified to have been given this opportunity to serve the bleeding disorders community in this exciting new role."* Mones said, *"This is a huge community with great needs but equally great potential."*

Grifols

Grifols' Introduces FlashLINK to Hemophilia: An Educational Tool to be used to assist with the management of hemophilia.

Grifols, with its Nurse Advisory Board, announces a new educational tool called FlashLINK to Hemophilia.* This interactive 4 GB flash drive contains valuable tools and educational pieces about hemophilia for parents and patients. It was developed by the Grifols Nurse Advisory Board to make it easier to educate and help keep track of routine hemophilia care.

FlashLINK is designed to be carried on a key ring and is transportable so that parents and patients always have the important information at their fingertips when they need it most. It is a tool that can help educate the patient, family, school teachers, school nurses, and coaches, as well as other physicians involved in the care of the patient and even in emergency situations. Specific material can be printed to be used as references for school or when traveling.

As payers are looking more closely at compliance and better health outcomes, the interactive FlashLINK is a great tool to help with the management of hemophilia. It is easily customized to include the patient's medical history. This information can be effortlessly updated as needed and specific patient information can be added. The various interactive forms on the flash drive that can be individualized by the hemophilia nurse or by the patient include:

- Individual emergency medical information
- Clinic follow-up sheet
- Infusion log sheet
- Inhibitor log
- Sample travel letter

Grifols hopes that parents and patients will explore FlashLINK to Hemophilia and find it a useful tool in the education and management of hemophilia. For more information on FlashLINK to Hemophilia please contact your local Grifols representative or your hemophilia nurse.

*FlashLINK to Hemophilia is not intended or developed as a giveaway or gift to any healthcare professional. Rather, it was developed and intended for the use of hemophilia patients and/or their parents.

Members of the community leadership have been invited to participate in an in-depth donor center tour, hear presentations from the company's leading scientists, and go into the manufacturing facility to see products being made.

Participants walk-away with a first-hand look at all the safety measures in place – from donor to consumer. For those who haven't been able to attend a Grifols boot camp, you can get a flavor of the program by watching a brief plasma safety video at: www.grifolsusa.com.

Scholarships

HANY Scholarship Program is available for persons with inherited genetic bleeding disorders. The deadline is June 3, 2011. Call for an application 212-682-5510.

Pfizer Pharmaceutical is offering the Soozie Courter Hemophilia Scholarship to undergraduate, graduate and vocations school students.
For more information, visit: www.hemophiliavillage.com

For a full list of available scholarships please visit LA Kelley Communication: (www.kelleycom.com)

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Vigorous research. Uncompromising innovation. Steadfast leadership. For over 150 years, Pfizer has been changing the course of diseases and lives through the introduction of new treatments. Today, with the strength of Pfizer behind us, Pfizer Hemophilia is committed to meeting the needs of the community with conviction and compassion.

Inspiration Biopharmaceuticals

Inspiration is conducting a trial on persons with Acquired Hemophilia A – OBI-1 (see link to Clinicaltrials.gov below)

http://www.clinicaltrials.gov/ct2/show/NCT01178294?term=acquired+hemophilia+inspiration&rank=1

Acquired hemophilia A is a rare but severe autoimmune bleeding disorder, resulting from the presence of autoantibodies directed against clotting factor VIII. The etiology of the disorder remains obscure, although approximately half of all cases are associated with other underlying conditions. A prompt diagnosis and appropriate management enable effective control of this acquired hemorrhagic disorder: the aims of therapy are to terminate the acute bleeding episode and eliminate or reduce the inhibitor. This disorder affects approximately one in a million individuals.

Inspiration Biopharmaceuticals is currently in Phase 3 clinical trials with IB1001, an intravenous recombinant factor IX concentrate for the treatment and prevention of bleeding in individuals with hemophilia B. In preliminary results reported at the 4th Annual Congress of the European Association for Hemophilia and Allied Disorders (EAHAD) in Geneva, Switzerland in February, the pharmacokinetics of IB1001 appear similar to those of BeneFIX®. Final safety and efficacy results are expected later in 2011.

