



## Step Out for Bleeding Disorders Annual Walk Fundraiser

**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.



HFMD's 5<sup>th</sup> Annual Walk fundraiser on Saturday October 3<sup>rd</sup> saw sponsors, affiliated Hemophilia Treatment Center staff, and so many members of this community coming together as one to raise funds for the HFMD. The event turned out to be a shining reflection of what this organization does; bringing all stakeholders together toward the common goal of serving this bleeding disorders community and having a whole lot of fun.

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It was a sunny and crisp fall day at the Como Park Picnic Pavilion in St. Paul where around 300 participants gathered to Step Out for Bleeding Disorders. A dedicated group of volunteers helped HFMD staff to set up the event; hanging banners, posting walk route path signs, setting up tables for exhibitors and general preparation for what turned out to be another fantastic Walk.

KQ 92 classic rock radio station rolled in with their enormous Urban RV to before registration opened at 10:00 a.m. to keep music going throughout the event. Minnesota Timberwolves mascot crunch arrived in the team ambulance, but not as a patient and completely unharmed. Crunch brought high energy excitement and antics for our youth walkers from start to finish.



Pickles the Clown was a big hit twisting balloon animals and balloon helmets to the delight of many kids. Memories and More photo-booth (sponsored by CSL Behring) had a steady flow of those seeking fun and whacky pictures. And face-painter extraordinaire Jennifer Paist brushed many a face with different themes.



*continued on pages 2-3*

Walk...continued from cover



**1<sup>st</sup> Place Team**  
**Team Naumann (Below)**  
Raised over \$4,800!!

**2<sup>nd</sup> Place Team**  
**Team Burke-Romarheim**  
Raised over \$2,900!!



**3<sup>rd</sup> Place Team**  
**Team Schulte Schufflers**  
Raised over \$2,400!!

Walk...continued

## Thanks so much to our generous Walk Sponsors & Exhibitors!!!

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### Board & Staff News

After four years as our Event Coordinator, Carrie Kissoon has left the HFMD to spend more time with her young family. Carrie has been a valuable asset for HFMD during her tenure here, and her creativity enhanced so many of our events. She brought high energy, good ideas, and a great sense of humor to the HFMD. Carrie will be missed by many of us in this bleeding disorders community.



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## Status of the North Dakota Chapter

My Friends,

I would like to provide an update to the status of the newest chapter in the American bleeding disorder's community. The Bleeding Disorders Alliance of North Dakota (BDAND) has been incorporated as a non-profit organization with the North Dakota Secretary of State. The Internal Revenue Service is currently processing the paperwork that, once approved, will provide tax-exempt status to BDAND.

We have chosen the name Bleeding Disorders Alliance of North Dakota to reflect the growing movement within the bleeding disorder's community to include all individuals affected by inheritable bleeding disorders. We welcome anyone affected by a bleeding disorder to participate in our activities. So far, we have put on a picnic at the park event. At this event our members learned, or were reminded of, some basic skills and knowledge necessary to thrive while affected by a bleeding disorder.

For now, we are an entirely volunteer organization with an eight member Board of Directors. With adequate funding, we plan to employ at least one staff member as an executive director. We will provide activities and programming for anyone living in North Dakota, and Northwestern Minnesota. The Directors meet monthly at Sanford's Roger Maris Cancer Center in Fargo. For more information, please email us at [bleedingalliance.nd@gmail.com](mailto:bleedingalliance.nd@gmail.com), or call Carson Ouellette at 701-350-1729

Sincerely,

Carson Ouellette

President  
Bleeding Disorders Alliance of North Dakota

**Save  
the Date**

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**Hemophilia Foundation of  
Minnesota & Dakotas**



**16th Annual  
Hearts of Hope Gala  
Saturday, February 20, 2016  
5:30PM**

## NHF Annual Meeting 2015 by Donald Glascock, HFMD Board Secretary

I expected to learn some interesting facts and to meet some great people at the 2015 NHF Annual Meeting in Dallas this last August 13<sup>th</sup>-15<sup>th</sup>, but I didn't expect to be surprised.

