BIG RED FACTOR

2016—Issue IV

Nebraska Chapter News

Inside this issue:

NEW ADDRESS

We are moving!

effective January 1, 2016

Our address is

8031 W Center Road, Suite 304

Omaha, Nebraska 68124

This move was made to better serve you and we will be located near both the HTC and Children's Hospital for your convenience. Please come visit us!

NEBRASKA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION
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.

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Development Coordinator
Kelsey Cunningham

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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.

2017
First Quarter Events

February 22, 2017
Advocacy Day
Nebraska State Capitol
Lincoln, Nebraska

March 23-25, 2017
Family Education Weekend
Lincoln, Nebraska
Registration Coming Soon!

More Activities Coming Soon!
Watch our website for updates and register Online!

A Proud Member of

COMMUNITY HEALTH CHARITIES℠ NEBRASKA

Town Hall Meeting 2016

On Saturday, November 5, we hosted a Town Hall Meeting at that Ramada Plaza Omaha. We invited our community members to join us for an open conversation on how we are doing as a chapter, what changes are needed and how we can best serve you in 2017. Dawn Rotellini, Senior Vice President of Chapter Development and Education from NHF came in to facilitate. The event was sponsored by CSL Behring, Shire, Pfizer and NCHS. We had a small but vocal group who gave us a lot of feedback regarding the chapter.

We found our strengths were connecting families and having bleeding disorder safe events where are able to put you in touch with other individuals or families that are similar to you. We plan to continue to host these events throughout 2017.

Additionally, we wanted to find ways that we can improve. In the last several years most of our events have taken place in Omaha and Lincoln and we haven't reached out to the greater Nebraska community. We have taken the steps to correct that in 2017. We will be hosting an Education Day in Kearney over Labor Day weekend in conjunction with the Nebraska State Fair. Additionally, we will be having industry dinners across the state. Nebraska NHF serves the entire state and we want our community who do not reside in Eastern Nebraska to feel included as well.

Our biggest event of the year is our Walk and we heard you loudly that you want a few changes. We are working to have more family activities and games at Walk next year. We have face painters and Storm Troopers already booked! We won't be serving lunch again this year, however we will have the Pancake Man out serving up a hot breakfast before the walk begins!

The Board and Staff of the Nebraska Chapter are small and we try to do as much as we can with our limited numbers. To counteract this next year we are going to be working hard to grow our Committees. Committees will work with board and staff on events, programs, fundraising and advocacy. If you want to help out with our Infusion: A Bloody Mary Mix Off, the Hemophilia Walk, Family Camp, Advocacy Days or any of our upcoming programs, we would love to have your help. The more our committees can help, the more the chapter will be able to provide to our community. It's the perfect way to give back and get involved. Please let Maureen or Kelsey know if you are interested in sitting on a Development, Program or Advocacy Committee in 2017.

The Town hall meeting was so beneficial to making sure the Nebraska Chapter is serving you effectively and successfully. We will be hosting a second Town hall meeting on November 4, 2017, location TBD to follow up on how things have gone in the past year and to hear your suggestions going forward. After this next year, we plan on hosting this meeting every other year as a way for you to have your voice heard and your concerns addressed on a regular basis.

It is truly an honor serving the bleeding disorder community in Nebraska. Thank you for letting us provide you with these services. This community truly is family and is unlike any other community out there. We aim to give you a great year next year. Please know you can come to me anytime with ongoing questions or concerns and I will do all I can to help.

Maureen Grace

Executive Director

2017 Calendar

February 22-	Advocacy Day, Lincoln, Nebraska
March 8-10-	Washington Days, Washington DC
March 24-25-	Family Education Weekend– Embassy Suites, Lincoln , NE
April 15-	Red/White Game, Lincoln, NE
May TBD-	Women's Spa Day with NCHS
May TBD	Mini-Golf Fore Good, Papillion, NE
June 24	Infusion Bloodly Mary Mix Off, Ralston, NE
July TBD	PING! Parent Information and Networking Group
August 11-13	Family Camp, Gretna, NE
August 24-26	NHF Annual Meeting– Chicago, IL
September 2	Kearney Outreach and Education Meeting with Nebraska State Fair
September 30	Nebraska Chapter Hemophilia Walk, Omaha, NE
October 14	Harvest Festival, Ashland, NE
November 4	2017 Town Hall Meeting
December 9	PING! Holiday Party, Lincoln Children's Museum, Lincoln, NE

Event Color Key:

Educational, Advocacy, Social, Fundraising, Industry

*****This is the 2017 Calendar as of December 27, 2016. Event dates are open to change. We will be adding several industry dinners across the state in 2017. We will make you aware of additions to the calendar as often as possible. Please stay up to date on our calendar by visiting www.nebraskanhf.org. *****

Virtual Reality Game Helping Young Hemophilia Patients Ignore Painful Treatments

The hemophilia team and design experts at Nationwide Children's Hospital partnered with students from Ohio State University's Advanced Computing Center for the Arts and Design (ACCAD) to develop a virtual reality game that aims to help the hospital's pediatric hemophilia patients during procedures.

Hemophilia patients often have to go through hundreds of infusions and other procedures that involve needle sticks, and for the youngest among them these procedures can cause not only pain, but also fear and stress, and risk leading to long-term anxiety about the healthcare system.

