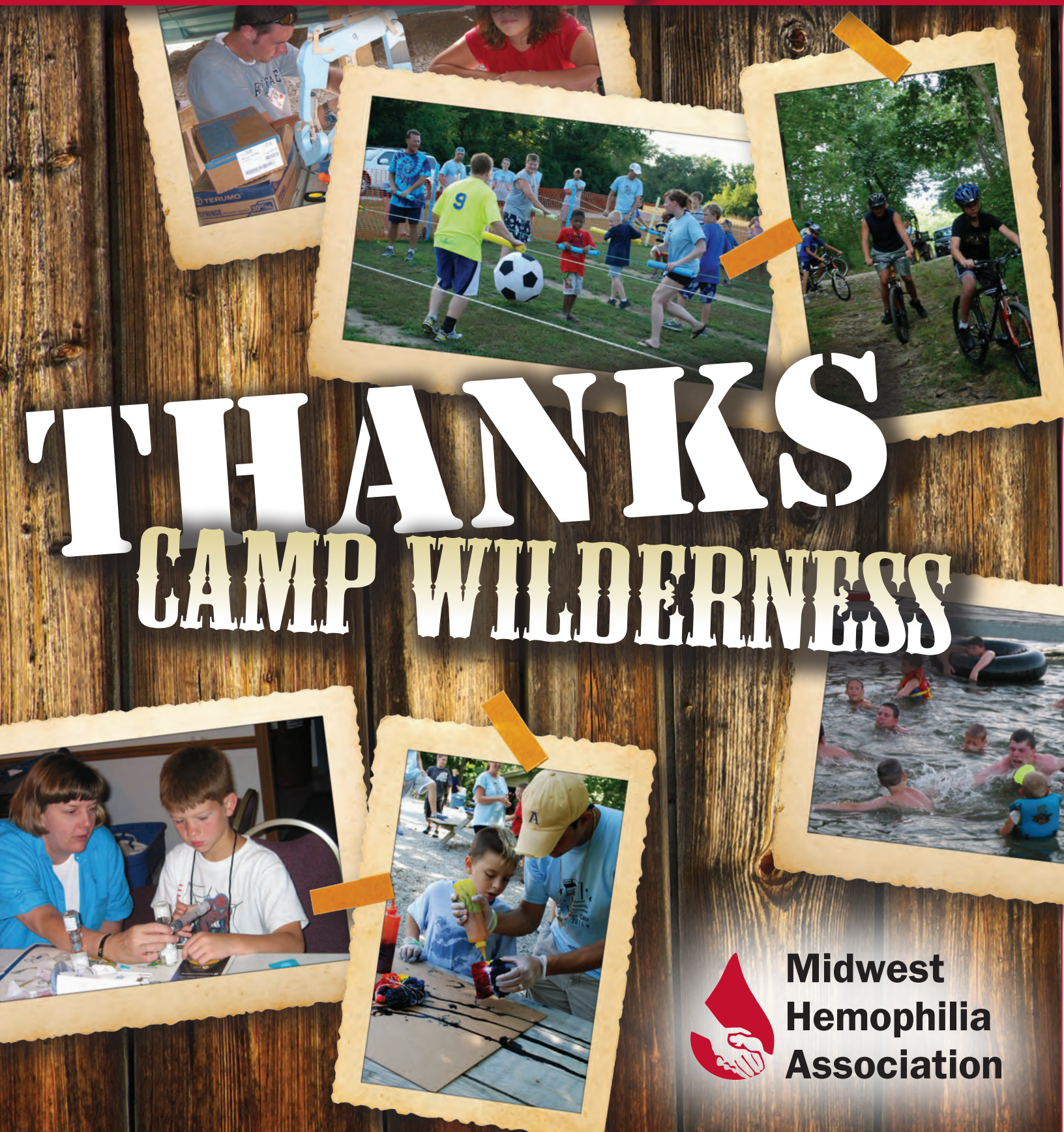
CHAPTER Factors

WINTER 2014



THANKS CAMP WILDERNESS

Midwest Hemophilia Association







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The Midwest Hemophilia Association

PO Box 412866
Kansas City, MO 64141
816-479-5900
www.midwesthemophilia.org

EXECUTIVE DIRECTOR

MARK COX
913-220-9687
mcox@midwesthemophilia.org

BOARD OF DIRECTORS
2014 OFFICERS

JOHN CARLETON
PRESIDENT
Home: (660) 438-5918
jrcarle@hotmail.com

AIMEE TEMPERA
VICE-PRESIDENT
Cell: (316) 518-0524
aimee@maxsweldingsupplies.com

DEBBIE NELSON
SECRETARY
Cell: (816) 456-2097
Work: (816) 802-1268
dlnelson@cmh.edu

MARK DUDLEY
TREASURER
Home: (816) 650-4035
Work: (816) 554-6750
mdudley@blueridgebank.net

2014 BOARD MEMBERS

ANGELA BROWN
(314) 952-6265
intangela@yahoo.com

CHARITY MEADOWS
(417) 353-0931
3meadowsboyz@gmail.com

ELLENE SANDER WHITMORE
(816) 377-7174
ellenesw@gmail.com

JENNIFER RENTSCHLER
(660) 888-1618
jenr@accuraterx.net

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News and Notes

Back in September we were informed that Camp Wilderness was going to close along with three other camps in the Missouri Methodist Conference. It was quite a jolt to say the least. Next year, MHA was going to celebrate 25 years at Camp Wilderness. There was sadness and anxiety at times, for after all, Camp Wilderness was "home" to MHA's Summer Camp. But as we have all learned, life is full of change and we must adapt. Some parents asked me, "Are we going to have a camp next summer?" I assured them we are, it just won't be at Camp Wilderness.