For example, when walking through the exhibit booths, I stopped at one booth that touted a new approach to prophylaxis and possibly to treating bleeding incidents, which made me smile. I'm fifty-two, and my blood stream wouldn't recognize much change in the factor that I've been receiving since I was seven (though of course my liver does). But these folks talked about two boys with severe Factor VIII who have the bleeding characteristics of someone with mild Factor VIII, and analysis showed that these boys were both very low in a compound called Antithrombin, which goes around knocking down blood clots: because these boys had less of it, their low levels of Factor VIII were presumably pedaling in less of a headwind, so to speak. I think I actually said, "What? What are you saying?" If these folks can make their Antithrombin product work, then we might be able to inject miniscule doses into our muscles (as though we were getting a flu shot) instead of twenty to forty milliliters into our veins, without risking inhibitors. This technique could be helpful for VIII, IX, and perhaps other factors as well. The potential of this drug was covered favorably in the NHF "New Products" session, so we'll have to watch for news on this front.

When Val Bias, who heads the NHF, asked the NHF chapters on Thursday morning to get behind his efforts to get 10,000 folks contributing to the anonymous "My Life, Our Future" genetic defects survey, I thought simply, "That's nice. Gee, I think I already contributed, but I'll ask our HFMD folks about stronger participation." I did not yet realize the importance of Val's requests, but on Saturday, in the Inhibitors session, the speakers reported some results from genetic defect surveys, and were able to assign a probability (probability, not foregone conclusion) that a given specific genetic defect in a given factor is likely to lead to an inhibitor. And how do we know which defect we have in our respective betroubled factor, you ask? Why, through the "My Life, Our Future" genetic survey, the speakers reported: our HTC can tell us these results, though the survey won't know who we are. So of course I'm very interested in talking with my HTC, as you should be as well, if you have not yet contributed or don't already know your odds.

I expected the Ethics session to discuss the role that we in the bleeding community each play in managing

our risky behaviors. And indeed the topic did come up. Briefly. I did not expect an ethics issue regarding missing yearly physicals, which drew a fair amount of comment from both healthcare providers and from bleeders like me. The issue presented was that factor is legally a drug, and, like almost every other drug, cannot be prescribed for more than a year: providers are required to assess the state of the patient before a prescription can be renewed. I thought this topic was somewhat overblown, but then it was reported that some HTCs (none in Minnesota and the Dakotas, as far as I know) withhold factor if the patient hasn't been seen within a year. I mentioned that my physicals haven't turned up much new since about 1997, and that I have felt that I was somewhat wasting my HTC's time by getting a yearly physical, but this session made me realize that the topic is more complex than I thought, and that I have a responsibility to my HTC that I did not appreciate. I don't know the preferences and policies for physicals at each HTC served by HFMD, but I contacted mine and I'm slated for a physical in a few weeks.

[The chapter-related sessions on donor relations and on working with volunteers seemed, shall we say, somewhat dry on the surface. But they weren't, to my great surprise. They both, in unique ways, pointed out that when you or I volunteer some time or donate some money, we want to know what our time or money will accomplish beforehand, and we want to know how the overall mission turned out afterwards. Both sessions offered lots of examples showing that the quality of the relationship between donor and the organization is the overwhelming factor that determines the likelihood of future donations of time or money.]

One of the sidebar events was the "Red Tie Challenge," which was announced somewhat like the 1960's "Stuckey's" highway signs: "What is it? Come and see." So I went to the "Dallas-4" conference room between sessions, and was asked if there were a person in the bleeding community whom I would like to honor on tape as I put on a red tie that they provided, and I thought of my mother's father, Col. Ben T. Starkey, and said, "yes." He had a very difficult turn-of-the-century childhood, made more complicated by Hemophilia-B and an abusive father who kicked him out of the house when we was about fourteen. When allowed, he enlisted in the Army Air Corps and flew hydrogen-filled balloons in front of enemy lines in World War I, and later flew biplanes, dirigibles, and many other aircraft. He educated

himself, and worked his way up from a private to a bird colonel, commanding air force bases in democratic China during World War II and in the States beforehand and afterwards. For the bulk of his life, he did not know what had killed a few of his siblings, or why he struggled with his health. Many of us have a bleeding disorder running back a few generations, and I'll bet that your family tree likewise has folks who met their challenges as best they could and in ways that inspire you like my grandfather does me.

I also attended several sessions geared toward us older Hemophiliacs, and they were great: both the older Hemophiliacs, and the sessions. There was a wrap session for us, in which we each asked the other bleeders there about topics that concern us most, and a session on retirement planning, which is a good challenge to have. And there was a session on health insurance for us older folks, as well, and a couple more, which I couldn't attend. I was surprised at the breadth and thoroughness of topics offered for the folks old enough to remember seeing (and being somewhat excited by) the "in Color" tag at the beginning of the early "Brady Bunch" episodes.

