NEWSLETTER OF THE HEMOPHILIA FOUNDATION OF MINNESOTA AND THE DAKOTAS

HFMD
HEMOPHILIA FOUNDATION
OF MINNESOTA/DAKOTAS

Veinline

Winter 2016

HFMD MISSION
To meet the needs and to enhance the quality of life for persons living with hemophilia, related inherited bleeding disorders and their complications.

Inside this issue:

Education Dinner & Mini-Golf at the Mall of America!

A large group of Italian food lovers and mini-golf aficionados gathered at Tucci Benucch Restaurant at the Mall of America in October at the invitation of Pfizer's, Deb Melhado, and the HFMD. While the group of over 40 people enjoyed a fresh salad and appetizers, Gladys Murillo, RN, began a presentation on living a healthier lifestyle through physical fitness and nutrition. The dinner continued with chicken marsala, beef lasagna, and eggplant parmigiana making their way family-style around the table. Given the topic of eating healthier, serving the dinner this way was helpful for those of us watching our intake, as well as beneficial for others who weren't so limited! Most of those attending enjoyed all entrees, as well as the salad and appetizer!

As we finished our meals, Gladys wrapped up the presentation and it was time for the group to work off a few calories at Moose Mountain Mini-Golf Course near Nickelodeon Universe. HFMD's Jim Paist distributed golf tickets and the group headed to the course for some friendly competition!

Many thanks to Deb Melhado, Gladys Murillo, and Pfizer, and for a warm, wonderful, and informative evening of good food and fun!

By Kerry Budinger

Junior National Championships (JNC)

Each fall CSL Behring hosts a unique sports related event known as the Junior National Championships (JNC). The participants are children with bleeding disorders who enjoy playing baseball or golf. Each NHF affiliated chapter like the HFMD is invited to nominate one child for golf and one for baseball, or two nominees for one sport.

This past fall October 23-25, the event was held in Phoenix, AZ. It opens with separate baseball and golf clinics where the fundamentals of each sport are emphasized in addition to the youth participants taking batting practice, fielding ground, balls, time on the driving range, and putting greens. The clinics are led by former professional golfers and semi-professional baseball players who also have bleeding disorders.

After two-days of fun-filled clinics and time for the kids to get to know each other over meals, it is time for the skills competitions to begin. Each participant is rated and the top 3 winners are announced in each sports for awards. An award is also given for good sportsmanship. HFMD's participants this year were two enthusiastic baseball players; Nathan Miller & Christian Germain. "I had fun playing baseball and participating in the competitions in Arizona. It was fun to meet the athletes and kids with hemophilia from other states. Thanks to CSL Behring." Nathan Miller

"They had 107 athletes attend, 60 out of 67 chapters were represented, even Hawaii and Alaska. It was amazing to be a part of this event. Thank you really doesn't cover it, but nonetheless, Thank You from our hearts. It was an amazing experience for Christian, and our family, and one we will never forget." Tresa Germain, Mother of Christian Germain.

ALPHANATE®

Antihemophilic Factor/von Willebrand Factor Complex (Human)

HIGHLIGHTS OF PRESCRIBING INFORMATION

These highlights do not include all the information needed to use Alphanate safely and effectively. See full prescribing information for Alphanate.

ALPHANATE (ANTIHEMOPHILIC FACTOR/VON WILLEBRAND FACTOR COMPLEX [HUMAN])

Sterile, lyophilized powder for injection.

Initial U.S. Approval: 1978

----------INDICATIONS AND USAGE ----------

Alphanate is an Antihemophilic Factor/von Willebrand Factor Complex (Human) indicated for:

- Control and prevention of bleeding in patients with hemophilia A.
- Surgical and/or invasive procedures in adult and pediatric patients with von Willebrand Disease in whom desmopressin (DDAVP) is either ineffective or contraindicated. It is not indicated for patients with severe VWD (Type 3) undergoing major surgery.

----------DOSAGE AND ADMINISTRATION ----------

For Intravenous use only.

