Dear Friends of the HFA,

We hope you are having a great summer. The Hemophilia Federation of America is extremely aware of its responsibility to provide leadership on behalf of the bleeding disorders community. Our Board of Directors and volunteers are comprised of individuals from the community and our staff remains dedicated and compassionate to those we serve. We recognize the importance of finding a cure for genetic disorders and we support and applaud all research toward that cure. The HFA appreciates this community’s medical professionals and homecare providers who take on the challenge of caring for our members on a daily basis. We particularly appreciate this challenge, as we too embrace it daily though our efforts of improving the quality of life for those with bleeding disorders.

The HFA assists individuals and families who struggle to keep a roof over their head, food on the table and fuel in the car in order to access healthcare professionals providing quality care. We seek out other agencies that can help families burdened by extraordinary challenges. The HFA Helping Hands program has experienced a record number of first time requests for assistance this summer.

Many member organizations are hosting HFA Dads in Action sessions at their annual meetings while HFA staff, committee heads and HTC professionals are working to enhance the program. The HFA Blood Brotherhood online chats have become quite popular, hosting discussions of interesting topics dealing with the aging issues faced by adult males. Our committee has presented HFA Blood Brotherhood sessions at annual meetings and is currently planning a retreat for the fall. The HFA Focus on the Feminine committee is planning an educational exhibit for Birmingham, AL in October as part of its ongoing efforts to educate the general public about bleeding disorders in women.

HFA has been recognized for many years for its strong grassroots advocacy efforts. In keeping this tradition, HFA has made two trips to Washington D.C. over the summer, training new advocates and planning another for later this month.

The HFA does not have answers and solutions to all of the daunting challenges that are forced upon our community. However, we DO KNOW that this community has banded together to overcome many obstacles in the past and HFA will continue to collaborate with other organizations to tackle obstacles one day, and one battle, at a time. We invite you to connect with your community by joining a HFA Committee today. Your participation can make a difference in the future of the bleeding disorders community.

Susan Swindle
HFA Executive Director
Corrections to Spring 2007 Issue

The “Dear Jill: HFA’s Focus on the Feminine Q & As” article noted in front page sidebar was erroneously omitted from the Spring 2007 issue and is included in this issue on page 15.

2007 HFA Educational Symposium Exhibitors (pp 10 -11) - Photo for National Cornerstone Healthcare Services was omitted from group layout. It can be found below.

Cyril Pharmacies was inadvertently left off of the 2007 Hemophilia Federation of America Honor Roll of Corporate Sponsors. Their generous donation placed them in the SILVER ($5,000 - $9,999) category.

Hemophilia Foundation of Minnesota and the Dakotas (HFMD) was incorrectly identified as HFA of Montana and the Dakotas (p.14, HFA Advocacy News). Jim Paist, E.D. was notified and graciously accepted our apologies on behalf of his organization.

The HFA appreciates feedback, comments and suggestions for improvements from our Dateline readers. Please accept our sincere apologies for the above errors.

- Editor
HFA Welcomes New University Interns

My name is Dawn Martin and I am excited about getting to know the bleeding disorders community. I am equally excited to be introducing myself in such a way that the members of Hemophilia Federation of America can get to know me a little better as well.

I graduated with a Baccalaureate of Science in Speech Pathology and Audiology in 2001 from the University of Louisiana, Lafayette. In 2005, I returned to the university to further my interests in becoming a helping professional. I was accepted to ULL Graduate School and am presently pursuing a Masters degree in Counselor Education. Currently, I am Graduate Assistant to Dr. Irving Esters, Counselor Education Department Head at ULL. Through that role, I have the opportunity to act as a liaison between the Counselor Education department head and the students in our Counseling program. I have maintained a 3.6 grade point average and serve as president our national honors organization, Chi Sigma Iota.

The ULL Counselor Education curriculum maintains that graduate students must complete a specific amount of Practicum and Internship Hours. I have experience working with Services for Students with Disabilities (SSD), an on-campus resource for students with learning, mental, physical, and psychosocial disabilities, and with a private Vocational Rehabilitation firm. At SSD, I was active initiating educational workshops and one-on-one counseling. My experience within a Vocational Rehabilitation setting allowed me experience with job searches and placement for individuals with disabilities. Since my time at SSD, I have been busy pursuing my internship with the Hemophilia Federation of America. I have enjoyed my new position as Helping Hands Coordinator and am very grateful for all the experience it has bestowed. I am looking forward to my continued educational experience here at HFA and hope to continue my involvement with this organization professionally.

Babir Siddique, from Atlanta GA, has been quite busy since he began his Senior Communications Internship as part of his Public Relations degree program at University of Louisiana at Lafayette (ULL) this spring. Babir comes with an impressive resume and a background in Computer Technology. He is also an awesome graphic artist.

In his short time with HFA, Babir has revamped HFA’s graphics to coincide with the launch of the new HFA website. Babir has redesigned Dateline Federation’s appearance and layout. We are certain our readers have noticed this with its premier in this issue. He has designed a new portable display board that will be premiered at the HFA booth at NHF’s Orlando Conference and has also created new logos for our Helping Hands and Teen Connection Programs.