And then there's Carson Ouellette, who has been a member of HFMD's board, and is firing up an NHF chapter local to the folks in North Dakota. Carson can seem like a quiet person who sticks to the sidelines, but I'll bet I'm not the only person who has met him and quickly learns that his leadership skills will take him far. Carson was recognized first by Val Bias in one of our chapter sessions, and then formally in the awards luncheon on Saturday, for which he received the Meritorious Service in Honor of Ryan White award, which he received directly from Ryan's mom. Ryan White died far too young of AIDS, and like Ricky Ray, had to endure the prejudices of fear that made his last years that much more complex. This award recognizes young people who, like Ryan, try to make a difference in the world through leadership that will benefit others in the bleeding community. Congratulations, Carson! We're all proud of you and your accomplishments. We're excited by the work you're doing and wish you the best!

Next year's 2016 NHF conference in Orlando will be unlike any ever before: for the first time ever, it will run alongside the yearly meeting for the World Federation of Hemophilia. There will be more folks gathered in one place regarding Hemophilia and bleeding disorders than ever before in the history of the world.

Here's a final string of surprises: gene therapy is

coming, but Prednisone may be needed to control the body's reaction to it; Koate still exists (though Konine, my first product, is gone), and Koate has a sixteen-hour half-life; Pfizer's factor-tracking app has an "activity" section that can read your Google Health data created by smart-watches and other devices; Carson can throw down on a dance floor like John Travolta; and lastly, there are many more topics to cover than will fit in this newsletter article. I suppose that's the biggest surprise of all.

## Facts First Education Program

HFMD partnered with Baxalta to host an education dinner for our members. This event filled the meeting room to the capacity of 25 at the Rojo Mexican Grill in Edina. Our group had the pleasure of enjoying a delicious dinner while absorbing some fascinating information from Sue Kovats-Bell, RN BSN. Sue shared an in depth presentation on how genetics can influence the likelihood of having a child born with hemophilia. In addition



to outlining the physiological aspects of genetics in relation to hemophilia, she also delved into the family lineage of some of history's most well-known carriers of hemophilia including Queen Victoria from 19<sup>th</sup> century England, to Tsarina Alexandra of Russia's last ruling family of the Romanov dynasty. After the presentation, there were some great questions and answers. HFMD thanks Stacie Cowen, Sue Kovats-Bell, Richa Sastry & Jodi McKelvey of Baxalta for sponsoring and co-hosting this event!

# Mayo Clinic HTC Family Education Weekend

September 18-20, 2015



Step Up to the Plate!



Friday Night Tailgating Fun!

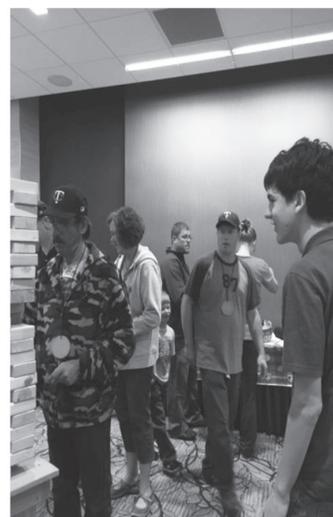


The Photo Booth was a hit!



Giant Jenga

Fun was had by "players" of all ages.



**Saturday Education & Activities  
Ramada Plaza Minneapolis**



**Jesse Schrader, former professional baseball player with Moderate Hemophilia A, inspires the group with his story and personal perspective.**



**Physician & Co-Director of the Mayo Clinic Sports Medicine Center, Dr. Ed Laskowski talks about fitness, strength, and stability.**



**Molly Mallory, Mayo Clinic Acupuncturist, shares information on the benefits of acupuncture.**



**The kids had a blast at Mayo Clinic Child Life's Activity Program where they learned all about blood, experienced music with Mayo Clinic Music Therapist Christina Wood (kneeling on the far left) and did many fun crafts. Christina also spoke with adults about the benefits of Music in one's life.**



**A highlight of the weekend was attending the Twins game at Target Center Saturday Night. Unfortunately the Twins lost, but the weather was perfect and we had a great time!**





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## Gettin In the Game at CHS Field



A big thank you to Mark Weiner, Dena Ianello-Zimmer & CSL Behring for partnering with the HFMD to host a group outing for our members at a St. Paul Saints baseball game on Sunday, September 23<sup>rd</sup>. The event opened prior to game-time with inspirational speaker Jessie Schrader who shared his storied baseball career which began as a young child excelling all the way through high school, college, *and* then to the professional level of the minor leagues. An important part

of Jessie's story is that he happens to have hemophilia. Our group then enjoyed a tasty buffet while settling in for the game in the shiny and new CHS field. There was plenty of time for members catching up with each other while watching baseball and the whacky antics occurring on the field between innings. A fun time was had by all.

