

# TEEN TALK

## Treatment Centers

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### Washington Days

The National Hemophilia Foundation took a trip to Washington D.C. for an event called Washington Days from March 1<sup>st</sup> to March 3<sup>rd</sup>. Over 200 people from all over the United States spent several days acting as lobbyists who were advocating issues on behalf of the bleeding disorder community.

Glenn Mones, NHF's Vice President of Public Policy, believes that Washington Days is an important event because people that have bleeding disorders can speak out and voice their opinions.

The Washington Day's agenda included:

- Rallying support for the Genetic Information Nondiscrimination Act as amended. This bill would prohibit discrimination in health insurance and employment based on predictive genetic information. The bill defines genetic information as information about the genetic tests of an individual or family member, or the occurrence of a disease or disorder in family members of an individual. On February 17<sup>th</sup>, 2006, the bill unanimously passed in the Senate

and has wide support in the House. NHF's rally only helped boost this support.

- A portion where attendees highlighted the need to extend Medigap policies. Medigap is an additional insurance, which you can buy to cover "the gap" in your Medicare insurance. It covers treatment that Medicare may not cover. This would allow people on Medicare, because of a disabling condition, to also use Medigap policies.
- Allowing participants to urge Congress to strengthen care for the bleeding disorder community. The participants asked for an additional 3 million dollars in funding from the Center for Disease Control and Prevention to be given to the treatment centers. Funding for treatment centers has not increased in 10 years, but the number of patients seen at treatment centers has skyrocketed. More and more people are beginning to see a treatment center annually, but the funding has not increased. As the bleeding disorder community continues to grow, funding for the

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treatment centers also needs to be increased to prevent changes in services.

As teens, we may not see the connection between government and change or the impact of changes in insurance or our access to treatment centers. Wake up – this is our future too!

Being an activist for yourself, your family, or your community is our responsibility too. While Washington Days may have been a success, next time this type of opportunity presents itself, consider participating. Speak out, voice your opinions, and do not rely on someone else to take on your responsibility or concern.

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## History and Impact of Organized Treatment

A few months ago, I attended the annual ACCESS Wisconsin Convention, a statewide meeting of the bleeding disorder community. Over the course of a day, I attended myriad seminars, each focused on a specific aspect of life with a bleeding disorder. ACCESS offered traditional lectures on advocacy and prevention, and more unique sessions on mediation as a coping mechanism. I'm sure most of you have been to, or at least heard about, similar seminars in your areas, and I don't intend to go through the details of the seminar. Rather, I'd like to explain a thought that occurred to me at the end of the convention. As I drove home that evening, I mentally reviewed the major ideas I'd taken away from the seminar, and was immediately struck by the persistence of one underlying theme. No matter what seminar I thought of or speaker I

remembered, I could not escape the truly fundamental importance of treatment centers in the everyday lives of the bleeding disorder community. I've always known that treatment centers contribute a great deal to the prevention and control of bleeding disorders, but it is still hard to really understand just how much they help us function on a daily basis.

Treatment centers collect data on management strategies from labs around the world. Because treatment centers are so closely associated with research centers, patients can be treated by professionals who are aware of the most cutting-edge research that's taking place in the field. Information on factor products is circulated through treatment centers, and in this way distributed to patients. Hemophilia treatment centers, in fact, are the only places where you can be sure to find a physician who knows how to treat bleeding disorders. It's truly amazing how many doctors and emergency room physicians have no understanding of bleeding disorders. But bleeding disorders have certainly existed far longer than treatment centers. So why were treatment centers created? What did people do without them? If you have a bleeding disorder, I'm sure you're familiar with treatment centers, and so I'm sure you're also a little curious when you stop and think about it. I found the answers, so here they are:

### Before Treatment Centers:

As early as the second century AD, some Jewish physicians became aware of a tendency for boys in certain families to bleed profusely from trivial injuries. Scholars now assume that the ancient texts in question were referring to some sort of bleeding disorder.

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Additional physicians of the eleventh and twelfth centuries seem to have recognized the hereditary nature of the condition. However, it was in 1803 that the first description of hemophilia was formally published. Dr. John Conrad Otto, a Philadelphian physician, identified the major traits of hemophiliacs, and traced a common ancestor in his patients. Hemophilia became notorious in the 19<sup>th</sup> century for its connection to the royal families of Europe.

Still, despite the gradual scientific recognition of bleeding disorders and advancements in their treatment, such disorders often proved fatal before the creation of treatment centers. In fact, if not for woman carriers, it's possible that hemophilia would have died out of the human gene pool, as it did in the royal families of Europe, because of the severe death rate of hemophiliacs throughout most of history. Treatments were crude and only marginally effective.

