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# BIG RED

2016—Issue III

## Nebraska Chapter News

The Nebraska Chapter  
Of the  
National Hemophilia Foundation  
Is hosting a  
**Townhall meeting**  
**November 5, 2016**  
**Ramada Plaza Omaha**  
**9 am - 1 pm**

Breakfast Included, RSVP today!  
Register at [www.nebraskanhf.org](http://www.nebraskanhf.org)





### **Our Mission:**

The National Hemophilia Foundation—Nebraska Chapter is dedicated to finding better treatments and cures for inheritable bleeding disorders and to preventing the complications of these disorders through education, advocacy & research.

### **Staff**

**Interim Executive Director**  
Maureen Grace

**Development Coordinator**  
Kelsey Cunningham

### **Advisory Board of Directors**

President - Patrick Quintana  
Vice President - Geri Murphy  
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Zach Blackman  
Samantha Clinkenbeard  
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Marlee Wernke

*The material in this newsletter is provided for your general information only. The Nebraska Chapter does not give medical advice or engage in the practice of medicine. NHF-NE does not recommend particular treatments for specific individuals and in all cases recommends that you consult your physician or local treatment center before pursuing any course of treatment.*

### **2016 Program and Events Calendar**

**Saturday, November 5, 2016**

Townhall Meeting  
Ramada Plaza Hotel  
Omaha, NE

**Saturday, December 10, 2016**

PING and Holiday Party  
Lincoln Children's Museum  
5:30-7:30

***\*\*Dates are Subject to change.  
More Activities Coming Soon!  
Watch our website for updates and register  
Online!***



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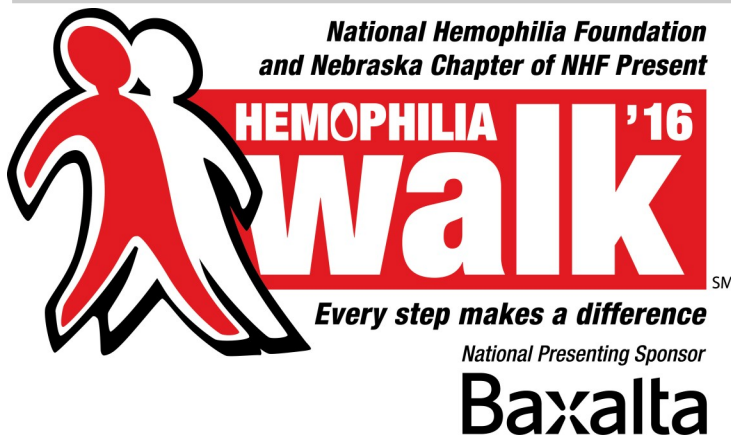
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# Hero Hemophilia Walk 2016



Can you believe another year has come and gone? And, we hit \$40,000! \$40,138.92, to be exact. Your drive and belief in us, the Nebraska Chapter of the National Hemophilia Foundation is how we raised so much for our chapter.

Coming out to Chalco Hills the day before to set up the walk, the energy was high and the weather uncertain for Saturday. All we could do was hope and pray for a perfect day, and perfect it was. You and your team of family and friends came out in masses to support NHF.

The morning kicked off with breakfast from Bagel Bin and Pettit's Pastries, everyone was stuffed and ready to go. Jordana Zeger from National came in from New York City to get us going. We were blessed with support from both the Lincoln and Omaha area businesses and non-profit organizations to be able to raffle off lots of prizes. We offered up basketball tickets, baseball tickets to both Creighton and the Lincoln Salt-dogs, Omaha Children's Museum passes, Morrill Hall passes, and many more.

Team Elliott came into the walk with a bang. They knocked out Oliver's Clotting Crew from our highest fundraising team of the past 3 years and raised \$8,825.92. The Mickeliunas recently joined the Nebraska Chapter of NHF, after having their newborn, Elliott, be diagnosed with Hemophilia. Their first born, Amelia Mickeliunas won our first every Top Youth Fundraiser. Read more about Amelia and her Lemonade Stand on page 12.