By Jim Paist

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**GRIFOLS**

## Grifols Facility Tour by Kris Manns, HFMD Board Treasurer

On August 31<sup>st</sup> and September 1<sup>st</sup> Grifols hosted a tour of their facilities in sunny California. The tour began Monday evening by networking with the Grifols management team along with NHF employees and leaders from other state chapters. Throughout the evening we learned about Grifols 75 year history and its mission to improve the health and wellbeing of people all over the world. They shared their plasma collection philosophy and discussed their dedication to the safety of their plasma donors and recipient patients.



The next morning we were given the opportunity to tour the Bellflower Plasma Center during normal operating hours so we could see the donation process in a live setting. The plasma center staff walked us through the extensive screening process and physical exam that must be completed by all new donors. They also explained the donation process for repeat donors. During this tour I was amazed to learn it takes more than 1,300 plasma donations to treat one patient for hemophilia for one year. The plasma collected is comprised of 93% water and only 7% protein. The protein collected is comprised of approximately 300 different proteins of which only a handful of proteins is used to treat bleeding disorders.

After our tour of the plasma center we traveled back to the US headquarters in Los Angeles. The Grifols team gave us a comprehensive overview of the manufacturing processes for the Factor 8 protein. We then took an extremely interesting walking tour of their manufacturing facilities. We completed the tour by visiting their museum on site which provided a comprehensive look at the past 75 years of operations.

I am very grateful to have been given the opportunity to meet the Grifols team and learn more about their company and manufacturing operations. The tour provided all of us valuable information to share with our bleeding disorders community and gave us more confidence in the safety of plasma derived products.

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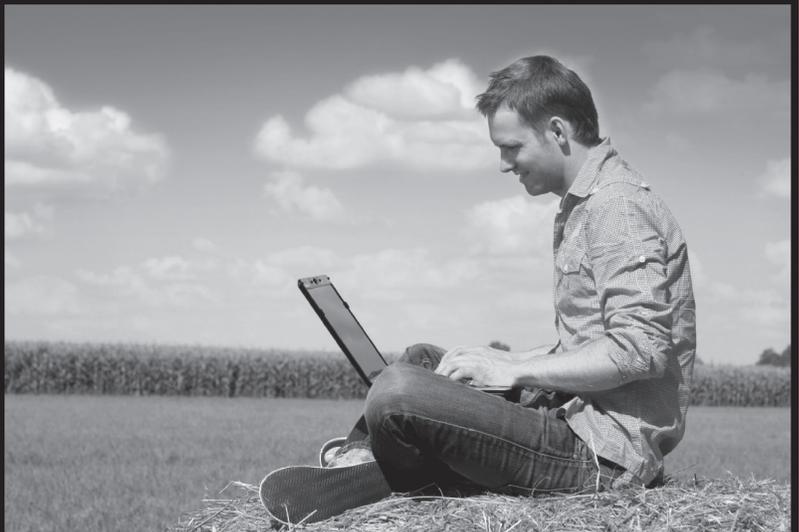
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### Mayo Comprehensive Hemophilia Center Mayo Clinic

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Rochester, MN 55905  
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...Contributions continued from page 13

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Dave Weierke  
Daydra Wernlund  
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



Michael, 30 years old, lives with hemophilia A.

An injectable medicine used to control and prevent bleeding in people with hemophilia A

**Novoeight® —  
designed to fit  
into your world**

Visit [Novoeight.com](http://Novoeight.com) today to learn more.



**Indications and Usage**

Novoeight® (Antihemophilic Factor [Recombinant]) is an injectable medicine used to control and prevent bleeding in people with hemophilia A. Your healthcare provider may give you Novoeight® when you have surgery.

Novoeight® is not used to treat von Willebrand Disease.

**Important Safety Information**

You should not use Novoeight® if you are allergic to factor VIII or any of the other ingredients of Novoeight® or if you are allergic to hamster proteins.