So the long and short of it is that the MHA Camp Committee had some work to do. There were many considerations in play such as available dates, location, capacity and cost. You can be proud of your Camp Committee who took this challenge on with dedication and purpose. The moniker was that camp was a place where lifelong friendships are formed, it's where "first infusions" took place, and it's where kids maybe grew up and learned a little about themselves, and others too. I could go on and on about the virtues of camp but space does not allow.

So after much research, and a few camp site visits the Camp Committee and the Board of Directors selected Lake Doniphan Conference and Retreat Center as the new camp site for MHA's Summer Camp. Lake Doniphan is located just outside Excelsior Springs, Missouri, which is about 10 miles south of the old camp. I think all the parents, campers, volunteers and counselors will be pleased with selection. I have provided a link to their web site should you want to go take a look – *http://lakedoniphan.com*. The dates for next year's camp will be August 2-7, 2015. Camp will be moved up one day with kids arriving on Monday, August 3rd, and parents picking up kids on Friday, August 7th.

And finally, I just wanted to give a special shout out to Dennis Hisek, Wilderness Retreat Site Director and his staff for being there for all those 24 wonderful years. They did a tremendous job in working with us over the years to make a MHA Wilderness Camp a wonderful and safe camping environment for our kids. On behalf of the MHA Board of Directors I want to say, "Thank you Dennis and staff." Job well done.

Mark Cox
Executive Director

2015 MEMBERSHIP APPLICATION

Name: _____

Address: _____

Phone: _____ Email: _____

☐ Individual/Family ($25) ☐ Corporate ($100)
☐ Additional Contribution: $_____

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Please mail this form and your membership fee to:
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Thank you for your support!

QUICK NOTES

Steps fof Living

In December, MHA board members Angela Brown and Debbie Nelson attended facilitator training with NHF leaders to learn more on how to use the Steps for Living resources within our own local community. They are excited to bring back what they learned and share some of the ideas, topics, and programs. Be watching for a Steps for Living activity near you!

Final Thoughts

By the time this hits the press my days will be numbered... on the MHA Board that is! I'm not sure of the length of time I've been on the board, but it is somewhere in the neighborhood of two decades plus. It was suggested that my final article as a board member be a retrospective of how the organization has changed during my tenure. I think we all need to honor the past and heed the lessons that can be learned from our collective experiences, but I tend to look more to what our future holds and what we can do to improve. Trust me, I am retiring from the board, but plan to stay active in the organization. Here we go!

As I look back one things stands out above all others: Summer Camp. I still credit Becky Dudley with being the driving force behind the beginning of camp. Those first few years had some growing pains, but every year has been a success. It is almost beyond comprehension all of the lives of children and adults that have been touched in a profound way by camp. First sticks and independence, lifetime friends and true feelings of belonging are just some of the results of camp. Most of you know at the end of this last summer Wilderness Camp shut down for financial reasons associated with the Missouri Methodist Conference. We are selecting and locking in a new camp for next summer as I write. The announcement should be made before Christmas.

Family Fun Fair has to be second on my list. I always feel the speakers and vendors are an important part of the event, but as much as anything it is an opportunity to network with other families dealing with the same issues and fears. Every year I look forward to seeing the many faces that have become friends. In the early days it seems we lost one or two of our community each year due to tainted product and infusions from the past. On the positive side, that seems to be in our past. I know some of our "older guys" are still fighting the battle, but most are doing well and have a quality of life we didn't dream we would see again.

The organization started as primarily serving the KC area. We have now expanded membership into at least four or five states and sponsor major events in KC, Columbia, Springfield and Wichita. I don't really want to bore you with the many events, educational dinners, walks, etc., but we have expanded our services and service area drastically.

Another accomplishment that is significant is our chapter spearheading the passage of the Standards of Care Act in MO. We were the first chapter in the US to get this done. Kristin Marema was a tireless worker on this and the driving force behind the effort for two years. She ended up being recognized by NHF as the Advocate of the Year due to her work. Yes, she is my daughter, but that only makes me more proud of her dedication and achievement as a representative of our chapter.

The final two major accomplishments of the chapter I am pleased with is the hiring of a full time executive director and our chapter becoming an official chapter of NHF. Both were long term goals that took years to accomplish. I am very proud that I was part of both efforts.

The future: I hope that in the years to come we are able to get enough volunteers to make the board consist entirely of consumers. I think there will always be a place for company reps to serve in an advisory capacity, but not as voting members. At this point in our history we don't have enough consumers applying for the board to make this happen. If we took all of the reps off of the board that serve we would be out of business at this time. I know all of the company people serving on the board at this time and they are all there for the right reasons and have their heads and hearts in the right place.

I would like to see a summer camp free of industry reps. Once again, at this time it is not possible unless we are able to find a camp that has its own full time staff. We would still need the full involvement of our HTC at camp and reps could come in to help with activities on a daily basis.

In closing, I hope my time on the board and, most recently as president, have been viewed by all as a positive for the organization. I can only tell you from

HELPFUL NUMBERS

NATIONAL HEMOPHILIA FOUNDATION (NHF)
1-800-42-HANDI • www.hemophilia.org

UNIVERSITY OF MISSOURIHOSPITAL AND CLINICS
HEMOPHILIA TREATMENT CENTER
1-573-882-9355
Dr. Barbara Gruner • Dr. Carl Freter • Dr. Tamara Hopkin • Lauren Grana, MSW

KANSAS CITY REGIONAL HEMOPHILIA CENTER
1-816-302-6869 • 1-800-236-1713
Dr. Brian Wicklund • Dr. William Jennings • Dr. Shannon Carpenter • Katie Foote, LMSW
Dr. Jill Moormeier • Judy Kauffman, RN, MS, CPNP • Andrew Wilson, RN, CPHON

my heart that I have never put my own agenda or company affiliation ahead of the organization. When I went to work in the industry the day I signed my contract I made it clear to my employer that I was first a consumer, second a representative of the membership of MHA and third an employee. I can go to bed each night knowing I have not violated my word.