Alphanate contains the labeled amount of Factor VIII expressed in International Units (IU) FVIII/vial and von Willebrand Factor:Ristocetin Cofactor activity in IU VWF:RCo/vial.

Hemophilia A: Control and prevention of bleeding episodes

- Dose (units) = body weight (kg) x desired FVIII rise (IU/dL or % of normal) x 0.5 (IU/kg per IU/dL).
- Frequency of intravenous injection of the reconstituted product is determined by the type of bleeding episode and the recommendation of the treating physician.

von Willebrand Disease: Surgical and/or invasive procedure in adult and pediatric patients except Type 3 undergoing major surgery

- Adults: Pre-operative dose of 60 IU VWF:RCo/kg body weight; subsequent doses of 40-60 IU VWF:RCo/kg body weight at 8-12 hour intervals post-operative as clinically needed.
- Pediatric: Pre-operative dose of 75 IU VWF:RCo/kg body weight; subsequent doses of 50-75 IU VWF:RCo/kg body weight at 8-12 hour intervals post-operative as clinically needed.

----------DOSAGE FORMS AND STRENGTHS ----------

- Alphanate is a sterile, lyophilized powder for intravenous injection after reconstitution, available as 250, 500, 1000, 1500 and 2000 IU FVIII in single dose vials.

----------CONTRAINDICATIONS ----------

- Patients who have manifested life-threatening immediate hypersensitivity reactions, including anaphylaxis, to the product or its components.

----------WARNINGS AND PRECAUTIONS ----------

- Anaphylaxis and severe hypersensitivity reactions are possible. Should symptoms occur, treatment with Alphanate should be discontinued, and emergency treatment should be sought.
- Development of activity-neutralizing antibodies has been detected in patients receiving FVIII containing products. Development of alloantibodies to VWF in Type 3 VWD patients has been occasionally reported in the literature.
- Thromboembolic events may be associated with AHF/VWF Complex (Human) in VWD patients, especially in the setting of known risk factors.
- Intravascular hemolysis may be associated with infusion of massive doses of AHF/VWF Complex (Human).
- Rapid administration of a FVIII concentrate may result in vasomotor reactions.
- Plasma products carry a risk of transmitting infectious agents, such as viruses, and theoretically, the Creutzfeldt-Jakob disease (CJD) agent, despite steps designed to reduce this risk.

----------ADVERSE REACTIONS----------

The most frequent adverse events reported with Alphanate in > 5% of patients are respiratory distress, pruritus, rash, urticaria, face edema, paresthesia, pain, fever, chills, joint pain and fatigue.

To report SUSPECTED ADVERSE REACTIONS, contact Grifols Biologicals Inc. at 1-888-GRIFOLS (1-888-474-3657) or FDA at 1-800-FDA-1088 or www.fda.gov/medwatch.

----------USE IN SPECIFIC POPULATIONS ----------

- Pregnancy: No human or animal data. Use only if clearly needed.
- Pediatric Use: Hemophilia A - Clinical trials for safety and effectiveness have not been conducted. VWD - Age had no effect on PK.

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GENEALOGY

My mother's father, Col. Ben Starkey, passed away in 1982 at 86 years of age: he lived a long life in spite of having Hemophilia-B. I remember him telling me when I was a boy, "You and I have to be careful." He was a sort of living history book, connecting me to family members past who also wrestled with Hemophilia, and whose struggles were much worse than mine: they made full lives for themselves with no factor products.

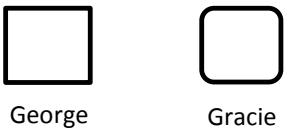
His life also overlapped the reign of Queen Victoria of England: she reigned from 1837 to 1901, and she is probably one of the most famous people connected to Hemophilia. She interests many of us because she, like nearly a third of us, became a carrier of Hemophilia through a genetic mutation, and her royal descendants, who married into the royal families of Europe, brought Hemophilia into these families as well.