It was a fight to the end for Top Fundraiser. The day of the walk, Samantha Clinkinbeard took this honor, raising \$2,290.00. With the close of our walk donations, on October 7th, Joe Mickeliunas has raised \$2,553.00, narrowly taking the top fundraiser position by \$263.00.

Mark Henry was the perfect super hero. The Fro Bros did not disappoint in their attire. You could not miss them with their red shirts and hair for days. Max and Hayden Henson and their love of superheros has brought out some awesome shirts. This year's walk shirt, all about the Hulk, took top prize for best shirt.

The perfect day, with perfect weather, right up until the end was filled with laughter, friends, and super hemo heroes. In the short time I have been apart of this community, I have noticed a family that cares and supports each other during the hard times and the fun times. When the storm rolled in, that community rallied and got everything taken in and packed away in no time. Maureen and I, and the rest of our NHF community were soaking wet and laughing about the magnificent time we just had. At the end of the day, all we could say was, YOU ROCKED IT.

Thanks for making our walk 2016 the amazing success that it was, we can't wait for next year!



# You Did It! Walk 2016







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- Hemophilia B
- Von Willebrand's Disease
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# Personalizing Patient-Reported Outcomes for Hemophilia

In a recent paper, a group of experienced hematologists reviewed two tools used for assessing patient-reported outcomes (PROs). While standard modes of outcome measurement, such as annualized bleeding rate and joint health score, are relatively effective in evaluating larger groups of bleeding disorders patients, they are not designed to capture the unique healthcare needs, perspectives and goals of each individual. The need for a personalized approach for people with hemophilia is even greater in light of dramatic changes in the clinical landscape over the last two decades, including the proliferation of progressively safer and more effective therapies, and the availability of preventive treatment regimens like prophylaxis.

The article, “Recognizing the Need for Personalization of Haemophilia Patient-Reported Outcomes in the Prophylaxis Era,” was published August 31, 2016, in the journal *Haemophilia*. The lead author of the study was Michael Recht, MD, a pediatric hematologist-oncologist at the Hemophilia Center at the Oregon Health & Science University in Portland. Recht and his colleagues assessed a pair of tools: the patient-reported outcomes measurement information system (PROMIS®) and the goal attainment scaling (GAS).

First launched in 2004 by the US National Institutes of Health (NIH), PROMIS takes the traditional questionnaire-based approach and employs modern measurement theory to develop new and enhanced PRO tools. The system improves on the traditional PRO techniques in part through the use of a psychometric method, which measures knowledge, abilities, attitudes and personality traits among individuals to produce scores associated with probable answers to questions.

These scores can then be used by computerized adaptive testing (CAT) to pinpoint the most informative follow-up question to an initial question from a predetermined bank of questions. According to investigators, PROMIS allows clinicians and researchers access to “efficient, precise, valid and responsive adult- and child-reported measures” in the physical, mental and social areas. These can then be applied across a broad range of chronic conditions, including hemophilia.

GAS involves a truly collaborative approach whereby a patient works with his or her physician to select important personal goals that are linked to the clinical or functional impacts of the patient’s condition. An assessment of actual goal attainment is made after a predetermined amount of time. According to the authors, GAS has been applied successfully in both clinical practice and research in patients with a broad range of other chronic conditions, including dementia, diabetes, acquired brain injury and various types of physical disabilities. One primary advantage of GAS is that it allows for the discovery of seemingly minor, though clinically and practically significant, changes, with real-world implications for a unique individual’s quality of life.

“We believe that this approach most directly addresses the need for personalization of outcome measurement in hemophilia,” concluded the authors. “Adoption of this or a similarly qualified patient-centric outcome measure will provide clinicians and researchers with an important innovation that addresses the contemporary challenge of measuring incremental but clinically meaningful improvement in hemophilia patients.”