In 1934, when R.G. Macfarlane reported that snake venoms effectively accelerated the clotting process, this was the most advanced treatment for hemophiliacs. In 1936, hemophiliacs were treated with a bromide extract of egg white. Even in 1966, a scientific journal called "Nature" published an article claiming that peanut flour was the most effective treatment of bleeding disorders. Treatment did improve significantly with advancements in the field of blood transfusion (first attempted in 1840), but even with this technology, many hemophiliacs could not receive the care they needed.

## **The Creation of Treatment Centers:**

In recent years, officials have recognized the necessity of a system of connected institutions offering specialized care to the bleeding disorder community. In Great Britain, a government-run organization for the treatment of hemophilia was formed in 1942, though it developed and morphed over the remainder of the twentieth century into 22 Comprehensive Care Centres within the United Kingdom. In the United States, treatment centers were not formed until the last half of the twentieth century. Now the Hemophilia Treatment Center program consists of approximately 140 treatment centers in the United States, funded through federal grants.

## **Treatment Centers Today:**

Today, treatment centers exist in every region of the United States, and equivalent organizations exist in other countries. They are available to help Americans cope with the entire spectrum of bleeding disorders. Specialists at treatment centers work with individuals and their families to prevent bleeds and other damaging effects of bleeding disorders. These specialists also offer the newest, most advanced methods of treatment. According to the Medical and Scientific Advisory Council of the National Hemophilia Foundation, treatment plans are optimized when "they are...in the network of federally recognized comprehensive hemophilia treatment centers (HTCs)." For such a specific set of conditions, it is essential to have physicians and staff (nurses, social workers and physical therapists) who can invest their time solely in the understanding of bleeding disorders.

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HTC's provide comprehensive care that is coordinated treatment and care from a variety of disciplines.

Unfortunately, treatment centers are often faced with funding shortages, and a lack of physicians who understand bleeding disorders. Treatment centers must also adapt to changes in the insurance industry, an increasing population requiring treatment, and new federal mandates.

Since their creation, treatment centers have created a momentous improvement in the quality of life experienced by the bleeding disorder community. Life expectancy for the bleeding disorder community has dramatically increased. Factor treatments and other preventative measures are more manageable. Those with bleeding disorders can participate in every aspect of life, with the support of treatment centers.

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## Project Red Flag

Until a few years ago, women had an especially difficult time in discovering why they had excessive bleeding, which was not caused by the usual reasons. Doctors were never trained to think that women could have a bleeding disorder. This caused many physicians to simply dismiss a woman's complaints of excessive bleeding that often occurred during their periods. Women were "cured" through removal of their uterus (hysterectomy) so that they would not have the excessive bleeding associated with their periods. A "side effect" of this treatment meant this procedure also eliminated the possibility that a woman would be able to have future children.

In most cases, women themselves didn't even know about the

possibility of bleeding disorder like von Willebrand Disease (VWD) or that if their sons had hemophilia they may have abnormal bleeding as carriers. In fact, it is estimated that 91% of woman have never heard of VWD, which is the most common bleeding disorder.

Therefore, it fell to the few women who had bleeding disorders themselves to address the role of advocacy. If the medical professional wasn't informed, the ability to educate women about their bleeding disorder needed to be addressed some other way. The ability for women with bleeding disorders to advocate for themselves took on new importance.

In the mid and late 1990s, the energies of these initial women paid off. Excessive bleeding in women caused by a bleeding disorder was a problem that started to receive greater attention. This helped get Project Red Flag, the NHF public awareness campaign, off the ground. Project Red Flag is sponsored by the Center of Disease Control and Prevention and Aventis Behring, but is also promoted by many treatment centers and doctors. Project Red Flag focuses on VWD including symptoms and how to get tested if you think you might have a bleeding disorder. In addition, treatment centers like the Great Lake Hemophilia Foundation have supplemented Project Red Flag by receiving grant money for a program they created called Women-to-Women. The Women-to-Women program's goal is to train women with bleeding disorders on VWD and its symptoms. These women hold information sessions in the community about VWD as well as their personal experiences. These sessions take place at health fairs, Girl Scout meetings, lunch and learn in corporations, YMCAs, sorority houses,

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and local Kiwanis and Rotary Clubs, as well as any other sites you can imagine. As speakers, these women try to connect potentially affected woman to regional resources like the Great Lakes Hemophilia Foundation and to appropriate treatment centers.

Both of these programs continue to help women become diagnosed and treated.