A great Wikipedia article reports that these families probably don't carry Victoria's Hemophilia gene today, though there is a remote chance that a couple of descendants may possibly have it. This Wikipedia article also reports that genetic tests on the remains of Alexei, the famous son of the last Russian Czar and one of Victoria's daughters, carried Hemophilia B, though we long believed that Victoria's gene was for Hemophilia A. You can find this and other related articles by Googling for "Queen Victoria Hemophilia site:wikipedia.com".

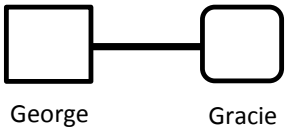
I like to think that America's revolutionary war introduced the notion that how you rise above your challenges defines you, instead of who your parents happened to be. As a result, your family tree and mine are valuable, even if none of us are monarchs.

There are lots of great applications and websites (ancestry.com and others come to mind) for building your family tree, though it isn't clear to me that these apps and sites are especially great at tracking inherited traits like bleeding disorders. Instead, I like to draw my family tree on paper, at least as a start, using a style well known to genealogists.

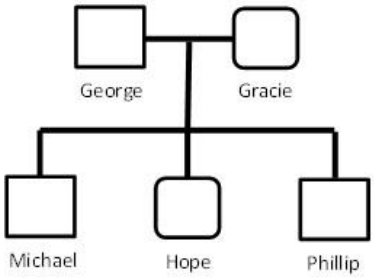
Using this diagramming technique, here's a man and a woman:



In this diagram, George and Gracie are married:

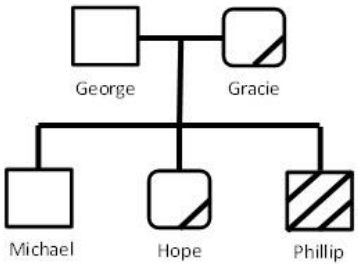


And let's say that they have three children:



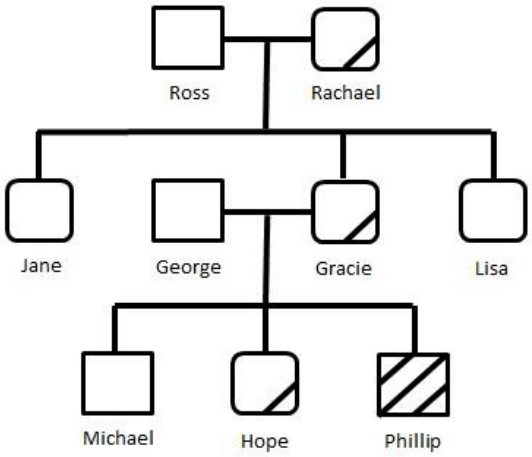
Continued on next page...

Let's suppose that Gracie carries Hemophilia A, one of the many X-linked recessive genetic disorders (color blindness being another), which means that each of her children has a fifty-fifty chance of receiving her X chromosome programmed for Hemophilia A. George and Gracie's family tree might look like this:



Gracie and Hope have one X chromosome programmed normally and one programmed for Hemophilia-A, so their shapes have one line through them to indicate this. Phillip, as a male, has only one X chromosome, and the one that he received from Gracie is the same one that Hope received: the one programmed for Hemophilia A. Since that is his only X chromosome, his shape has several lines through it, indicating that he has Hemophilia A.

Family trees that follow the transmission of X-linked recessive inherited traits like Hemophilia tend to follow one side of the family: in this case, Gracie's, since Hemophilia A traveled through her family:



Notice that George's shape's only connection shows his marriage to Gracie: his siblings and parents aren't represented here. In this diagram, Rachael passed her Hemophilia-A-programmed X chromosome to (only) Gracie.

When you create your family tree, you can ask your HTC for help. There are also few good explanations for X-linked recessive inheritance, such as this one on Wikipedia:

https://en.wikipedia.org/wiki/Sex_linkage

Diagrams like these can trace the travel of inherited bleeding disorders back through as many generations as your relatives' memories and notes can go. Your ancestors lived with a bleeding disorder, and you can, too: you can shine for them, and keep their memory alive.