*Source: Hemophilia News Today, September 12, 2016*



# Harvest Festival

The weather, again, surprised us and it was hot! Way too hot for mid October, but no one was going to complain about a picture perfect day at Vala's Pumpkin Patch. Thanks to CSL Behring, Octapharma, Bayer, Superior Biologics, and Novo Nordisk, NCHS for sponsoring our Harvest Festival. And a big thanks to Accredo for hosting our educational portion. Who knew that you could get 30+ kids to pay attention to someone while so many awesome things were happening around them at Vala's.

Between eating hotdogs, visiting with friends, and exploring Vala's, everyone had the opportunity to learn about clean sanitation and sterile sanitation. Glitter was thrown everywhere, while the kids figured out how germs work in the world. After the glitter filled clean sanitation station, if your child came near you, you ended up covered in glitter. This only reinforced the teachings with the adults as well!

Following the education portion of the afternoon, we had s'mores around the campfire. All the glitter covered children, became ooey gooey marshmallow messes on a sugar high. We could not have asked for anything better at our Harvest Festival.



Pfizer Cordially Invites You to Attend  
An Educational Program

*Featuring* Gladis Murillo, RN

CNE Speaker

**Overcoming Challenges**

**Thursday, November 17, 2016**

**6:00 PM Registration**

Dinner and Presentation to Follow

Fireworks Restaurant

5750 South 86th Street

Lincoln, NE 68526

(402) 434-5957

Hosted by the Nebraska Chapter National Hemophilia Foundation

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**Please RSVP via phone or email to Maureen Grace**

**402-499-8025 mgrace@hemophilia.org**

Thank you!

*Pfizer respects your privacy. We require your RSVP for headcount only. When you RSVP, it is not necessary to provide your name; you should simply identify yourself as a consumer who is accepting the invitation. Pfizer's educational programs for consumers are conducted in accordance with the same high ethical standards that we apply to our programs for health care professionals. The sole purpose of consumer programs is to educate you on general healthcare issues. Pfizer cannot provide diagnosis, treatment, or other medical advice to you. If you have any medical questions regarding your own health, diagnosis, or treatment, please consult your health care provider.*







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\*The Free Trial Program is available to newly diagnosed patients and patients who are currently using other therapy. Participation in the Free Trial Program is limited to 1 time only. This program is complimentary and is not an obligation to purchase or use a Bayer product in the future. Reselling or billing any third party for the free product is prohibited by law.

†The Free Trial Program includes up to 6 free doses to a maximum of 5,000 IU for new patients and 40,000 IU for previously treated patients.

‡The program does not guarantee that patients will be successful in obtaining reimbursement. Support medication provided through Bayer's assistance programs is complimentary and is not contingent on future product purchases. Reselling or billing any third party for free product provided by Bayer's patient assistance programs is prohibited by law. Bayer reserves the right to determine eligibility, monitor participation, determine equitable distribution of product, and modify or discontinue the program at any time.

§People with private, commercial health insurance may receive co-pay or co-insurance assistance based on eligibility requirements. The program is on a first-come, first-served basis. Financial support is available for up to 12 months. Eligible patients can re-enroll for additional 12-month courses. The program is not for patients receiving prescription reimbursement under any federal-, state-, or government-funded insurance programs, or where prohibited by law. All people who meet these criteria are encouraged to apply. Bayer reserves the right to discontinue the program at any time.



## NHF's Annual Meeting

The National Hemophilia Foundation hosted their annual meeting this year in sunny Orlando, Florida in conjunction with the World Federation of Hemophilia's World Congress. The Nebraska Chapter sent one Maureen Grace and the Henson family to the Annual Meeting. Additionally, the Henry family received a scholarship from our National office to attend as well. This year's meeting focused on a Brighter Future Together.

Those in attendance were able to choose from several different session tracks that included focuses on adult men, families, industry symposiums, spouses and partners, teens and young adults, Von Willebrand Disease and Women with Bleeding Disorders.