One last comment: Please, step up and commit to helping YOUR organization. Show up at events, apply for a seat on the board, and contribute your time and talents. YOUR organization needs you to prosper in the future and continue to be your voice in the state and national venues.

— By John Carleton, President

Applications Now Available

The Midwest Hemophilia Association is pleased to offer a $1,000 scholarship for post-secondary education to a person with a bleeding disorder who lives in MHA's service area. MHA also offers the Georgia Northway Scholarship in conjunction with the Truman Heartland Foundation. Applications for both scholarships can be found online at *www.midwesthemophilia.org*. Or contact Mark Dudley *mdudley@blueridgebank.net* for more information.

The National Hemophilia Foundation also provides scholarship opportunities. Contact NHF at 1-800-42- HANDI or their website *www.hemophilia.org* for more information.

FDA Approves HCV Oral Combination Therapy

On November 5, 2014, the US Food and Drug Administration (FDA) approved the combination use of two previously approved separate oral therapies, Simeprevir (Olysio™) and sofosbuvir (Sovaldi™), for the treatment of chronic hepatitis C viral (HCV) infection. It is a ribavirin- and interferon-free regimen, both of which were notorious for causing debilitating side effects.

Simeprevir, manufactured by Janssen Therapeutics, is a protease inhibitor that halts the progression of HCV, thus preventing it from reproducing. Sofosbuvir, manufactured by Gilead Sciences, is a daily oral nucleotide analogue inhibitor composed of a small molecule compound that blocks HCV's ability to replicate. The FDA approval encompasses the combination use of simeprevir/sofosbuvir for both treatment-naive and treatment-experienced patients. Trial regimens included a 24-week duration for patients with cirrhosis (scarring of the liver) and 12 weeks for those without cirrhosis, both of which excluded the use of either ribavirin or interferon.

The new FDA approval is based on results of the COSMOS study, a phase II trial that included patients with HCV genotype 1. Rates of sustained virologic response (SVR, meaning they no longer had detectable virus in their blood) measured 12 weeks after treatment ended were 93% among those treated with the combination for 12 weeks, and 97% among those treated for 24 weeks. The most common adverse reactions reported by more than 10% of treated patients during 12 weeks of combination treatment were fatigue in 25%, headache (21%), nausea (21%), insomnia (14%), itching (11%), rash (11%), and sensitivity to light (7%). Dizziness (16%) and diarrhea (16%) were the most commonly reported among those patients treated for 24 weeks.

— Source: Family Practice News, November 6, 2014.

2015 MHA CALENDAR

January 17, 2015
MHA Board Meeting

January 25-27, 2015
NHF Hemophilia Walk Training
Las Vegas, NV

February 21, 2015
Wichita Education Event
Wichita, KS

February 25-27, 2015
NHF Washington Days
Washington, DC

March 11, 2015
Bleeding Disorder Advocacy Day
Jefferson City, MO

March 12, 2015
Legislative Days for KS

April (date TBD) 2015
Columbia Education Event
Columbia, MO

April 11, 2015
Western Kansas event

April 25, 2015
Kansas City Pull for a Cure – A Sporting Clay Event
Lenexa, KS

May 11-14, 2015
NHF Regional Meeting
Phoenix, AZ

June 6, 2015
Ozarks Pull for a Cure – A Sporting Clay Event
Walnut Shade, MO

June 13, 2015
Wichita Adult Event

June 20, 2015
Springfield Education Event
Springfield, MO

August 2-7, 2015
25th Annual Summer Camp
Lake Doniphan Conference and Retreat Center, Excelsior Springs, MO

August 12-16, 2015
NHF Annual Meeting
Dallas, TX

September 18, 2015
17th Annual MHA Golf Tournament
Drumm Farm Golf Club
Independence, MO

September 19-20, 2015
21th Annual MHA Family Fun Fair
Kansas City, MO

October (dates TBD) 2015
Hemophilia Walk(s)

ALPROLIX™
[Coagulation Factor IX (Recombinant), Fc Fusion Protein]

Now Available

A new treatment for hemophilia B

ALPROLIX provides protection* from bleeds starting with at least a week between prophylaxis infusions.

Dosing regimen can be adjusted based on individual response.

*Protection is the prevention of bleeding episodes using a prophylaxis regimen.

To learn more, contact CoRe Manager **Vicki Oberkrom**
E: vicki.oberkrom@biogenidec.com T: 660.281.2447

Indications and Important Safety Information

Indications

ALPROLIX, Coagulation Factor IX (Recombinant), Fc Fusion Protein, is a recombinant DNA derived, coagulation factor IX concentrate indicated in adults and children with hemophilia B for:

- Control and prevention of bleeding episodes
- Perioperative management
- Routine prophylaxis to prevent or reduce the frequency of bleeding episodes

ALPROLIX is not indicated for induction of immune tolerance in patients with hemophilia B.

Important Safety Information

Do not use ALPROLIX if you are allergic to ALPROLIX or any of the other ingredients in ALPROLIX.

Tell your healthcare provider if you have or have had any medical problems, take any medicines, including prescription and non-prescription medicines, supplements, or herbal medicines, have any allergies and all your medical conditions, including if you are pregnant or planning to become pregnant, are breastfeeding, or have been told you have inhibitors (antibodies) to factor IX.

Allergic reactions may occur with ALPROLIX. Call your healthcare provider or get emergency treatment right away if you have any of the following symptoms: difficulty breathing, chest tightness, swelling of the face, rash, or hives.