**editor’s note: Dawn and Babir will continue their internships with HFA this fall.**
HFA Visits with AHF in Connecticut

Susan Swindle, HFA Executive Director, and HFA Program Director, Carole Lancon, were invited to visit the AHF, Inc. Headquarters in Enfield, CT and attended the Donald Colburn Memorial Friends & Family Picnic, an annual AHF event. Susan was presented the Kathy Ann Keenan Award for Excellence from Mark S. Zatycka, AHF Manager of Client Relations. Carole, a registered art therapist, conducted a Magic Wand & Fairy Art workshop for the children in attendance.

The Saturday, August 11th event took place at Forest Park, Springfield, MA. Susan & Carole visited with AHF employees and their families, along with many of AHF’s clients. The family-friendly gathering featured author Brandon Mull, signing copies of his latest book in the FableHaven series, Rise of the Evening Star; games & prizes for children and adults; and a wonderful spread of food prepared by Burnt Offerings.

Susan and Carole thoroughly enjoyed the hospitality of the entire AHF staff and their reprieve from the 100 degree weather back at the HFA headquarters in Lafayette, LA.
Since the introduction of the Medigap Access Improvement Act last year, HFA has worked with NHF and COTT along with other plasma user groups to get this matter on the radar screen of our legislators. Representative Phil English (R-PA) and Representative Bobby Rush (D-IL) co-sponsored our bill in the last session of Congress and reintroduced it this year as HR 1282.

HFA sponsored a Hill Blitz in November, 2006 and another June 23-24, 2007. We invited the other national organizations, home care and manufacturers to join us in each Blitz and have two more scheduled for this year. There will be one focusing on young people as our lobbying team on August 8 and 9th and another one September 24th and 25th. During each of the last two sessions, we visited between 40 and 50 key legislators each time.

Our goal is to get this important legislation to committee and then to the floor for a vote before the end of the session. We are also working toward getting co-sponsors to introduce a similar bill in the Senate. As this article is being written, we have close to 40 bipartisan co-sponsors.

Thank you to those of you who have logged in to our Legislative Action Center to encourage your legislators to support these efforts. All of those contacts are important in reaching our goal and they do remember those e-mails, faxes and letters when we visit their offices.
We had a wonderful turn out at our Hemophilia Awareness Day event in the Legislative Building on May 15, 2007. The day began with a wonderful lunch (compliments of Bayer) where we had a chance to chat and talk about the days events. After that, we had a private audience with the Speaker of the House, Representative Joe Hackney and Representative Bob England, M.D., who was the primary sponsor of the bill.

In our meeting we discussed the current status of the High Risk Pool Bill (HB 265). We also discussed the need for adequate healthcare coverage for all, challenges facing the community and additional funding needed for HTC’s. We were very impressed with the questions that Representative Hackney posed and his interest in hemophilia. Representative England has treated patients with hemophilia in his practice and has long been an advocate for the community.

At the conclusion of the meeting, we moved to the Legislative House Chamber where the Speaker of the House acknowledged those in the audience from the hemophilia community. The bill that is going for signature to law will designate May as Hemophilia Awareness Month in North Carolina each year.

Our next opportunity to celebrate this milestone will be when the Governor signs the bill into law. We should, once again, use that as an opportunity to discuss items of interest to the community and acknowledge the recognition we are receiving. As soon as I have the date available, I will communicate it to everyone.

Our thanks to the following people who attended the event on May 15, 2007: Donna Compton, Matthew Compton, Bennett Barnes, Chris Barnes, Tim Duncan, Jim Haase, Todd Holder, Vickie Strange, Rossa Ward, & Edwin Wilson

We also would like to continue to thank Mr. Jim Haase, Bayer - Senior Regional Manager, State Government Affairs, for his efforts in guiding this act through the process. We’d like to also acknowledge Jeff Harper and his friends of the hemophilia community who came to the event but were unable to stay.

**The NC State Legislature passed HB 265 on August 2, 2007, creating a government-sponsored insurance pool for people with serious illnesses who cannot afford or qualify for private coverage. It could help as many as 14,000 people in North Carolina within 10 years.**

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Pictures from Hemophilia Awareness Day North Carolina – May 15, 2007

From left to right: The group together with Speaker of the House, Joe Hackney and Representative Bob England, M.D.; Our next generation politician, Bennett Barnes, and his mother, Chris Barnes, waiting in the Legislative House Chamber balcony
During a visit to Washington DC as delegates to the Annual PPTA Fly-In, HFA staff and board members met with Dept of Health & Human Services officials on May 9, 2007 concerning HFA programs and services; HTC funding; Medigap Legislation; Medicare Reimbursement; Medicaid Provider; Blood safety and availability; and HCV Compassionate Access. Later in the day the three HFA representatives met with a staffer on House Appropriation Sub-Committee where discussions were held about CDC funding. During the week-long Capital Hill visit, HFA staff made eighteen visits to both House and Senate offices in support of HR 1282: The Medigap Access Improvement Act. On May 9th, Paul Brayshaw, Jan and Susan had a meeting with Dr. Agwunobi, Assistant Secretary for Health.

On May 10th, Jan, Susan and Paul attended the BSAC meetings along with other representatives from the community.