Several new medications are coming down the pipeline and it was exciting to hear from our industry partners where they look to be heading in the next couple years. Gene therapy was a big topic of discussion as well.

The final night was spent at Universal Studios, sponsored by BioGen. It was a wonderful evening of food from around the world, music, rides and fun. Our families had an amazing time and learned a lot. Save the date for the NHF Annual Meeting next year in Chicago from August 24-26, 2017.



The Hensons, featured left, enjoyed their time at the NHF meeting along with their two boys Max and Hayden



The Henrys, with their three boys during NHF.

## Amelia's Lemonade Stand

If you know kindergartners, they LOVE to have lemonade stands. Amelia had been dying to have one all summer, and on her own decided to support the Nebraska Chapter of NHF, in honor of her new baby brother Elliott.

Through the help of her parents, Joe and Jenny Mickeliunas, a date was picked and word spread. Turns out, Amelia's Lemonade Stand just so happened to coincide with a Husker game. Despite everyone else having plans that day to watch football, Amelia was able to raise over \$500.

Watching Amelia and her drive to support her little brother, the top youth fundraiser prize was born. We can't wait to see what everyone can do next year, age does not matter, clearly as shown by Amelia Mickeliunas, through the wonderful support of her parents, Joe and Jenny Mickeliunas.



## Chapter of Excellence Award

The Nebraska Chapter of the National Hemophilia Foundation is a proud recipient of the **Partnership Chapter of Excellence Award** in recognition of our chapter's participation in shared initiatives, trainings and programs of NHF and our commitment to the relevance and vitality of our national chapter network as we work together to improve the lives of the bleeding disorder community.



This award was present to the chapter at the 2016 Annual Meeting in Orlando, Florida. Maureen Grace, Interim Executive Director and Dan Henson, Chapter Board member accepted the award on behalf of the chapter. This award also came with one free registration for our chapter to use for next year's Annual Meeting in Chicago!

We are proud to be a chapter of excellence and hope to branch out into other categories of excellence as we work to make our chapter stronger in the coming years. Thank you to everyone who made this honor possible.

## New Research Sheds Light on Disease Suppression

Researchers from the University of North Carolina (UNC) at Chapel Hill School of Medicine have published a new study suggesting that genetic material known as heterochromatin performs a key role in disease suppression. The study, “Direct Interrogation of the Role of H3K9 in Metazoan Heterochromatin Function,” was published August 2016, in the journal *Genes & Development*. The new findings could have future therapeutic implications for conditions such as cancer and hemophilia.

Heterochromatin represents one of two distinct groupings of DNA found within cells known as chromatin. Loosely-packed euchromatin carries out several important functions, including the efficient packaging of DNA so that it fits into the nucleus of a cell. In contrast, heterochromatin is densely packed and relatively inactive. Both are found in chromosomes, the thread-like structures located inside the nucleus of all animal and plant cells. DNA, which when passed from parents to offspring, carries with it the specific genetic instructions that account for an individual’s unique hereditary traits.

While scientists have generally assumed that heterochromatin is responsible for controlling gene expression and cell proliferation, UNC investigators may have assigned it some newfound relevance. Using *Drosophila* fruit flies they demonstrated that heterochromatin actually works to suppress the activity of transposons, or “jumping genes,” a notable finding as these genes have the capacity to replicate and paste copies throughout the genome. By inserting themselves into certain key genes, transposons can cause adverse cellular changes such as disrupting tumor-suppressing genes or fragmenting DNA to destabilize the chromosome. These and other molecular level changes have been associated with several conditions, such as cancer and hemophilia.

Lead investigator Robert Duronio, PhD, and his colleagues also discovered that heterochromatin form when a protein called histone H3 is chemically modified or “methylated,” a theory tested in the *Drosophila* fruit flies. The researchers subsequently observed a 98% mortality rate amongst the flies, which had their working H3 genes replaced with a mutant form, which allowed the transposons to infiltrate important genes. The finding is significant as it suggests that by removing working H3 genes, investigators also eliminated the flies’ ability to produce heterochromatin and its critical jumping gene suppressing function.