Your body can also make antibodies called “inhibitors” against ALPROLIX, which may stop ALPROLIX from working properly.

ALPROLIX may increase the risk of formation of abnormal blood clots in your body, especially if you have risk factors for developing clots.

Common side effects of ALPROLIX include headache and abnormal sensation of the mouth. These are not all the possible side effects of ALPROLIX. Talk to your healthcare provider right away about any side effect that bothers you or does not go away, and if bleeding is not controlled using ALPROLIX.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

Please see Brief Summary of full Prescribing Information on the next page. This information is not intended to replace discussions with your healthcare provider.

biogen idec®

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ALPROLIX [Coagulation Factor IX (Recombinant), Fc Fusion Protein], Lyophilized Powder for Solution For Intravenous Injection.

FDA Approved Patient Information

ALPROLIX™ /all' pro liks/
[Coagulation Factor IX (Recombinant), Fc Fusion Protein]

Please read this Patient Information carefully before using ALPROLIX™ and each time you get a refill, as there may be new information. This Patient Information does not take the place of talking with your healthcare provider about your medical condition or your treatment.

What is ALPROLIX™?

ALPROLIX™ is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia B. Hemophilia B is also called congenital Factor IX deficiency.

Your healthcare provider may give you ALPROLIX™ when you have surgery.

Who should not use ALPROLIX™?

You should not use ALPROLIX™ if you are allergic to ALPROLIX™ or any of the other ingredients in ALPROLIX™. Tell your healthcare provider if you have had an allergic reaction to any Factor IX product prior to using ALPROLIX™.

What should I tell my healthcare provider before using ALPROLIX™?

Tell your healthcare provider about all of the medicines you take, including all prescription and non-prescription medicines, such as over-the-counter medicines, supplements, or herbal medicines.

Tell your doctor about all of your medical conditions, including if you:

- are pregnant or planning to become pregnant. It is not known if ALPROLIX™ may harm your unborn baby.
- are breastfeeding. It is not known if ALPROLIX™ passes into breast milk or if it can harm your baby.
- have been told that you have inhibitors to Factor IX (because ALPROLIX™ may not work for you).

How should I use ALPROLIX™?

ALPROLIX™ should be administered as ordered by your healthcare provider. You should be trained on how to do infusions by your healthcare provider. Many people with hemophilia B learn to infuse their ALPROLIX™ by themselves or with the help of a family member.

See the Instructions for Use for directions on infusing ALPROLIX™. The steps in the Instructions for Use are general guidelines for using ALPROLIX™. Always follow any specific instructions from your healthcare provider. If you are unsure of the procedure, please ask your healthcare provider.

Do not use ALPROLIX™ as a continuous intravenous infusion.

Contact your healthcare provider immediately if bleeding is not controlled after using ALPROLIX™.

What are the possible side effects of ALPROLIX™?

Common side effects of ALPROLIX™ include headache and abnormal sensation in the mouth.

Allergic reactions may occur. Call your healthcare provider or get emergency treatment right away if you have any of the following symptoms: hives, chest tightness, wheezing, difficulty breathing, or swelling of the face.

ALPROLIX™ may increase the risk of forming abnormal blood clots in your body, especially if you have risk factors for developing blood clots.

Your body can also make antibodies called, "inhibitors," against ALPROLIX™, which may stop ALPROLIX™ from working properly. Your healthcare provider may need to test your blood for inhibitors from time to time.

These are not all the possible side effects of ALPROLIX™.Talk to your healthcare provider about any side effect that bothers you or that does not go away.

How should I store ALPROLIX™?

Store ALPROLIX™ vials at 2°C to 8°C (36°F to 46°F). Do not freeze.

ALPROLIX™ vials may also be stored at room temperature up to 30°C (86°F) for a single 6 month period.

If you choose to store ALPROLIX™ at room temperature:

- Note on the carton the date on which the product was removed from refrigeration.
- Use the product before the end of this 6 month period or discard it. not return the product to the refrigerator.
- Do not use product or diluent after the expiration date printed on the carton, vial or syringe.

After Reconstitution:

- Use the reconstituted product as soon as possible; however, you may store the reconstituted product at room temperature up to 30°C (86°F) for up to 3 hours. Protect the reconstituted product from direct sunlight. Discard any product not used within 3 hours after reconstitution.
- Do not use ALPROLIX™ if the reconstituted solutionis cloudy, contains particles or is not colorless.

What else should I know about ALPROLIX™?

Medicines are sometimes prescribed for purposes other than those listed here. Do not use ALPROLIX™ for a condition for which it was not prescribed. Do not share ALPROLIX™ with other people, even if they have the same symptoms that you have.

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Cambridge, MA 02142
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THANKS CAMP WILDERNESS

Camp Wilderness has been the home of MHA's Summer Camp since 1990. It has the place of many memories that will last a lifetime. Our members share a few thoughts as we bid farewell.

Wilderness camp is a magical place! Over the past 4 years, I have been blessed to see the growth each child and volunteer experiences, from that first day being away from mom and dad to friendships that will last a lifetime. I am honored and humbled to be a part of a such a tremendous tradition!"

— Andrew Wilson

The giggles and the laughter of a child is 100% guaranteed to bring a smile to anyone's face! Those giggles are what I look forward to each and every year as a camp counselor! My son, Dakota has attended Wilderness Camp from the time he was just 7 years old. Dakota is now 19 years old and thoroughly enjoys the opportunity to not only give back to the community, but to make a difference in children's lives for that one week as a mentor, as a camp counselor! There isn't anything more precious than to witness the lifelong friendships created year after year at camp. I just have to share the amazing experience of Dakota sticking himself for the very first time at camp at just 10 years old! From then on he became quite the "show-off" with special thanks to our incredible nursing staff! Our family is truly thankful to Midwest Hemophilia Association and all who are dedicated to the bleeding disorder community for their support and hard work making camp the most memorable week in our "little campers'" lives! After all of these years, I continue to look forward to being a part of that very special week at camp and look forward to all of those giggles and all of that laughter that brings so much joy to my life!