By Donald Glascock, HFMD Board Secretary

FDA-Approved Patient Labeling

Patient Information

ELOCTATE™ /el' ok' tate/
[Antihemophilic Factor (Recombinant), Fc Fusion Protein]

Please read this Patient Information carefully before using ELOCTATE 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 ELOCTATE?
ELOCTATE is an injectable medicine that is used to help control and prevent bleeding in people with Hemophilia A (congenital Factor VIII deficiency).

Your healthcare provider may give you ELOCTATE when you have surgery.

Who should not use ELOCTATE?
You should not use ELOCTATE if you had an allergic reaction to it in the past.

What should I tell my healthcare provider before using ELOCTATE?
Talk to your healthcare provider about:

- Any medical problems that you have or had.
- All prescription and non-prescription medicines that you take, including over-the-counter medicines, supplements or herbal medicines.
- Pregnancy or if you are planning to become pregnant. It is not known if ELOCTATE may harm your unborn baby.
- Breastfeeding. It is not known if ELOCTATE passes into the milk and if it can harm your baby.

How should I use ELOCTATE?
You get ELOCTATE as an infusion into your vein. Your healthcare provider will instruct you on how to do infusions on your own, and may watch you give yourself the first dose of ELOCTATE.

Contact your healthcare provider right away if bleeding is not controlled after using ELOCTATE.

What are the possible side effects of ELOCTATE?
Common side effects of ELOCTATE are joint pain and general discomfort.

Allergic reactions may occur. Call your healthcare provider or emergency department 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 ELOCTATE, which may stop ELOCTATE from working properly. Your healthcare provider may give you blood tests to check for inhibitors.

How should I store ELOCTATE?

- Keep ELOCTATE in its original package.
- Protect it from light.
- Do not freeze.
- Store refrigerated (2°C to 8°C or 36°F to 46°F) or at room temperature [not to exceed 30°C (86°F)], for up to six months.
- When storing at room temperature:
  - Note on the carton the date on which the product is removed from refrigeration.
  - Use the product before the end of this 6 month period or discard it.
  - Do not return the product to the refrigerator.

Do not use ELOCTATE after the expiration date printed on the vial or, if you removed it from the refrigerator, after the date that was noted on the carton, whichever is earlier.

After reconstitution (mixing with the diluent):

- Do not use ELOCTATE if the reconstituted solution is not clear to slightly opalescent and colorless.
- Use reconstituted product as soon as possible
- You may store reconstituted solution at room temperature, not to exceed 30°C (86°F), for up to three hours. Protect the reconstituted product from direct sunlight. Discard any product not used within three hours.

What else should I know about ELOCTATE?
Medicines are sometimes prescribed for purposes other than those listed here. Do not use ELOCTATE for a condition for which it was not prescribed. Do not share ELOCTATE with other people, even if they have the same symptoms that you have.

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Issued June 2014

A Tribute to Joni Osip

The HFMD could not carry out the quality of programs and service that we provide without the close collaboration and support of our affiliated Hemophilia Treatment Centers. Joni Osip, (RN) has pioneered and exemplified what clinic staff do for this bleeding disorders community through the HFMD.

Joni has led countless education presentations from pain management to the benefits of good nutrition and fitness for hundreds of HFMD members over the years at our Annual Meeting, Family Education Events, and Blood Brotherhood programs. At clinic and through presenting at HFMD events, Joni has helped our members and families to become so well informed on medical treatment and better health. As a camp planner, and as a volunteer during our camp session; Joni also played a key role in making HFMD camp such an amazing experience for children with bleeding disorders.

As Program Manager of MHealth several years ago (formerly U of MN Medical Center, Fairview), Joni helped to create and launch our Men's Night Out program, which evolved into our current Blood Brotherhood program for adult men with bleeding disorders. With nearly 35 years of award-winning caregiving for so many HFMD members, Joni has treated some from birth to the present.