“It seems that the major role for the methylation of histone H3 that triggers this type of heterochromatin is to keep transposons from jumping around and screwing up the genome,” explained Duronio.

The UNC team plans to conduct additional research to further their understanding of the biological relationship between transposons, heterochromatins and the genome. “During embryonic and fetal development, there is normally a high-fidelity replication of the genome, and that is a significant mechanism for repressing cancer and other diseases,” concluded Duronio. “With studies like these, we’re understanding how heterochromatin does its job in that respect.”



## THE FIRST FACTOR VIII WITH A PROLONGED HALF-LIFE

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### Indications

ELOCTATE [Antihemophilic Factor (Recombinant), Fc Fusion Protein] is a recombinant DNA derived, antihemophilic factor indicated in adults and children with Hemophilia A (congenital Factor VIII deficiency) for: control and prevention of bleeding episodes, perioperative management (surgical prophylaxis), and routine prophylaxis to prevent or reduce the frequency of bleeding episodes. ELOCTATE is not indicated for the treatment of von Willebrand disease.

### Important Safety Information

Do not use ELOCTATE if you have had an allergic reaction to it in the past.

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, are breastfeeding, are pregnant or planning to become pregnant, or have been told you have inhibitors (antibodies) to Factor VIII.

Allergic reactions may occur with ELOCTATE. 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 ELOCTATE, which may stop ELOCTATE from working properly.

Common side effects of ELOCTATE are joint pain and general discomfort. These are not all the possible side effects of ELOCTATE. Talk to your healthcare provider right away about any side effect that bothers you or that does not go away, and if bleeding is not controlled after using ELOCTATE.

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.

**Please see Brief Summary of full Prescribing Information on the next page.**

**This information is not intended to replace discussions with your healthcare provider.**

## **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?**

You can have an allergic reaction to ELOCTATE. 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. This can stop ELOCTATE from working properly. Your healthcare provider may give you blood tests to check for inhibitors.

Common side effects of ELOCTATE are headache, rash, joint pain, muscle pain and general discomfort.

These are not the only possible side effects of ELOCTATE. Tell your healthcare provider about any side effect that bothers you or does not go away.