Pictured Above: Dr. John O. Agwunobi, Assistant Secretary for Health, U.S. Dept. of Health and Human Services; Susan Swindle, HFA Administrative Director; Paul Brayshaw, HFA Board/Advocacy Committee Chairperson; Jerry Holmberg, PhD, Executive Secretary of HHS Advisory Committee on Blood Safety and Availability; and (seated) Jan Hamilton, HFA Advocacy Director.
For 9-year-old Hunter Day, coping with hemophilia is difficult enough. But living with the bleeding disorder became even more challenging for the young boy and his family when Hunter suffered from spontaneous bleeding into his joints. Before coming to Children’s Healthcare of Atlanta, Hunter experienced recurrent bleeds in his left ankle joint, resulting in irreparable damage to his ankle. So when the same thing began to happen in his right ankle, Hunter’s mother, Cristal, did not hesitate to seek specialist treatment quickly.

When Hunter’s symptoms did not resolve with routine factor administration, a team of physicians from the comprehensive hemophilia program recommended orthopaedic intervention. Michael Busch, M.D., Surgical Director of the Children’s Healthcare of Atlanta Sports Medicine Program determined that arthroscopic surgery was the right treatment for Hunter. The result, Cristal Day said, was that Hunter was off his crutches and playing with his friends within weeks of the surgery with no apparent long-term damage to his right ankle.

Dr. Busch said that early intervention is key to such success. “What we have learned is that joint disease starts very commonly in the joints of the knees, ankle, elbows and shoulders. This debilitating complication typically appears when children begin to walk, causing painful joint disease as early as 2 to 4 years old. Orthopaedic intervention, such as arthroscopic surgery when appropriate, can prevent this shift toward arthritis or other serious, long-term problems.

Multidimensional Treatment
In patients with hemophilia, joint bleeding arises from the synovial membrane, also known as the joint lining. Patients may not recognize small bleeds, but as bleeding progresses, they may report feelings of stiffness, fullness, pain, swelling, warmth and tenderness in the joint. As more bleeds occur, the synovium thickens and is infiltrated by blood vessels, which tend to break and bleed, perpetuating the cycle. Without appropriate intervention, this pattern repeats and leads to degeneration of the cartilage and
severe and painful arthritis, potentially necessitating joint replacement at an early age.

Much of hemophilia management focuses on eliminating or limiting joint bleeds. Patients initially are treated with infusions of either clotting factors VIII or IX— the substances that patients with hemophilia most often lack to form blood clots. If bleeding events cannot be halted and signs and symptoms persist, patients may be offered alternate treatment options, including orthopaedic intervention. However, treatment is not limited to just infusions and surgery. Treating hemophilia is a complex endeavor, requiring the expertise of many specialists.

“Children’s is part of a nationwide network of hemophilia treatment centers,” said Amy Dunn, M.D., a pediatric hematologist with the Aflac Cancer Center and Blood Disorders Service of Children’s Healthcare of Atlanta. “Being part of that network, we have a comprehensive approach to the treatment of children with bleeding disorders. Not only do we have specialists in hematology, but also in orthopaedics, physical therapy, social work, psychology, as well as clinical outreach and research nursing.”

Orthopaedic Intervention: Small Incisions, Big Gains
In 1987, Dr. Busch advanced the use of the arthroscopic synovectomy— surgery on the joint lining— in pediatric patients. Previously, the procedure had been reserved for adult patients with joint disease. At Children’s, arthroscopic surgery on pediatric patients with hemophilia is a multidisciplinary effort with intensive planning to ensure that the patient is a proper candidate for surgery. A hematologist evaluates the patient’s ability to achieve normal clotting levels with the help of supplemental factors, and a team of healthcare providers works with the family and the patient to make sure they are appropriately prepared. The surgery is performed in an outpatient setting under general anesthesia.

During surgery, the target joint is filled with fluid and a scope is inserted through small incisions. The primary issue is inflammation of the joint lining.

“The joint lining ought to look smooth and silky, like a bed sheet,” said Dr. Busch. “However, in patients with hemophilia who also have joint disease, the joint lining develops villi and looks more like a sea anemone or shag carpet.”

Dr. Busch uses an arthroscopic shaver to carefully remove all of the abnormal, thickened joint lining.

“Many parents worry about what will happen once the joint lining is removed,” he said. “The answer is that we take out the abnormal membrane and the body replaces it with a layer of smooth, healthy joint lining.”

Children with hemophilia-related joint disease also may suffer from abnormalities on the surface cartilage of the joint. But arthroscopic synovectomy allows surgeons to address both joint lining and cartilage problems during a single procedure.

After the operation, patients return home with a pump that provides a continuous infusion of their missing clotting factor protein. This ensures that their clotting ability remains at a normal level for approximately five to seven days, after which they are transitioned back to their standard treatment plan. Physical therapy is initiated the day after the procedure and continues for six to 12 weeks to help patients regain their range of motion and limb strength.

All of the pediatric patients with hemophilia who received arthroscopic synovectomy at Children’s have shown improvement. Dr. Busch estimates an average reduction in the frequency of bleeds of 80 percent to 90 percent.
“That is significant,” he said. “In turn, this helps to decrease inflammation in the joints, and in the long run, to reduce risk of developing arthritis.” Furthermore, the patients receiving arthroscopic synovectomy at Children’s rarely need additional operations on the same joint.