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## Pilates

With the increased identification of women with bleeding disorders, it is important to consider the special exercise needs of these members of our community. Experiencing common bleeding disorder symptoms like easy bruising, frequent nosebleeds, or heavy periods often makes us wonder if we should exercise and how our body will react to some of the challenges of exercise. Despite this setback, teens, especially woman, with bleeding disorders are still able to stay active doing a wide range of activities. In fact, studies have shown that regular exercise helps raise levels of von Willebrand factor (VWF) by stimulating the release of adrenaline, which may help women with von Willebrand Disease.

Personally, I stay active through a type of exercise called Pilates. This was recommended by my physician, which is important for anyone thinking of starting a new type of exercise. Pilates is a type of exercise that involves yoga moves, ballet footwork, and the use of a machine called a reformer. The reformer is a big machine that has springs, wooden bars, and ropes. The reformer uses all of these devices to provide resistance. The user is able to sit

on a sliding platform and pull or push one of the devices. By pushing or pulling on a device, you are able to build strength and endurance. Another benefit is the reformer does not put much strain on the joints because it is in a position that has minimal interference with gravity. In addition, there are many interesting and fun exercises you can do on the reformer that you cannot do on the floor. This allows you to vary your exercise routine and keep it interesting.

As I mentioned earlier, Pilates also involves ballet footwork and yoga moves. I love this part of the exercise program because it allows me to do some challenging but interesting moves I cannot do elsewhere. Sometimes I feel like a ballerina, standing on my tiptoes and other times I feel like an angry cat lying on the floor. Pilates offers an entire variety of exercises and seems more geared towards teens.

I have been doing Pilates for three years and have noticed a significant increase in my endurance, strength, and my joints have become more stable. One of the keys to my success is that I have my own personal trainer who watches me exercise. This way, I do not do the exercises wrong and damage my joints. My personal trainer continually helps me improve my form and shows me new and exciting exercises. Each time we meet, I learn something new that allows my interest in Pilates to continue.

Overall, for me, doing Pilates has changed my life. I now enjoy exercise more and have a routine. Don't get me wrong, there are times my bleeding has caused me to cancel Pilates or other activities, but overall I've been able to keep this exercise up. Before, while I felt that it was important to stay fit and have a regular exercise program, I could not get into a routine or I had too many

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bleeding episodes with the exercises I tried.

No matter what type of exercise you are interested in continuing or beginning, it is essential to find something you truly enjoy and fits your situation. Stay active and be healthy! Think outside the box, maybe Pilates is something to investigate.

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## Links

In this issue of Teen Talk, we reviewed Project Red Flag's website at [www.projectredflag.org](http://www.projectredflag.org). Project Red Flag is the [National Hemophilia Foundation's \(NHF\)](#) public awareness campaign, which reaches out to more than two and a half million women nationwide with undiagnosed bleeding disorders. The campaign helps educate women and their healthcare providers about the symptoms of bleeding disorders. The primary bleeding disorder Project Red Flag focuses on is [von Willebrand disease \(VWD\)](#), as it is the most common bleeding disorder among women. Therefore, this link was reviewed based on how effective the site seemed to be in helping women identify a possible condition and empower them to get to a hemophilia treatment center (HTC).

This site would be a great starting point if you are a woman who thinks she may have a bleeding disorder and need **basic** information on VWD. All the information on this site is focused on VWD and includes information on common symptoms and how to get diagnosed. If you are really interested you can even sign up for an e-newsletter regarding Project Red Flag. This web site gives you great information on HTCs and can easily get you in contact with the

treatment center in your area. However, the end result of your internet search is dependent on how the hemophilia treatment center handles the inquiry. It would be nice to have an outline of the steps a woman could use to get to the right health professional or a HTC or access to a good testing lab. This step seems under-emphasized.

There is not an extensive variety and quantity of information. The focus on VWD is great, but it would be nice to have links to carriers or discuss carrier issues too. On the homepage, there are browse options, resources, and contact information. For every topic included on this web site, there is at least one personal account or link that led to even more information.

One problem that I encountered was the fact that sometimes the web site focused too much on personal stories and not enough on facts. While the stories added a personal touch, sometimes it was hard to separate the facts from the stories. While the stories were good, I wondered if I would tune out or easily dismiss my symptoms if I couldn't find a story that represented my personal situation.

The sitemap was good and the web pages were very well organized. The site was very straight to the point. There was lots of information packed on a page, which had a nice flow. Any teen, a science geek or not, would be able to navigate the site. The site does help the individual who wants to find information on the diagnosis of VWD and contact their local treatment center. The reading level was understandable. There were few pictures, which helped the viewer focus on the content on the page. There was no search engine, but I felt that one was not needed as the sitemap seemed sufficient. Project Red Flag's web site seems to focus on VWD,

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and has information and personal stories. Overall, the site is a good starting point if you think you have a bleeding disorder or to get simple information about it. The pages are very well organized and laid out.