#### **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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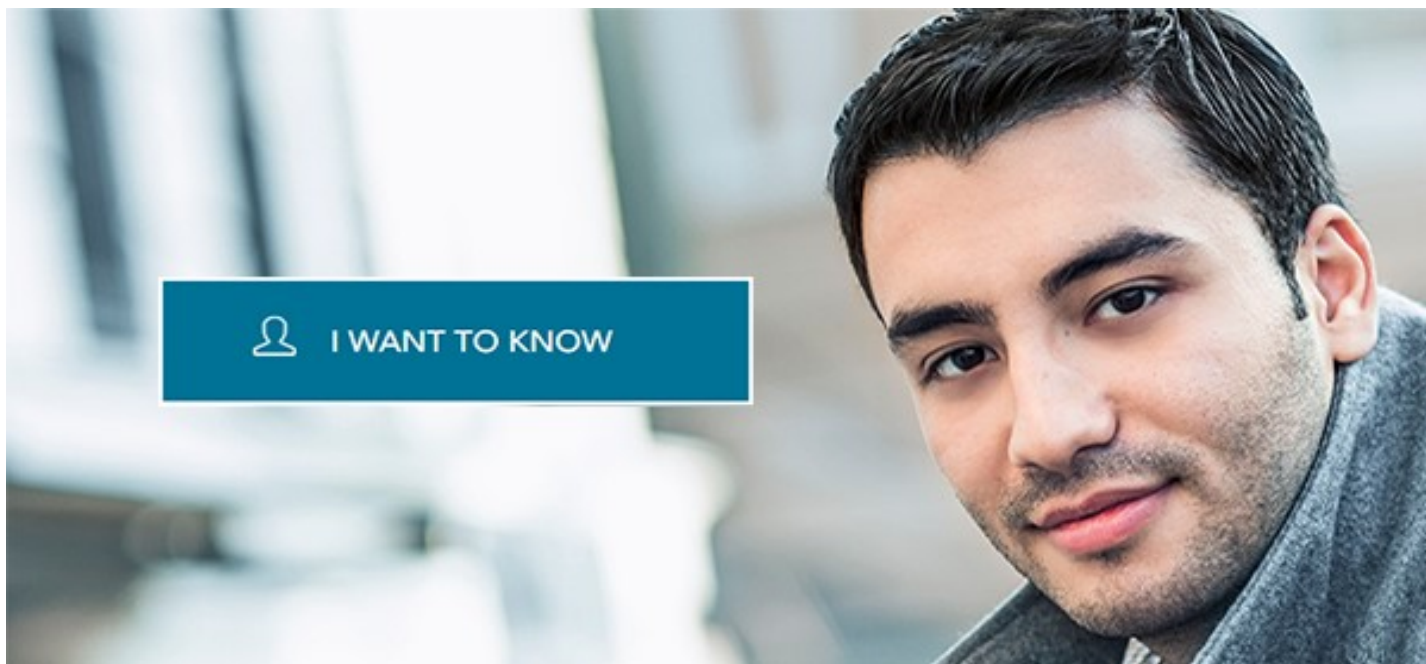
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## Help NHF improve education for men with VWD. Please Take this anonymous Survey



To increase awareness of VWD in men, NHF is developing the men's section of our "Better You Know" website.

**BetterYouKnow.org** is a new website for men and women who may have symptoms of a bleeding disorder, but have not yet been diagnosed.

If you are a male who has VWD and is over 18, please take this anonymous survey by Sunday, November 20, 2016.

By taking this anonymous survey, you are helping us make the men's section relevant to your needs and informing our educational programming for people with VWD.

**Take Survey**



# Kid's Corner

## Getting Ready for Surgery: Help Is Nearby



Illustration by John Haslam

Some kids who have bleeding disorders are pretty comfortable with doctors, hospitals and even needles. Still, having a surgery can feel scary and make you worry.

Those feelings are normal. Ask your family and your care team about anything that concerns you. And make sure you understand the answers. It will help you feel better, knowing what to expect.

Here are some questions you might ask before having your tonsils out or ear tubes put in:

### Q: Is it going to hurt?

Doctors and nurses have many ways to make sure you do not feel pain during the surgery. You may be given a “general anesthesia” that helps you stay asleep through the surgery. Or you may be given a “local anesthesia.” This means that the part of your body the doctor is operating on does not feel anything. After the surgery, tell your family and your doctors if you’re in pain. Your medical team

can give you medicine that helps with pain and helps you rest.

### Q: How long will I be in the hospital?

Your family and your doctors can answer this. How long you stay in the hospital depends on what your surgery is and how you are healing. For some surgeries, you get to go home the same day. For others, you might stay over a few nights.

### Q: Can my parents be with me?

Parents aren’t usually allowed to come into the surgery room. But they can be with you before and afterward, when you’re recovering.

### Q: What if I’m scared?

It’s OK to be scared. Just remember: Your medical team will take good care of you every step of the way. Your family will be close by, waiting to see you as soon as possible. Take your mind off of scary thoughts and try to feel calm. Deep breathing, listening to music, and drawing or coloring can help you do this. Just think: Soon you’ll be home, enjoying summer fun again.

Join us for a night of  
fun, laughter, and education  
at

# PING

And our Holiday Party

December 10, 2016

Lincoln Children's Museum

5:30 pm –7:30

Dinner will be provided

Please register online at

[www.nebraskanhf.org](http://www.nebraskanhf.org)