— Kimberly Rosenfelt

Dennis and his staff were so great to work with over the years. Camp Wilderness was more than a job to everyone who worked there and it showed not only to us, but to the kids as well. Camp Wilderness was a special place where so many MHA campers grew up. We will miss everyone associated with Camp Wilderness.

— Mark Cox, Executive Director

Wilderness Camp has been an amazing place for the Kansas City Hemophilia Treatment Center. I have been to other hemophilia camps in other states, but never felt that the year-round camp staff were terribly invested in the hemophilia mission. At Wilderness it was very obvious in every interaction with the staff that they were "in it" with us. They did everything they could to help us have successful camps, and were always available to help. We taught quite a few of their staff about the bleeding disorders, and had often questions from them about family members or friends that had bleeding symptoms needing evaluation. We even had someone from their staff become a nurse and start her first nursing job at Children's Mercy because of our ongoing relationship with the camp. We felt that we were in partnership with Dennis and his staff at Wilderness Camp. Moving to a new camp will give us opportunity to grow and serve more kids with bleeding disorders, but we will truly miss working with the staff at Wilderness Retreat Center.

— Judy Kauffman

Our New Home: LAKE DONIPHAN

The Lake Doniphan Conference and Retreat Center located in Excelsior Springs, Missouri will be the new home for MHA's Summer Camp. It provides a peaceful natural environment for education and recreation.

The Center encompasses 300 acres on the eastern edge of town and offers a variety of lodging and meeting room options. Its Main Lodge features 33 bedrooms plus the dining hall and large multi-purpose room. Their two small mini lodges offers accommodations for 64 in eight rooms of eight. The 19 cabins are great in warmer weather but are also equipped with air conditioning.

The Center offers a variety of amenities sure to occupy the days of the MHA campers. Activities include swimming in the outdoor pool, boating, fishing, hiking, outdoor volleyball and basketball courts plus indoor recreation room for shuffleboard, ping pong and pop-a-shot.

We look forward to enjoying our new summer home and exploring all they have to offer while we continue making new memories.

what's your story?

By Angela Brown

Despite being extremely shy, I am a people-lover. I also love a good story. So, when I meet a new friend with a connection to the bleeding disorder community, I especially like to pick their mind to find out about their experiences and how much they know or understand about the community. Recently, this curiosity led me to an interview with Kathryn, a spouse of someone affected by a bleeding disorder. Here is her story.

Angela: How did you and Ben meet?
Kathryn: My first meeting was certainly a unique one. Ben and I met through my best friend April who invited a group of friends to watch the Transformer movie. I decided to join the group, despite just finishing an overnight shift, donating plasma, barely eating food or water that day, and being in need of a shower. I was asked to arrive early to pick up tickets. Long story short, I ended up passed out from dehydration on the bathroom floor of a Jimmy John's where Ben had to rescue me. That's how we met for the first time.

Angela: What attracted you to him?
Kathryn: Ben is hilarious–his sense of humor most definitely. I also love that he is tall, has a defined chin, and magical bluish-green eyes. He also gives good hugs.

Angela: Had you heard of hemophilia or other bleeding disorders prior to meeting Ben?
Kathryn: The most I had ever heard was something about Queen Victoria's family. And I related it to leeches being stuck on you for medicinal purposes.

Angela: How long did you date before Ben shared about his bleeding disorder?
Kathryn: I found out before we started dating from my friend, April.

Angela: What was your response?
Kathryn: Truthfully I went through stages. At first I was just curious. I looked it up on Wikipedia. When it was apparent that we both had feelings for each other and we started dating, worry and concern kicked in. I got scared and we had the "let's just be friends" talk as a result. That didn't last long because we ended up together. It really took me deciding that I wanted to be with Ben, more than anyone else – with or without a bleeding disorder. Then I wanted to know as much as I could about it.

Angela: How did he propose?
Kathryn: Ben proposed at a surprise birthday party he planned for me with friends and family all around. We got married March 23, 2013.

Angela: Did you discuss any of your concerns you had about hemophilia prior to getting married?
Kathryn: Yes. This was a deal breaker. My ignorant self imagined him helpless and in a wheel chair by the age of 50. The more we talked about it the more comfortable I became with it. His family was so helpful in informing me about what to expect and the kind of hurdles we could face. Ben and I also talked about how hemophilia affected him. My goal as his wife is to not allow his hemophilia to define him or hold him back. It most definitely affects day to day life, but if it weren't hemophilia it would be something else.

Angela: What is your understanding of the genetics of his bleeding disorder?
Kathryn: I know it is carried on the X-chromosome. Typically males are affected and females are carriers.

Angela: What kind of conversations have you had about starting a family?
Kathryn: We have normal conversations like anyone else. We do want to have kids. It is nice to marry someone with hemophilia who has been dealing with it his whole life. There is less mystery in knowing what to expect. We also talk about the things we would like to have before we have kids: a house, one nice vacation, and at least one completed degree between us. We also talk about foster care and adoption.