"She's been one of the most consistent and stablizing influences throughout my childhood and young adult years. During the very difficult years of Hemophilia's history, Joni Osip provided professional and emotional support to my family and many others. I hope people reading this understand Joni's impact on the community, and what a loss it will be to no longer have her part of the day to day operation of the HTC and to those who will not receive her care in the future. You are one of the best and I will miss the hugs at the comprehensive clinics and all of the support. You will be missed." *Casey MacCallum (HFMD Board Vice President)*

As a result of her dedication to patients and exemplary skill as a nurse, Joni Osip was awarded the National Hemophilia Foundation "Nurse of the Year" in 2007. As Program Manager during that time at the clinic, Joni also substantially increased the U of MN annual donation to the HFMD. In addition, Joni also served on the HFMD Board for over 3 years. Joni has been a big part of this organization's success for many years. After 35 years at the U of MN clinic (MHealth), Joni Osip is going to work as a Clinical Support Specialist – Hematology for Bayer.

By Jim Paist

Group Fitness Event at Pinz in Oakdale

Who doesn't love bowling, pizza, and lazar tag? The HFMD returned to Pinz for another Fall group fitness activity. Over 50 HFMD members came out to roll strikes, spares, and yes; a few gutter balls here and there.

Physical Therapist Cheryl Hansen from Children's Hospitals and Clinics opened the day by getting our group limber and stretched out with jumping-jacks, toe-touchers, and deep arm stretches. HFMD families from Minnesota and Western Wisconsin also had plenty of time to mingle, eat pizza (& salad) share stories, and catch up in between the thunderous sounds of crashing pins. Parents, children, and blood brothers bowled for more than two hours before playing some hard core lazar tag. After a good hour of zapping each other, the event winded down. Members from Mayo Clinic, MHealth, and Children's all came together to make this another fun-filled event. Special thanks to Cheryl Hansen, Dr. Susan Kearney, and Stephanie Davis of Children's Hospitals & Clinics for helping to make the event a success!
By Jim Paist

Sled Hockey Puts Hemophilia on Ice

Student doesn't let his bleeding disorder call the shots

By Beth Marshall | 11.18.2015

Justin McClanahan of the Rochester Mustangs practicing his puck-handling skills.

In each issue of HemAware*, we spotlight people in the bleeding disorders community. Here, we talk with Justin McClanahan, a 29-year-old from Rochester, Minnesota, about his involvement with the Rochester Mustangs, a sled hockey team. Justin has severe hemophilia A.*

How does sled hockey differ from regular hockey?
It's adaptive hockey. So you sit in what's called a sled, with two blades in the back and a rubber guide in the front. You have two shortened sticks, which have ice picks on one end and regular hockey sticks on the other end. You use the ends with the picks to propel yourself and the other ends for shooting and puck handling.

How did you get involved with the Rochester Mustangs?
I grew up as an athletic kid and was on a basketball team when I was around 11 or 12. But because I had so much joint damage from early bleeds, I really wasn't able to play team sports after that. Seven years ago, I had my right knee replaced, and last December I had my left ankle fused. I felt like I was never going to be able to find something to play until a buddy of mine who plays in an amateur adult league picked up a flyer for the Rochester Mustangs and gave it to me. Two weeks later I went to their board meeting, and two weeks after that I was learning how to play.

Tell us about the players on your team.
We have 11 players on the team, all with some sort of disability. We have several players with spinal cord injuries, who are paralyzed from the waist down. The youngest player on our team is 9 years old and he lost his legs in an accident. And then there's me—left ankle fusion, right ankle replacement and severe hemophilia.

Why do you believe that participating in a sport like sled hockey is important for people with disabilities?
Everyone on the team has his own unique story about why he's in that sled, and they're all stories about having something being taken from you. When I'm playing, I feel like I'm taking something back that my disability has robbed me of. That's the great thing about team sports, especially when you have a disability. It gives you back that feeling of control. When we're on the ice, everyone is equal. Everyone is just part of the team.