Call your healthcare provider right away and stop treatment if you get any of the following signs of an allergic reaction: rashes or hives, difficulty breathing or swallowing, tightness of the chest, swelling of the lips and tongue, light-headedness, dizziness or loss of consciousness, pale and cold skin, fast heartbeat, or red or swollen face or hands.

Before taking Novoeight®, you should tell your healthcare provider if you have or have had any medical conditions, take any medicines (including non-prescription medicines and dietary supplements), are nursing, pregnant or planning to become pregnant, or have been told that you have inhibitors to factor VIII.

Your body can make antibodies called "inhibitors" against Novoeight®, which may stop Novoeight® from working properly. Call your healthcare provider right away if your bleeding does not stop after taking Novoeight®.

Common side effects of Novoeight® include swelling or itching at the location of injection, changes in liver tests, and fever.

**Please see brief summary of Prescribing Information on following page.**

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

Novo Nordisk Inc., 800 Scudders Mill Road, Plainsboro, New Jersey 08536 U.S.A.

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**novoeight®**  
Antihemophilic Factor  
(Recombinant)

# novoeight®

## Antihemophilic Factor (Recombinant)

### Patient Product Information

**Novoeight® (NÖ-vö-eyt)**  
**Antihemophilic Factor (Recombinant)**

#### Rx Only

**This is a BRIEF SUMMARY of important information about Novoeight®.**

**Read the Patient Product Information and the Instructions For Use that come with Novoeight® before you start taking this medicine and each time you get a refill. There may be new information.**

This Patient Product Information does not take the place of talking with your healthcare provider about your medical condition or treatment. If you have questions about Novoeight® after reading this information, ask your healthcare provider.

#### **What is the most important information I need to know about Novoeight®?**

**Do not attempt to do an infusion yourself unless you have been taught how by your healthcare provider or hemophilia center.**

You must carefully follow your healthcare provider's instructions regarding the dose and schedule for infusing Novoeight® so that your treatment will work best for you.

#### **What is Novoeight®?**

Novoeight® is an injectable medicine used to replace clotting factor VIII that is missing in patients with hemophilia A. Hemophilia A is an inherited bleeding disorder that prevents blood from clotting normally.

Novoeight® is used to control and prevent bleeding in people with hemophilia A.

Your healthcare provider may give you Novoeight® when you have surgery.

Novoeight® is not used to treat von Willebrand Disease.

#### **Who should not use Novoeight®?**

You should not use Novoeight® if you

- are allergic to factor VIII or any of the other ingredients of Novoeight
- if you are allergic to hamster proteins

Tell your healthcare provider if you are pregnant or nursing because Novoeight® might not be right for you.

#### **What should I tell my healthcare provider before I use Novoeight®?**

You should tell your healthcare provider if you

- Have or have had any medical conditions.
- Take any medicines, including non-prescription medicines and dietary supplements.
- Are nursing.
- Are pregnant or planning to become pregnant.
- Have been told that you have inhibitors to factor VIII.

#### **How should I use Novoeight®?**

Treatment with Novoeight® should be started by a healthcare provider who is experienced in the care of patients with hemophilia A.

Novoeight® is given as an injection into the vein.

You may infuse Novoeight® at a hemophilia treatment center, at your healthcare provider's office or in your home. You should be trained on how to do infusions by your hemophilia treatment center or healthcare provider. Many people with hemophilia A learn to infuse the medicine by themselves or with the help of a family member.

Your healthcare provider will tell you how much Novoeight® to use based on your weight, the severity of your hemophilia A, and where you are bleeding.

You may need to have blood tests done after getting Novoeight® to be sure that your blood level of factor VIII is high enough to clot your blood. This is particularly important if you are having major surgery.

Your healthcare provider will calculate your dose of Novoeight® (in international units, IU) depending on your condition and body weight.

**Call your healthcare provider right away if your bleeding does not stop after taking Novoeight®.**

#### **Development of factor VIII inhibitors**

Your body can also make antibodies called "inhibitors" against Novoeight®, which may stop Novoeight® from working properly.

If your bleeding is not adequately controlled, it could be due to the development of factor VIII inhibitors. This should be checked by your healthcare provider. You might need a higher dose of Novoeight® or even a different product to control bleeding. Do not increase the total dose of Novoeight® to control your bleeding without consulting your healthcare provider.