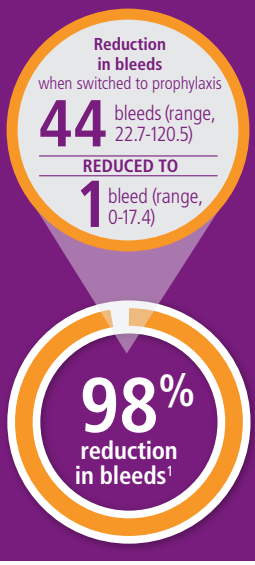
Angela: How do you participate in Ben's treatment?
Kathryn: I know Ben is pretty independent with his treatment, but I'm not afraid to ask if he's achy, needs to infuse, or order more medication. I try not to nag Ben about infusing. Ben is more than happy to allow me to be a part of his treatment. As far as his medicine administration goes, the most I do is watch. I'm still gathering the courage to actually stick the needle in his vein. I do have a set of practice tools.

Angela: How would you like to be involved in the bleeding disorder community?
Kathryn: I would like to meet more spouses who are married to someone with a bleeding disorder. No one wants to be alone. I think people may not feel comfortable reaching out to others in similar situations.

Angela: What kind of information would be helpful to you as a spouse?
Kathryn: Anything and everything!

Angela: What advice would you give to others about dating/marrying someone with a bleeding disorder?
Kathryn: My advice would be to learn as much as you can. Not so you can judge the person by their diagnosis, but be educated and better understand what they are going through. If you really love someone, it doesn't matter what sort of disorder they have.

ADVATE
[Antihemophilic Factor (Recombinant)]
There's more to life.



ADVATE PROPHYLAXIS MAY HELP YOU PREVENT OR REDUCE THE FREQUENCY OF BLEEDS[1]

SIGNIFICANT REDUCTION IN MEDIAN ANNUAL BLEED RATE (ABR) WITH PROPHYLACTIC TREATMENT COMPARED WITH ON-DEMAND TREATMENT[1]

- **42% of patients experienced 0 bleeds during 1 year on prophylaxis[1]**
- **98% reduction in median ABR from 44 to 1 when switched from on-demand to prophylaxis[1]**

In a clinical study, after switching from 6 months of on-demand treatment to 12 months of prophylaxis with ADVATE in 53 previously treated patients (PTPs) with severe or moderately severe hemophilia A.

A clinical study that evaluated treatment efficacy (the ability to control and reduce bleeds) of 2 prophylaxis regimens—Every-Second-Day (standard) prophylaxis dosed at 20 to 40 IU/kg every 48 hours and Every-Third-Day (pharmacokinetic-driven) prophylaxis dosed at 20 to 80 IU/kg every 72 hours, targeted to maintain factor VIII trough levels ≥1%.

INDICATIONS

ADVATE is a medicine used to replace clotting factor VIII that is missing in people with hemophilia A (also called "classic" hemophilia). ADVATE is used to prevent and control bleeding in adults and children (0-16 years) with hemophilia A. Your healthcare provider may give you ADVATE when you have surgery. ADVATE can reduce the number of bleeding episodes in adults and children (0-16 years) when used regularly (prophylaxis).

ADVATE is not used to treat von Willebrand Disease.

DETAILED IMPORTANT RISK INFORMATION

You should not use ADVATE if you:

- Are allergic to mice or hamsters.
- Are allergic to any ingredients in ADVATE.

Tell your healthcare provider if you are pregnant or breastfeeding because ADVATE may not be right for you.

You should tell your healthcare provider if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Have been told that you have inhibitors to factor VIII (because ADVATE may not work for you).

Your body may form inhibitors to factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop ADVATE from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to factor VIII.

You can have an allergic reaction to ADVATE.

Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.

Side effects that have been reported with ADVATE include cough,headache, joint swelling/aching, sore throat, fever, itching, unusual taste, dizziness, hematoma, abdominal pain, hot flashes, swelling of legs, diarrhea, chills, runny nose/congestion, nausea/vomiting, sweating, and rash.

Tell your healthcare provider about any side effects that bother you or do not go away or if your bleeding does not stop after taking ADVATE.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

Please see Brief Summary of ADVATE Prescribing Information on the following page.

Reference: 1. ADVATE Prescribing Information. Westlake Village, CA: Baxter Healthcare Corporation; April 2014.

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Baxter

ADVATE [Antihemophilic Factor (Recombinant)]

Lyophilized Powder for Reconstitution for Intravenous Injection

Brief Summary of Prescribing Information: Please see package insert for full Prescribing Information.

INDICATIONS AND USAGE

ADVATE [Antihemophilic Factor (Recombinant)] is a recombinant antihemophilic factor indicated for use in children and adults with hemophilia A (congenital factor VIII deficiency or classic hemophilia) for:

- Control and prevention of bleeding episodes.
- Perioperative management.
- Routine prophylaxis to prevent or reduce the frequency of bleeding episodes.

ADVATE is not indicated for the treatment of von Willebrand disease.

CONTRAINDICATIONS

ADVATE is contraindicated in patients who have life-threatening hypersensitivity reactions, including anaphylaxis, to mouse or hamster protein or other constituents of the product (mannitol, trehalose, sodium chloride, histidine, Tris, calcium chloride, polysorbate 80, and/or glutathione).

WARNINGS AND PRECAUTIONS

Hypersensitivity Reactions

Allergic-type hypersensitivity reactions, including anaphylaxis, have been reported with ADVATE. Symptoms include dizziness, paresthesia, rash, flushing, facial swelling, urticaria, dyspnea, and pruritus.

ADVATE contains trace amounts of mouse immunoglobulin G (MulgG) ≤0.1 ng/IU ADVATE, and hamster proteins ≤1.5 ng/IU ADVATE. Patients treated with this product may develop hypersensitivity to these non-human mammalian proteins.

Discontinue ADVATE if hypersensitivity symptoms occur and administer appropriate emergency treatment.