As with any surgery, there is a small risk of infection or damage to a nerve or blood vessel. Some patients may experience stiffness in the affected joint, particularly if the joint was previously affected by arthritis. Older patients with more advanced disease have an increased risk of complications. According to Dr. Busch, this underscores the importance of early intervention, and the unique advantages of the pediatric hemophilia program at Children’s.

“Most adults have had joint disease since childhood, and by then, it is often too late,” he said. “The earlier we intervene in the appropriate cases, the more effective we are at limiting complications and eliminating or reducing arthritis.”

While surgery can salvage the joints of some patients, it is not an option in every case. Some children with hemophilia have an inhibitor, which induces their body to respond as if they have an “allergy” to clotting factors. These patients cannot easily undergo surgery as they do not respond normally to factor VIII or IX infusions to maintain adequate clotting levels during surgery. For them, radionuclide synovectomy can be an effective procedure that both spares the joint and eliminates the need for surgery.

Radionuclide synovectomy is a procedure in which a small amount of radioactive material is injected into the joint space, scarring the abnormal joint lining and relieving pain and inflammation. There is some risk to using radioactive materials, and thus it is recommended that patients without inhibitors receive arthroscopic synovectomy. Approximately 5 percent to 10 percent of the pediatric patients with hemophilia who need a synovectomy at Children’s receive a radionuclide synovectomy each year. This makes Children’s one of the only treatment centers nationwide to offer both arthroscopic synovectomy and radionuclide synovectomy at one center.

Follow-up care after either procedure is essential. For 9-year-old Hunter, his family- with the support of the team at Children’s- has integrated his care into every part of his life. During school field trips, ice bags and acetaminophen are always close at hand. There is a pool in Hunter’s backyard, where he swims every day during the summer. He also stays active by participating in physical education classes at school and playing with his friends during recess.

“Diet and exercise are incredibly important to maintaining good joints for everyone,” said Dr. Dunn. “They are especially important for patients with hemophilia because the heavier patients are, the more pressure they put on their joints- and the more likely they are to bleed.”

Hunter’s mother said the surgery has made a big difference in Hunter’s quality of life. “I just wish we were at Children’s when he was a baby,” she said. “They saved his right ankle and they could have saved his left.”

Michael Busch, M.D., is the Surgical Director of the Children’s Sports Medicine Program and Arthroscopic Surgery at Children’s at Scottish Rite. He is also the Surgical Director, Arthroscopic Surgery, at Children’s Orthopaedics of Atlanta.

Amy Dunn, M.D., is a Pediatric Hematologist at the Aflac Cancer Center and Blood Disorders Service of Children’s Healthcare of Atlanta. She is also Assistant Professor of Pediatrics at Emory University School of Medicine.
### 2007 Hemophilia Federation of America Honor Roll of Corporate Sponsors

#### ANGEL ($100,000)
- Baxter Healthcare Corporation
- Novo Nordisk
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#### DIAMOND ($50,000 - $100,000)
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- Hemophilia Health Services (HHS)
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- Atlantic Biologicals
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- CoaguLife
- CoAg Therapeutics
- Crescent Healthcare

#### FRIEND (Up to $2,000)
- Inalex Communications
- Patient Service, Inc.
- Coalition for Hemophilia B
- Factor Foundation

*2006 donation for 2007 calendar year*

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**HFA Helping Hands Update**

The HFA Helping Hands program is one of our oldest and most valuable programs in terms of its direct effects on the bleeding disorders community.

This valuable program was launched in 1997 as a means of providing emergency financial assistance to those persons who have been affected by Hemophilia or von Willebrands. The program was designed to establish a rapid, non-invasive source of relief for emergency situations. Unfortunately, due to the enormous financial burden placed on families living with a bleeding disorder, this is a common occurrence. Helping Hands funds are used to assist qualifying families with housing, transportation, utility and other one-time emergency needs.

HFA Helping Hands’ goal is to provide a balanced program that evaluates and gives careful consideration to each applying individual/ family with a minimum invasion of privacy. All applicants must be referred thru their HTC, homecare company representative/advocate, or hemophilia state organization. For more information, visit our website (www.hemophiliafed.org) or call our toll-free number at 800-230-9797.

The Helping Hands program is partially sponsored by generous grants from Wyeth Pharmaceuticals and Hemophilia Health Services.

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**HFA Blood Brotherhood Update**

Men with Hemophilia or von Willebrands Disease can join in discussions presently taking place on the HFA Blood Brotherhood Online Forum. All you have to do is go to our website www.hemophiliafed.org, navigate to About Us/ On Line Community/ Blood Brotherhood/ Register. Once you register, you will be assigned a user name and password and then be able to join in on the great dialogue.

The Blood Brotherhood is currently discussing the pros and cons of joint replacement surgery, planning a Blood Brotherhood retreat, and discussing other issues pertinent to older men in the bleeding disorders community. The HFA Blood Brotherhood Program is partially sponsored by a generous grant from Grifols USA, Inc.
The Hemophilia Federation of America is delighted to announce the winners of their 2007 Educational Scholarships. This valuable program provides members of the bleeding disorders community and their families with financial assistance towards continuing education beyond high school. The HFA Scholarship Committee (Wayne Cook, Chairperson, Susan Dill, Peter Bayer, Lynne Capretto, and Dan Tinklenberg) worked diligently in reviewing over fifty scholarship applications and narrowed the group down to the ten winners listed below.