How are you getting the word out about this new league?
We're going to be playing a few exhibition games against teams with able-bodied players who will be using sleds. We're excited about one in February, where we'll play against local celebrities, like radio hosts and the chief of police. I've started Facebook and Twitter accounts for the Rochester Mustangs to try to raise our profile. I'm going to school for public relations, so I'm trying to use the skills I'm learning in school to help raise the profile of the team. Hopefully, people who may have felt that they could never play a team sport can find us and join.

Why do you feel it's important for people with bleeding disorders to participate in sports?
I was born before prophylaxis became standard treatment for kids, so I didn't start it until I was about 6 years old. By that point, I had already developed arthritis in my joints. But there are so many kids now who, because of good products and prophy, have no reason not to find a safe way to be active. I never wanted to let hemophilia run my life. By keeping active and keeping your muscles and joints strong, you can be in charge of your own life, rather than letting hemophilia dictate what you can do.

Courtesy *HemAware* Magazine, National Hemophilia Foundation

The HFMD gratefully acknowledges our donors who have given so generously. These are donations received from January 1, 2015 through December 31, 2015.

If you have made a donation and your name is not listed, please contact HFMD.

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South Dakota Center for Bleeding Disorders
1600 West 22nd Street
P. O. Box 5039
Sioux Falls, SD 57117
605-312-1000

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Mayo Clinic
Mayo 10-75E
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Rochester, MN 55905
507-284-8634 or 1-800-344-7726
brown.heather@mayo.edu

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University of Minnesota Medical Center, Fairview
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612-626-6455

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Children's Hospital and Clinics of Minnesota (CHCMN)
2525 Chicago Avenue, CSC-175
Minneapolis, MN 55404
612-813-5940
angela.boyd@childrensmn.org

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on behalf of Nathan Kvittem
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Tami Waltz
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Jessica Wolff
Terry Wotzka
Brian & Darlene Yager
Mike & Sue Zachmann

In Memory of Dr. J. Roger Edson
Margaret Beauvais
Cheryl Ellefson
Jody Hargrove
Elizabeth Merchant
Jeanne Mugge
Stewart Rosoff
James & Bonnie Schmidt
U of M Physicians, Faculty & Staff Dept of Laboratory Medicine & Pathology

In Memory of Dorie Gilmer
Duane Oesterich
Ronald & Julie Reimann
Stephen Rudenick
Rick & Nancy Van Buren
Jack & Jeri Veach

Staff & Board News

Meet Brianna Hager, HFMD's new Event Coordinator. Hired on in early December, Brianna brings over six years of nonprofit event experience, and high energy to our team. She has hit the ground running in gearing up for our Gala, and is involved with other upcoming events. Brianna will also be the site Coordinator for our Blood Brotherhood program.

The HFMD recently recruited Adam Alver to join our Board. Adam has a unique skillset as a senior at the University of Minnesota, finishing a degree in political science; and he is also a public policy analyst for the Hemophilia Federation of America. Adam's involvement on the HFMD's Advocacy committee was another attribute he brings. Welcome to the HFMD Adam & Brianna!

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NEWSLETTER OF THE HEMOPHILIA FOUNDATION OF MINNESOTA AND THE DAKOTAS

HFMD
750 South Plaza Drive
Suite 207
Mendota Heights, MN 55120

Phone: 651.406.8655
Fax: 651.406.8656
1-800-994-4363
Email: hemophiliafound@visi.com

HFMD
HEMOPHILIA FOUNDATION OF MINNESOTA/DAKOTAS
Website at hfmd.org

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Calendar of Events

Feb 20,2016	Hearts of Hope Gala/Radisson Blu, Mall of America
April 3, 2016	Blood Brotherhood,Target Center MN Timberwolves game (for adult men with bleeding disorders)
April 22-23	HFMD Annual Meeting/ Hilton (airport)
July 10-15	HFMD Summer Camp for Kids at Courage North (True Friends)

HFMD
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