Neutralizing Antibodies

Neutralizing antibodies (inhibitors) have been reported following administration of ADVATE predominantly in previously untreated patients (PUPs) and previously minimally treated patients (MTPs). Monitor all patients for the development of factor VIII inhibitors by appropriate clinical observation and laboratory testing. If expected plasma factor VIII activity levels are not attained, or if bleeding is not controlled with an expected dose, perform an assay that measures factor VIII inhibitor concentration. [see *Warnings and Precautions*]

Monitoring Laboratory Tests

- Monitor plasma factor VIII activity levels by the one-stage clotting assay to confirm the adequate factor VIII levels have been achieved and maintained when clinically indicated. [see *Dosage and Administration*]
- Perform the Bethesda assay to determine if factor VIII inhibitor is present. If expected factor VIII activity plasma levels are not attained, or if bleeding is not controlled with the expected dose of ADVATE, use Bethesda Units (BU) to titer inhibitors.
  - If the inhibitor titer is less than 10 BU per mL, the administration of additional antihemophilic factor concentrate may neutralize the inhibitor and may permit an appropriate hemostatic response.
  - If the inhibitor titer is above 10 BU per mL, adequate hemostasis may not be achieved. The inhibitor titer may rise following ADVATE infusion as a result of an anamnestic response to factor VIII. The treatment or prevention of bleeding in such patients requires the use of alternative therapeutic approaches and agents.

ADVERSE REACTIONS

The serious adverse reactions seen with ADVATE are hypersensitivity reactions and the development of high-titer inhibitors necessitating alternative treatments to factor VIII.

The most common adverse reactions observed in clinical trials (frequency ≥10% of subjects) were pyrexia, headache, cough, nasopharyngitis, vomiting, arthralgia, and limb injury.

Clinical Trial Experience

Because clinical trials are conducted under widely varying conditions, adverse reaction rates observed in the clinical trials of a drug cannot be directly compared to rates in clinical trials of another drug and may not reflect the rates observed in clinical practice.

ADVATE has been evaluated in five completed clinical trials in previously treated patients (PTPs) and one ongoing trial in previously untreated patients (PUPs) with severe to moderately severe hemophilia A (factor VIII ≤2% of normal). A total of 234 subjects have been treated with ADVATE as of March 2006. Total exposure to ADVATE was 44,926 infusions. The median duration of participation per subject was 370.5 (range: 1 to 1,256) days and the median number of exposure days to ADVATE per subject was 128 (range: 1 to 598).[3]

The summary of adverse reactions with a frequency ≥5% (defined as adverse events occurring within 24 hours of infusion or any adverse event causally related occurring within the trial period) is shown in Table 3.

No subject was withdrawn from a clinical trial due to an adverse reaction. There were no deaths in any of the clinical trials.

Table 3
Summary of Adverse Reactions[a] with a Frequency ≥5% (N = 234 Treated Subjects[b])

MedDRA[c] System Organ Class	MedDRA Preferred Term	Number of ADRs	Number of Subjects	Percent of Subjects
General disorders and administration site conditions	Pyrexia	78	50	21
Nervous system disorders	Headache	104	49	21
Respiratory, thoracic, and mediastinal disorders	Cough	75	44	19
Infections and infestations	Nasopharyngitis	61	40	17
Gastrointestinal disorders	Vomiting	35	27	12
Musculoskeletal and connective tissue disorders	Arthralgia	44	27	12
Injury, poisoning, and procedural complications	Limb injury	55	24	10
Infections and infestations	Upper respiratory tract infection	24	20	9
Respiratory, thoracic, and mediastinal disorders	Pharyngolaryngeal pain	23	20	9
Respiratory, thoracic, and mediastinal disorders	Nasal congestion	24	19	8
Gastrointestinal disorders	Diarrhea	24	18	8
Gastrointestinal disorders	Nausea	21	17	8
General disorders and administration site conditions	Pain	19	17	8
Skin and subcutaneous tissue disorders	Rash	16	13	6
Infections and infestations	Ear infection	16	12	5
Injury, poisoning, and procedural complications	Procedural pain	16	12	5
Respiratory, thoracic, and mediastinal disorders	Rhinorrhea	15	12	5

[a] Adverse reactions are defined as all adverse events that occurred (a) within 24 hours after being infused with investigational product, or (b) all adverse events assessed related or possibly related to investigational product, or (c) adverse events for which the investigator's or sponsor's opinion of causality was missing or indeterminate.

[b] The ADVATE clinical program included 234 treated subjects from 5 completed studies in PTPs and 1 ongoing trial in PUPs as of 27 March 2006.

[c] MedDRA version 8.1 was used.

Immunogenicity

The development of factor VIII inhibitors with the use of ADVATE was evaluated in clinical trials with pediatric PTPs (<6 years of age with >50 factor VIII exposures) and PTPs (>10 years of age with >150 factor VIII exposures). Of 198 subjects who were treated for at least 10 exposure days or on study for a minimum of 120 days, 1 adult developed a low-titer inhibitor (2 BU in the Bethesda assay) after 26 exposure days. Eight weeks later, the inhibitor was no longer detectable, and *in vivo* recovery was normal at 1 and 3 hours after infusion of another marketed recombinant factor VIII concentrate. This single event results in a factor VIII inhibitor frequency in PTPs of 0.51% (95% CI of 0.03 and 2.91% for the risk of any factor VIII inhibitor development).[3,4] No factor VIII inhibitors were detected in the 53 treated pediatric PTPs.

In clinical trials that enrolled previously untreated subjects (defined as having had up to 3 exposures to a factor VIII product at the time of enrollment) , 5 (20%) of 25 subjects who received ADVATE developed inhibitors to factor VIII.[3] Four subjects developed high titer (>5 BU) and one patient developed low-titer inhibitors. Inhibitors were detected at a median of 11 exposure days (range 7 to 13 exposure days) to investigational product.