**Tyson Fearon** of Saco, ME is attending Albany College of Pharmacy in Albany, NY. Tyson wrote “thank you for choosing me as a scholarship recipient. It is a great feeling to know that I was thought of as being suitable for such an honor. I am expanding my knowledge of the blood clotting process and becoming more aware of advancing medical treatments for hemophiliacs. This school has also given me the opportunity to educate others … [and has] . . . helped me on my quest for pharmacy. I will not let you down”.

**Ashley Weaver** of East Haddam, CT will be attending St. Anselm College in Manchester, NH. In her acceptance letter, Ashley stated “being a person living with von Willebrands [disease], I am excited that I have chosen the path of being a nurse. I will hope that my skills in self infusing and being a patient myself will help me be a compassionate, caring and professional nurse. I had the pleasure of hosting a very successful blood drive this fall and it made me feel very proud knowing that this contribution saved many lives”.

**Michael Weintraub** of West Windsor, NJ was awarded a scholarship to University of Pennsylvania in Philadelphia, PA. Michael wrote “I thank you for your generosity. It is with gratitude and appreciation that I accept this scholarship award. My college plans include the study of biological research and medical life sciences. I have a passion for helping others through the sciences, especially addressing the health needs of children. Without scholarship patrons like HFA, students such as me would not be able to pursue the career of their dreams”.

**Nathan Strauss** from St Louis, MO will attend Harvard University, Cambridge, MA. Nathan stated “Thank you so much for the HFA Scholarship for students with hemophilia. I was honored to receive a scholarship this year and hope to do full justice to this award over the following year of my education. I am currently planning to major in mathematics and economics and earn my M.A. in statistics by the time I graduate form Harvard in 2010. This award will certainly help my family to offset a portion of the money required for my continued education”.

**Raymond Sowinski, Jr** from Beaver Falls, PA received a scholarship to Smeal College of Business at Pennsylvania State University and **Sadie Tollman** from Golden Valley, MN will attend University of Minnesota Duluth.
Two Sibling Continuing Education Scholarships were awarded. **Nicole Wright** of Stanton, NE, will be attending Wayne State College in Wayne, NE and **Anna Vetter** of Champaign, IL will attend Illinois State University in Normal, IL. Anna wrote, “I would like to thank the entire HFA for awarding me with this generous scholarship. I will be attending Illinois State University in the fall and your gift will make a difference in furthering my education. I appreciate your generosity and look forward to continuing my work within the Hemophilia community for many years to come”.

**Deborah O’Connor** from Tempe, AZ was awarded a Parent Continuing Education Scholarship to Midwestern University in Glendale, AZ. Deborah wrote, “I am truly thrilled to learn that I was one of the recipients of HFA’s scholarship program this year. A year ago I embarked on …my Masters of Medical Science in Physician Assistant Studies- and I’m loving it. I am about to begin my 15 months of clinical medical rotations and can’t wait for the direct patient care experience. HFA’s acknowledgement via the scholarship has reminded me of the generosity of the hemophilia community, and why it was so important for me to pursue this new career”.

**Molly Evers** of Pittsburgh, PA received an Artistic Encouragement Grant to the Khaiff School of Dance in Pittsburgh, PA. In her acknowledgement letter, she wrote, “Thank you… Your kindness and generosity will not be forgotten. With your help, I have no doubt that I will be able to reach my Artistic goals! I’ll be sure to update you on my progress”.

HFA congratulates all scholarship winners and hopes to see their continued involvement in HFA. They are the future leaders of our bleeding disorders community!
Teens Connecting Through HFA

This all started with a chance meeting. My father, Salvatore LiVolsi, a HFA and Hemophilia Foundation of Illinois board member, was at an NHF leadership gathering and happened to sit next to Janet Angell, President of the Hemophilia Foundation of Idaho. Janet and my father spoke and she mentioned a boy with hemophilia from Idaho who had been severely burned. The Idaho Member Organization was hosting a bowl-a-thon for him on the 14th of July. That boy’s name is Myles and this is his story.

In February 2007, Myles was severely burned in an accident. He was flown to a Salt Lake City burn center with 2nd and 3rd degree burns to over 50% of his body. At the burn center, Myles fought through blood poisoning, organ failure, blood clots, and the trial and error of treatment that the doctors had to go through because there is so little information on treating burn victims with hemophilia. After spending a month in the burn center, Myles finally came home. Myles has to endure extremely painful wound care almost every day.

My father passed on this story to me and asked if I thought I could do anything for him because I am the head of the Youth Leadership Council for the Hemophilia Foundation of Illinois. I wasted no time in making up fliers and talking to family and friends. I also contacted Janet and asked her if she could pass my email on to Myles and his family so I may get to know them. In the meantime, the Illinois foundation gathered donations. During that time period I went to Washington D.C. with HFA for a Medigap blitz. While in D.C., I mentioned Myles’ story to a few people, including Carl Weixler, HFA President. After talking to Carl for a short period of time, he said that he would see if HFA could make a donation to the benefit. With that information in mind, I decided that I wanted to attend the Idaho bowl-a-thon and present whatever donations we could obtain.