#### **Use in children**

Novoeight® can be used in children. Your healthcare provider will decide the dose of Novoeight® you will receive.

#### **If you forget to use Novoeight®**

Do not inject a double dose to make up for a forgotten dose. Proceed with the next injections as scheduled and continue as advised by your healthcare provider.

#### **If you stop using Novoeight®**

If you stop using Novoeight® you are not protected against bleeding. Do not stop using Novoeight® without consulting your healthcare provider.

If you have any further questions on the use of this product, ask your healthcare provider.

#### **What if I take too much Novoeight®?**

Always take Novoeight® exactly as your healthcare provider has told you. You should check with your healthcare provider if you are not sure. If you inject more Novoeight® than recommended, tell your healthcare provider as soon as possible.

#### **What are the possible side effects of Novoeight®?**

##### **Common Side Effects Include:**

- swelling or itching at the location of injection
- changes in liver tests
- fever

##### **Other Possible Side Effects:**

You could have an allergic reaction to coagulation factor VIII products. **Call your healthcare provider right away and stop treatment if you get any of the following signs of an allergic reaction:**

- rashes including hives
- difficulty breathing, shortness of breath or wheezing
- tightness of the chest or throat, difficulty swallowing
- swelling of the lips and tongue
- light-headedness, dizziness or loss of consciousness
- pale and cold skin, fast heart beat which may be signs of low blood pressure
- red or swollen face or hands

These are not all of the possible side effects from Novoeight®. Ask your healthcare provider for more information. You are encouraged to report side effects to FDA at 1-800-FDA-1088.

Tell your healthcare provider about any side effect that bothers you or that does not go away.

#### **How should I store Novoeight®?**

##### **Prior to Reconstitution:**

Store in original package in order to protect from light. Do not freeze Novoeight®.

Novoeight® vials can be stored in the refrigerator (36–46°F [2°C–8°C]) for up to 30 months or up to the expiration date, or at room temperature (up to 86°F [30°C]) for a single period not exceeding 12 months.

If you choose to store Novoeight® at room temperature:

- Note the date that the product is removed from refrigeration on the box.
- The total time of storage at room temperature should not exceed 12 months. Do not return the product to the refrigerator.
- Do not use after 12 months from this date or the expiration date listed on the vial, whichever is earlier.

Do not use this medicine after the expiration date which is on the outer carton and the vial.

The expiration date refers to the last day of that month.

##### **After Reconstitution** (mixing the dry powder in the vial with the diluent):

The reconstituted Novoeight® should appear clear to slightly unclear without particles.

The reconstituted Novoeight® should be used immediately.

If you cannot use the Novoeight® immediately after it is mixed, it should be used within 4 hours when stored at ≤ 86°F (30°C). Store the reconstituted product in the vial.

Keep this medicine out of the sight and out of reach of children.

#### **What else should I know about Novoeight® and hemophilia A?**

Medicines are sometimes prescribed for purposes other than those listed here.

Do not use Novoeight® for a condition for which it is not prescribed. Do not share Novoeight® with other people, even if they have the same symptoms that you have.

For more information about Novoeight®, please call Novo Nordisk at 1-844-30-EIGHT.

**More detailed information is available upon request.**

**Available by prescription only.**

Revised: 09/2014

*Novoeight® is a trademark of Novo Nordisk A/S.*

For information about Novoeight® contact:

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**NEWSLETTER OF  
THE HEMOPHILIA  
FOUNDATION OF  
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THE DAKOTAS**

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OF MINNESOTA/DAKOTAS

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## 2015 Calendar of Events

- |                     |   |
|---------------------|---|
| November 6-8, 2015  | NOW (National Outreach vonWillebrand) Conference @<br>Pointe Hilton Squaw Peak Resort in Arizona (1 <sup>st</sup> of two<br>sessions offered) |
| November 7, 2015    | PINZ Bowling and Laser Tag<br>(Space is limited. Sign up early)   |
| February 20, 2016   | 2016 Hearts of Hope Gala<br>Radisson Blu, Mall of America   |
| April 22 – 23, 2016 | HFMD's Annual Meeting<br>Hilton Minneapolis/St. Paul Airport Mall of America  |
| April 22 – 24, 2016 | NOW (National Outreach vonWillebrand) Conference @<br>Pointe Hilton Squaw Peak Resort in Arizona (2nd of two<br>sessions offered)             |

Visit our web site at [www.hfmd.org](http://www.hfmd.org) for more information and updates on events!