The web site has lots of general information on VWD and not always many specifics. However, since the goal is to be a starting point for a large and diverse group, the main goal of the site is met.

Overall rating: Good

	Excellent	Very Good	Good	Poor
Amount of Info		Good for VWD only		
Info for Teens			*	
Easy to Use	*			
Searchable	Not Applicable			

## Guest Corner

Teen Talk is still looking for a guest columnist for the next issue! If you write and send us a publishable article concerning Advocacy, you could receive ten dollars! The article can be a story, idea, opinion, or tip! Be creative, it's up to you! The article needs to be well written and polished so we can easily put it in our newsletter. Also, limit your article to 500 words, please. So get those pens out and start writing! You can send those publishable articles to Ali and Derick Stace-Naughton at <[pjstacen@wisc.edu](mailto:pjstacen@wisc.edu)> with the subject line "Teen Talk"!

## A Behind-the-Scenes Perspective of Hemophilia Treatment Centers

Over the past half century, the treatment of bleeding disorders has transformed, advancing from primitive trial and error herbal remedies to highly specialized methods of blood transfusion and comprehensive treatment plans. Today, all of this knowledge is centralized in bleeding disorder treatment centers, devoted to helping families cope with their circumstances. But how do treatment centers work, and how can we make the most of them? To get a behind-the-scenes perspective of the treatment centers, Teen Talk had the opportunity to talk with Mary Anne Schall, Coordinator of the Region V-West Federal Bleeding Disorders program. Ms. Schall is responsible for "the administration and coordination of activities required to obtain and maintain federal funding for 13 treatment centers throughout the States of Illinois, Wisconsin, Minnesota, North Dakota, and South Dakota." This is what she said:

**Q:** What is the relationship between the Great Lakes Hemophilia Foundation and Hemophilia Treatment Centers?

**A:** Great Lakes serves the treatment centers in two ways -- as: 1) a regional core center and 2) a chapter. As the regional core center, GLHF administers the federal grants that provide funding to the centers. As the chapter, GLHF provides education, outreach, advocacy, and support services to clients in Wisconsin. Chapter services complement the services provided by the treatment centers to Wisconsin families.

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**Q:** How much do you feel the treatment of bleeding disorders has improved since you first became a part of the bleeding disorder community?

**A:** There have been significant advances in hemophilia treatment over the past 20 years. Today, youth with hemophilia who are seen through the treatment center network and participate in home-infusion therapy can expect to live longer and healthier lives. Prophylaxis, the scheduled infusion of clotting factor designed to keep factor levels high enough to prevent most bleeding episodes, has opened new vistas for youth with hemophilia - a life with fewer bleeds, decreased risk of permanent joint damage, elimination of pain, and greater peace of mind to enjoy activities and pursue careers that to previous generations were unthinkable.

**Q:** How would you suggest that patients maximize the care they receive from treatment centers and the support available through GLHF?

**A:** The two keys for assuring a longer healthier life are: 1) knowing all you can about your disorder and 2) actively participating in comprehensive care. With the improvements in clinical care, youth are reaching adolescence without the complications of recurrent bleeds. This progress, however, can be lost if they become lax about their treatment plan (prophylaxis and /or early treatment of bleeds) and their annual comprehensive assessment.

**Q:** What do you feel is the greatest problem facing treatment centers today?

**A:** The single greatest problem facing treatment centers is the lack of

funding to support diagnosis and care.

**Q:** What advice would you give to teens with bleeding disorders, in regards to injury prevention, treatment, or lifestyle decisions?

**A:** I would suggest that they develop a solid foundation of knowledge that will help guide them to make appropriate decisions about activities, safety, and treatment. I would also suggest that they give special priority to addressing the adult issues of self-care, school, career, and insurance.

**Q:** You are a key part of the Project Red Flag task force; what do you see in the future for women with bleeding disorders?

**A.** The future is brighter for women with bleeding disorders. Information regarding bleeding disorders is getting out to women and their healthcare providers. A record number of women are receiving care through the treatment center network. Women are being diagnosed earlier. There is increased research and medical dialogue focusing on women's bleeding issues. A great deal of work remains to be done but thanks to the efforts of the Centers for Diseases Control and Prevention, the National Heart Lung and Blood Institute, and the National Hemophilia Foundation, we are moving in the right direction.

*Special thanks to Ms. Schall for the time and energy that made this article possible.*

**Don't Forget to Look for  
Our Next Issue of Teen  
Talk on Planning Your  
Future with a Bleeding  
Disorder!**