I talked to Myles’ mom, Sherry, about coming out for the bowl-a-thon and she generously offered for me to stay at their house while I was in Idaho.

So with help from family and friends, I was on a plane to Boise, Idaho Friday morning. I was picked up by Myle’s family at the airport and we went to their home. I spent a fantastic evening getting to know everyone, playing games with Myles, and enjoying a delicious meal prepared by Sherry. Saturday morning I finally got to meet Myles’ older brother Aaron. That afternoon we went to the bowling alley. At the alley, I had the great honor of presenting the check (which no one in attendance knew about) to Myles and his family. The local news station was at the bowl-a-thon and covered my presentation of the check. After that, we bowled 3 games and everyone was very glad that Myles could bowl due to the severity of the burns on his hands. He did pretty well, beating me all three games (I think) and getting quite a few strikes. Afterwards we returned to their home and enjoyed another delicious meal and a movie. I returned to Chicago Sunday morning with new friends, no, a new family, in my heart.

While staying with Myles and his family I was amazed by what Myles has gone through and what he still goes through on a day-to-day basis. Myles is truly an amazing person. He is always happy, never asks “why me?” and hardly ever complains. IF he does, its not for long since he knows that he has to endure the pain in order to get better.

The amount of pain he goes through is impossible to comprehend, even for someone who also has hemophilia. He has to get debrided almost every day, which means getting all of his graft sites scrubbed until they bleed. He also wears pressure gloves, sleeves, and a vest, and any time he has to take them off, it brings him to tears because of the blood rushing back into those parts of his body. But with all that, he hardly says a word against it.

You can find videos, pictures, and posts from Myles and his family, on their blog (http://MylesGanley.blogspot.com). This is an ongoing benefit, as the Hemophilia Foundation of Idaho will be holding another event at a date to be announced. I would like to say “Thank you” to everyone that contributed to the benefit in one way or another.

by Daniel LiVolsi
Dear Jill: HFA’s Focus on the Feminine Q & A’s

Hello! My name is Jill Williams and I’m the new advice columnist for HFA’s Focus on the Feminine. I look forward to your questions and concerns about bleeding disorders. Please send your questions to me at info@hemophiliafed.org re: FOFMQA. There’s no such thing as a dumb question – we all can learn from one another!

Dear Jill:

What do you think can be done to educate OB/GYNs on bleeding disorders so women can be diagnosed sooner?

Albuquerque

Dear Albuquerque:

Currently, product manufacturers and bleeding disorder organizations conduct outreach to physicians and medical associations such as the American College of Obstetricians and Gynecologists (ACOG). These efforts are valuable, to be certain. But each of us can, at the grassroots level, make it our individual mission to educate our personal OB/GYN and his/her office staff about bleeding disorders.

Explain your bleeding disorder – if your physician seems confused or disinterested in what you have to say, enlist someone from your treatment center, chapter or HFA to help communicate the essential facts about your particular bleeding problem. Don’t give up!

For ourselves, and for our daughters, we carry a great responsibility – to pass along accurate bleeding disorder information in whatever arena we find ourselves.

Dear Jill:

Should women with von Willebrand Disease (vWD) get a “baseline” of their joints when they are diagnosed?

Colorado

Dear Colorado:

You’ve asked a “hot topic” question in the bleeding disorders community, particular for people with vWD. Whether or not an individual with vWD can have joint bleeding is still a point of controversy among medical professionals in our community. Some treatment centers say “yes” while others insist “no.” That being said, my best advice to you is to go every year to Comprehensive Clinic at your Hemophilia Treatment Center (HTC). During the course of Comprehensive Clinic, a physical therapist examines and evaluates your joints for flexibility and strength. It is important to report any issues you are experiencing with your joints. Over time, your Comprehensive Clinic record will help illuminate any joint issues you may be having.

If a joint becomes painful, or you suffer an accidental joint injury or trauma, call your HTC right away to report your symptoms. Together, you can develop a treatment plan.

Jill Williams, a woman with von Willebrand Disease, works as a vWD Specialist for Critical Care Systems. She is a long-time advocate in the bleeding disorders community, and has authored numerous national articles, pamphlets and booklets on the medical and psychosocial issues of women with bleeding disorders.

In Memoriam

Marcus Darnell McClure, aka “The Marksman” for his hip-hop CD tracks on Hemophilia, HIV, and HEP C, passed away on Wednesday, August 08, 2007. Marcus was the son of Greg and Diane McClure. Greg is a Social Worker in Chicago IL and serves on the HFA Medical Advisory Panel.

Marcus was admitted to RUSH University Medical Center on Saturday, August 4th after suffering a stroke. Over seventy-five family and friends stopped by the hospital to say goodbye to Marcus. Others called or e-mailed the family with prayers and encouragement during their bedside vigil. Marcus passed away peaceably and without pain early Wednesday morning.