FDA Approves FXIII Drug

CSL Behring receives FDA Approval of Corifact™ for Treatment of Congential Factor XIII Deficiency

Corifact™ is the first and only factor XIII concentrate approved in U.S. to treat extremely rare and potentially life-threatening bleeding disorder.

Last month, the U.S. Food and Drug Administration (FDA) approved Corifact™. Factor XIII Concentrate (Human), for the routine prophylactic treatment (intravenous (IV) Infusion approximately every 28 days) of congenital factor XIII (FXIII.) also known as Fibrin-stabilizing factor deficiency. This is a disorder in which the blood clots normally, but the clots formed are unstable, leading to recurrent bleeding. It is estimated that the condition affects one person in two million. With an incidence in the U.S. of approximately 150 people.

Symptoms of congenital FXIII deficiency include bleeding from the umbilical cord after birth, poor wound healing, miscarriages, subcutaneous bleeding, and excessive bleeding in joints and muscles following trauma. Patients lacking the FXIII protein are also at high-risk for intracranial hemorrhage (ICH) bleeding inside the skull that can be life-threatening.

"FDA approval of Corifact is a very special opportunity to make a positive difference in the lives of people with bleeding disorders." said Lynne Powell, CSL Behring Senior Vice President, North America Commercial Operations. For more information please visit www.corifact.com

Community News

Sandra Garcia gave birth to a beautiful baby boy. ***Santiago Emanuel Garcia*** was born on December 25, 2010. He weighed in at 6 lbs, 15 oz. Proud grandparents, Felix and Yolanda Garcia, are just beaming with joy! We wish them all much happiness!

On November 18, 2010, Amy Templin gave birth to a healthy 7 lbs, 9 oz. sweet baby girl, ***Allyson Saige Templin***. Chris and Amy are delighted to share the good news with you all We wish them all the best!

Allyson is pictured with her Christmas dress and John Deere boots!

Save the Date!

Hemophilia Federation of America Symposium

April 14-16, 2011
Louisville, Kentucky

THE COALITION FOR HEMOPHILIA B SPRING FACTOR NINE FAMILY MEETING

Visit the Coalition for Hemophilia B Booth!
Factor Nine Family Meeting Saturday, April 16, 12:15 – 1:15 pm., Room: Bluegrass1

In conjunction with the Hemophilia Federation of America Conference
Marriott Downtown Hotel, Louisville Kentucky
We look forward to seeing you!

2011 Inhibitor Summits Update

June 16-19, Miami, FL and July 14-17, San Francisco, CA
Summit for Spanish-speaking patients, May 20-22, Miami, FL

NHF has been awarded the grant from Novo Nordisk
Please visit www.hemophilia.org under "Educational Conferences"

Camp Little Oak

August 7 -13, 2011

32 Cleveland Avenue; Binghamton, NY 13905 - Near Lowville (in northern New York) 607-729-7969

Camp Little Oak, a free summer camp program especially for girls with bleeding disorders ages 7 to 17 is going into it's 6th year! The goal of Camp Little Oak is to give the girls a place made just for them. The girls will get to meet other girls just like them who share the same challenges of living with a bleeding disorder and the same hopes for the future.

Applications for Camp Little Oak will be available soon, so contact us if you're interested. We're also looking for volunteers who'd like to be counselors at camp. Please remember we can only accept a limited number of campers. Families should apply as soon as they know their girls can attend camp. If you have any questions please contact Hope or Homer. We know the girls will have fun!

Homer Everson – Camp Director
E-mail: homer.everson@ymail.com
Phone : 315-807-6170

Hope Woodcock, RN – Health Director
E-mail : Hope-mw@hotmail.com
Phone: 607-222-8412

Reminder

The Factor Nine Group moderated by Jill Lathrop is now located on Facebook search Hemophilia B Group

For back issues of **Factor Nine Newsletter** or for more information on research, please call or write to:
Kim Phelan; 825 Third Avenue, Suite 226; New York, New York 10022; Telephone (212) 520-8272
Telefax (212)520-8501; E-mail: hemob@ix.netcom.com Website: www.coalitionforhemophiliab.org