Immunogenicity also was evaluated by measuring the development of antibodies to heterologous proteins. 182 treated subjects were assessed for anti-Chinese hamster ovary (CHO) cell protein antibodies. Of these subjects, 3 showed an upward trend in antibody titer over time and 4 showed repeated but transient elevations of antibodies. 182 treated subjects were assessed for mulgG protein antibodies. Of these, 10 showed an upward trend in anti-mulgG antibody titer over time and 2 showed repeated but transient elevations of antibodies. Four subjects who demonstrated antibody elevations reported isolated events of urticaria, pruritus, rash, and slightly elevated eosinophil counts. All of these subjects had numerous repeat exposures to the study product without recurrence of the events and a causal relationship between the antibody findings and these clinical events has not been established.

Of the 181 subjects who were treated and assessed for the presence of anti-human von Willebrand Factor (VWF) antibodies, none displayed laboratory evidence indicative of a positive serologic response.

The detection of antibody formation is highly dependent on the sensitivity and specificity of the assay. Additionally, the observed incidence of antibody (including neutralizing antibody) positivity in an assay may be influenced by several factors including assay methodology, sample handling, timing of sample collection, concomitant medications, and underlying disease. For these reasons, comparison of the incidence of antibodies to ADVATE with the incidence of antibodies to other products may be misleading.

Post-Marketing Experience

The following adverse reactions have been identified during post-approval use of ADVATE. Because these reactions are reported voluntarily from a population of uncertain size, it is not always possible to reliably estimate their frequency or establish a causal relationship to drug exposure.

Among patients treated with ADVATE, cases of serious allergic/hypersensitivity reactions including anaphylaxis have been reported and factor VIII inhibitor formation (observed predominantly in PUPs). Table 4 represents the most frequently reported post-marketing adverse reactions as MedDRA Preferred Terms.

Table 4
Post-Marketing Experience

Organ System [MedDRA Primary SOC]	Preferred Term
Immune system disorders	Anaphylactic reaction[a] Hypersensitivity[a]
Blood and lymphatic system disorders	Factor VIII inhibition
General disorders and administration site conditions	Injection site reaction Chills Fatigue/Malaise Chest discomfort/pain Less-than-expected therapeutic effect

[a] These reactions have been manifested by dizziness, paresthesias, rash, flushing, face swelling, urticaria, and/or pruritus.

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— 66th Annual —
NHF MEETING

By Mark Dudley, Treasurer, MHA

What a great setting for the 66th Annual National Hemophilia Foundation Meeting, Our Nation's Capital, Washington, DC. The meeting was September 18-21, 2014 and was jam packed with lots of information, networking, and opportunities to see how far the bleeding disorder community has come over the past 66 years. The meetings started on Thursday morning and ended with a group wide event on Saturday evening. I arrived on Wednesday and was able to meet two of my college friends who live in the area for dinner that night. I had not seen one of them in over 25 years. It was great to catch up and we had a really good time. Bright and early Thursday morning I headed to the first session of the "Chapter Staff/Volunteer" tract of programing. The meeting is divided into "tracts" that have topics related to your work in the community. Besides the Chapter tract, there are tracts for consumers, nurses, social workers, physicians, and more. I did venture out to a few sessions in other areas and there are a lot of good things happening. One thing is for sure, the bleeding disorder community is nationwide and also worldwide. Sometimes we forget that there are chapters just like us all over the country. The number is approaching 50 NHF chapters.

One session of particular interest covered all the data that is being collected and how it is being utilized in research, improving treatment, and the search for a cure. All of the information from patients participating in the various data collection programs IS being put to good use. (You all know me and know I am a numbers guy!). Seeing the information and knowing that many of MHA's folks had a part in supplying that information gave me a great sense of pride. Please keep up the good work by participating in studies and providing all the data requested. It is vital in the search for better outcomes and a cure. The other thing that was interesting to see was the results of some of the clinical research on the longer lasting factor products. There are lots of exciting things going on.

Please keep up the good work by participating in studies and providing all the data requested. It is vital in the search for better outcomes and a cure.

Time at the meeting was also spent reflecting back as this is the 20th anniversary of the "Ricky Ray" legislation. Getting this legislation passed was pivotal in the bleeding disorder community being recognized as a force to be reckoned with on a national level.

At the NHF annual meeting, there are numerous opportunities to visit with our vendor's and supporters of MHA and of the community as a whole. The "Exhibit Hall" where all the companies affiliated with various products and services display their material is quite a site to see. You can learn about products, network with folks and just say thanks for all your support of our chapter and the community as a whole. I saw lots of familiar faces, some old and some new and on top of that, you get fed while doing this. Sure saves on the expenses of travel (that makes the treasurer in me happy). Back to the sessions, I learned about what NHF has in store for chapter support in the next year. There is a new "Chapter Standards" agreement coming out and you will be glad to know MHA is compliant with nearly all of the standards.

They spoke about the hemophilia walks and their success including the fact that there was a walk in Alaska this year for the first time. It was a long three days as sessions went from early in the morning until late in day. I think the only time I was in my Hotel room was to sleep at night.

The conclusion of the meeting was a group wide event at the Air and Space Museum which is part of the famous Smithsonian Museum. This was of particular interest to me as my father worked on airplanes for 10 years in the Navy (during and after WWII) and for 33 years at what was then McDonnell Douglas Corporation now Boeing. Many of the planes on display, he actually worked on. Driving to the museum from the hotel, our bus driver went by many of the historical monuments and buildings in the area. It was great to get to see them and hear the stories of some of our national treasurers.

Finally, I want to thank the MHA Board for allowing me to attend this year's event. It was a great opportunity and left me looking forward to an exciting 2015.

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