Marcus played the keyboards at the McClure family’s church and also served as camp counselor for HFI. He worked on CD projects for various Bleeding Disorder Organizations, including GLHF (The Great Lakes Hemophilia Foundation) and COTT (the Committee of Ten Thousand). His father stated that Marcus’ last words were “Jesus.” Arrangements are pending and the HFA family sends the McClure family its condolences.

Dateline Federation - Summer 2007
FLORIDA HEMOPHILIA ASSOCIATION

September 8th: First Step Mother’s Brunch – Tampa, FL
September 21st: Swim with the Dolphins, Key Largo, FL
October 1, 2007: Swing for the Kids Golf Tournament, Jacaranda Golf Club, Plantation, FL
November 1-3: FL Host Chapter for NHF Annual Meeting
December 1, 2007: Holiday Duo Picnic Fundraiser, CB Smith Park, Pembroke Pines, FL

FHA’s Compassionate Care program provides emergency assistance funds for individuals and families impacted by bleeding disorders. These funds can be utilized for emergencies affecting basic living requirements, such as rent/mortgage payments, utilities, food, and phone card to call the treatment center. If you like to learn more, please visit our website at: http://www.floridahemophilia.org/

HEMOPHILIA FOUNDATION OF NEVADA

September 15th: Consumer Expo Meeting- Reno
September 16th: Blood run- Reno
October 13th: Consumer Expo Meeting- Las Vegas
October 20th: 5k Run/1 Mile Walk- Las Vegas

GATEWAY HEMOPHILIA ASSOCIATION

September 24th: “Tee Off for Hemophilia” Golf Tournament- Annbriar Golf Course, Waterloo, IL
October: Halloween Hayride (Sponsored Event)
December 8th: Holiday Membership Meeting & Magic House

NORTHERN OHIO HEMOPHILIA FOUNDATION

September 14th & 15th: NOHF Annual Meeting, “Straight Talk About Product” Sheraton Suites, Akron/Cuyahoga Falls
October 16th: Baxter Facts First-Insurance Issues Blue Canyon, Twinsburg
December 1st: Splash Party Zone
December 11th: Baxter-Facts First TBD

HEMOPHILIA FOUNDATION OF SOUTHERN CALIFORNIA

Semi-Annual Events Regional Educational Seminars (for families with hemophilia & other bleeding disorders) Dates to be announced
September 28th-29th: Camp Malibu
Man/won Program (for adults w/bleeding disorders, spouses, partners & siblings)
Mentoring Program (for children, teens, young adults with bleeding disorders)
Call HFSC for more information 1-800-371-4123 or 626-793-6192
October 15th: Golf & Tennis Tournament
December: Holiday Party, Valley & Ventura County, Santa Barbara

OKLAHOMA HEMOPHILIA FOUNDATION

September 24th: Board Meeting-Tulsa
September: OHF Golf Classic-OKC
October 13th: Fall Festival-Glenpool
October 22nd: Board Meeting-OKC
December 1st: Christmas Party-OKC

TEXAS CENTRAL HEMOPHILIA ASSOCIATION

September 29th: Jokers Are Wild Casino Night/Gala

NEBRASKA CHAPTER OF THE NHF

September 10: James Holllrah Memorial Golf Tournament, Wilderness Ridge in Lincoln
October 7: Vala’s Pumpkin Patch

Contact Chapter office @ 402-742-5663 for details
HEMOPHILIA FOUNDATION OF ILLINOIS
September 19th  Annual Golf Outing, Cantigny Golf Course, Wheaton, IL
November 16th  Holliday Wine Auction & Dinner

HEMOPHILIA OF INDIANA
New Address:  5170 E 65th Street - Indianapolis, IN 46220
Phone Numbers:  317-570-0039-Main #,  317-570-0057-Patient Dental Service, 800-241-2873, 317-570-0058-fax

THE HEMOPHILIA FOUNDATION OF ARKANSAS
September 21-23  Family Retreat Camp Winnamocka, Arkadelphia
December 8  Christmas Party Fisherman’s Galley, Conway 1:00 p.m. - 4:00 p.m.
The Hemophilia Foundation of Arkansas exists to lend support, education, and services to the bleeding disorders community in Arkansas. Special programs include summer camp, educational meetings, patient financial assistance and more. For additional information, please contact Donna Tozer toll-free at 888-941-HEMO or email at donna.tozer@yahoo.com.

TENNESSEE HEMOPHILIA & BLEEDING DISORDERS FOUNDATION
September 22, 2007  Sporting Clay Tournament, TBD
October 6, 2007  Gala, Liberty Hall, The Factory at Franklin
November 19 - December 14, 2007  Poinsettia Sale

TRI-STATE BLEEDING DISORDER FOUNDATION
September 8th  Sleeping with the Fish – VA Beach area
October 1st  Fishing Trip – Adult Retreat – VA Beach area
October 6th  Golf Tournament - Richmond
December  Holiday Parties – Hosted by UVA, VCU, and CHKD HTC’s

HEMOPHILIA OF NORTH CAROLINA
September 28-30  Regional HTC Women’s Retreat  Lake Junaluska, NC
October 6th  Junior National Championship  Glen Allen, VA
October 20th  Tennis Tournament  Cary, NC
November  Hearts for Hemophilia-Casino Night  Raleigh, NC
December 1st  Holiday Celebration  Greensboro, NC

SANGRE de ORO / HEMOPHILIA FOUNDATION OF NEW MEXICO
October 26th – 28th  Bowl-a-Thon/Family Weekend, Albuquerque, NM

HEMOPHILIA ASSOCIATION OF THE CAPITOL AREA
September 30th  Blood, Sweat & Gears Bike Event
October 28th  Annual Educational Seminar

HEMOPHILIA FOUNDATION OF MINNESOTA / DAKOTAS
September 10, 2007  HFMD Golf Tournament Indian Hills Golf Club, Stillwater, MN
November & December  Poinsettia Sales begin at HFMD

MARY M. GOOLEY HEMOPHILIA CENTER
September 23rd  5th Annual Finger Lakes Triathlon, Canandaigua, NY
For more information, Please call the Hemophilia Center @ 585-922-4168

UNITED VIRGINIA CHAPTER OF NHF
October 6th  Junior National Championship sports day, Virginia Crossings Resort, Glen Allen, VA

HFA member organizations are encouraged to post announcements and events by emailing the information to s.aultman@hemophiliafed.com.
On July 20, 2007, a Think Tank session was held at the headquarters of the Hemophilia Federation of America in Lafayette, LA., to evaluate the progress of and brainstorm improvements to the HFA Dads in Action Program. DIA Committee Chairs Joey Privat and Tom Vaclavik are continually searching for ways to insure that this valuable program meets the needs of the HFA Member Organizations. To do this, they enlisted the help of Don Molter, Career Counselor with the Indiana HTC and Dr. Charles Gilbert of the Penn State HTC. These dedicated gentlemen spent an entire day working out the details of an improved DIA Program.

The Dads in Action program was created in 2003 as a proactive response to feedback received from fathers within the bleeding disorders community indicating that they were searching for direction in terms of support, education, and interaction with other fathers who face similar challenges. Dads in Action provides training to help fathers build strong bonds with all of their children by giving dads support, a sense of belonging and keys to strengthening family ties. It includes both fathers of children with hemophilia and fathers with hemophilia who have children. Interested fathers from each HFA member organization are provided with specialized training that involves education on validated research surrounding benefits to children reared in families with actively-involved fathers, communication skills, opportunities for networking and support from other fathers of chronically-ill children. Trained facilitators go back to their chapter and conduct Dads in Action activities in their state.

The Think Tank members revised the present program goal to provide the measurable outcomes needed to encourage greater ownership by our Member Organizations. They also identified nine areas of education and skills development that a proactive, responsible, respectful and positive parent would find necessary to develop into a dynamic Dad in Action. The revised program will be launched in May 2008 at the HFA Annual Educational Symposium in Little Rock, AR. For more information, contact info@hemophiliafed.org.

Industry News

**Wyeth Begins Marketing and Distributing BeneFIX® in Europe**

Wyeth Pharmaceuticals has secured marketing and distribution rights to BeneFIX® nonacog alfa Coagulation Factor IX (Recombinant) in Europe from Baxter Healthcare Corporation. This announcement follows the June 30, 2007 conclusion of a 10-year distribution agreement for BeneFIX between Baxter and Genetics Institute. Genetics Institute, the original developer of BeneFIX, was acquired by Wyeth in 1996.

Wyeth is now the only manufacturer and marketer of exclusively recombinant products for the treatment of both hemophilia A and hemophilia B.

Representatives of Wyeth and Baxter have worked closely together to ensure a structured transition between companies and an uninterrupted supply of BeneFIX to people with hemophilia B. Please contact your local Wyeth office with questions.

To view this article in its entirety, go to www.hemophiliafed.org and proceed to the Industry News section.
WHY JOIN THE HFA?

Your membership in the Hemophilia Federation of America helps to support the following:

- Grassroots Advocacy
- Educational Symposium
- Helping Hands
- Dads in Action
- Focus on the Feminine
- Blood Brotherhood
- Comprehensive Children’s Programming
- Teen Connection
- Educational Scholarships
- Consumer Directory
- Informative Website
- Educational Resources
- Community Chat Rooms

To join, visit our website at www.hemophiliafed.org or complete and return the membership form found on the back cover of this issue.
BECOME A MEMBER OF THE HEMOPHILIA FEDERATION OF AMERICA

IN ONE OF THE FOLLOWING WAYS:
Visit our website at www.hemophiliafed.org, use PayPal to send payment
or
Complete the information below and mail to address listed below.

I would like to become a partner of the Hemophilia Federation of America. Please accept my donation in the following category.

☐ Corporate Angel Partner ($100,000)
☐ Corporate Diamond Partner ($50,000)
☐ Corporate Plantinum Partner ($25,000)
☐ Corporate Gold ($10,000)
☐ Corporate Silver ($5,000)
☐ Corporate Bronze ($2,000)
☐ Corporate Friend (below $2,000)
☐ Chapters ($750)
☐ Individual Diamond ($1,000)
☐ Individual Platinum ($500)
☐ Individual Gold ($100)
☐ Individual Silver ($50)
☐ Individual Bronze ($25)

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Company

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Email Address

Work Phone
Work Fax

Please make checks payable to Hemophilia Federation of America.