The game, called Voxel Bay, is now in a pilot study at Nationwide. It was specifically designed to engage pediatric patients in an environment filled penguins, pirates, and hermit crabs during procedures, to distract them from the infusions or other painful but necessary treatments they undergo.

A nurse clinician in the comprehensive hemophilia treatment center at Nationwide for 30 years, Charmaine Biega, saw 6-year-old Brody Bowman fully relaxed while receiving his infusion, something she says she had never seen before.

"Brody just started getting his treatments through IV on a regular basis and was having a really rough time," Biega said in a press release. "But the first time he used the game in clinic, he was so completely engaged in the game when the IV was administered, he just barely flinched. The difference in how patients react during a procedure when they are playing these interactive games is remarkable."

A tablet allows nurses to interact with the patients through the game, and see exactly what they are seeing in their game headset, allowing for interaction. The disposable, light-weight headset, created by the design team, is both easy for children to use and, of course, hands-free — an important feature for patients who need infusions.

The pilot study is funded with a National Hemophilia Foundation research grant, and testing how well virtual reality technology integrates into the clinic setting. Parents, patients and nurses are providing feedback on the game's usability and likability.

"I work with pediatric patients with bleeding disorders and know all too well the fears and anxiety that they and their families experience related to frequent needle sticks," said Amy Dunn, MD, director of Hematology at Nationwide Children's. "I took this problem to our incredible design team and asked them to help our hemophilia team create a solution that would be cost-effective, friendly, safe, engaging for children of any age, and help with adherence to treatments ultimately leading to better outcomes."

The hemophilia team is now exploring what applications this technology could have in the home setting, and how virtual reality aid in patient education.

"The feedback we have gotten so far has been really positive," Dunn said. "[W]e designed an approach that is truly engaging and immersive for kids and is customized to their needs, and we believe it will really make a difference in their treatment and outcomes."

Source: Hemophilia News Today, October 12, 2016

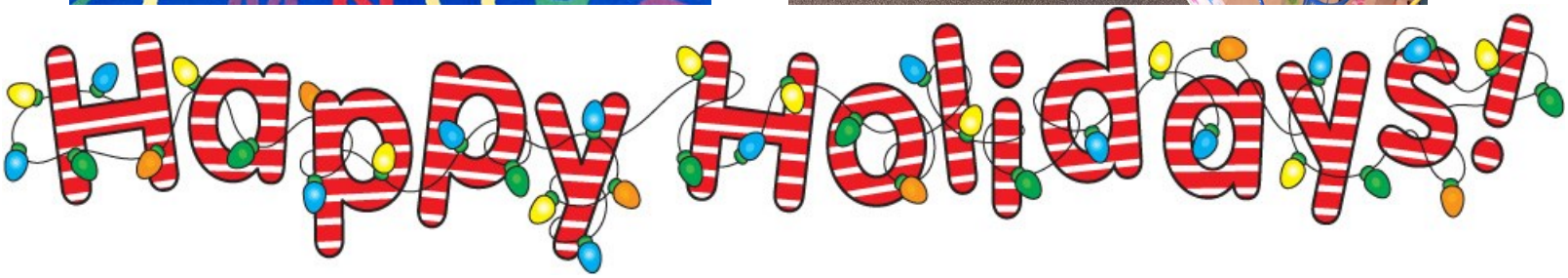
PING at the Lincoln Children's Museum

The turnout was amazing for our Holiday Party and PING at the Lincoln Children's Museum. Once the museum closed its doors, the party was on! We had Jessica Walker speaking on behalf of Bayer. Pain management is such a huge topic in the lives of persons with blood disorders and she gave us plenty of new tips on how to deal with that pain. There were silly brain exercises, that taught everyone methods on retraining your brain during painful moments.

Valentino's and Eileen's cookies kept our dinner "in Nebraska" . The pasta, pizza, and cookies fueled the kiddos and they ran for the next 90 mins straight. Kids were able to explore the entire museum, all three floors of fun!

Big thanks to our industry partners who made the night possible!

- Shire
- Octapharma
- CSL Behring
- Pfizer
- CVS Speciality
- NCHS
- Bayer
- OptionCare
- BioRX
- Superior Biologics



HOLIDAY PARTY

Clearing a Path: Women Need a New Diagnosis

‘‘During the past twenty years, several workers have claimed that abnormal bleeding occurs, and significant prolongation of the coagulation-time can be demonstrated, in a proportion of the female carriers of haemophilia.”

This quotation1 may not strike some of our community advocates as particularly surprising, given the recent surge in advocacy efforts regarding the identification and treatment of “symptomatic carriers,” that is, women who carry a mutation for hemophilia and have abnormal bleeding symptoms themselves. But what may surprise most advocates is that the quotation was drawn from a scientific article published about sixty-five years ago in an esteemed medical journal. The authors described a study in which they sought to identify a reliable method to measure this coagulation “defect” in known carriers (for example, women with more than one son with hemophilia). They reported bleeding symptoms in some of these carriers, such as prolonged bleeding after tooth extraction. Then, using various laboratory methods that were newly developed at that time, the authors observed abnormal clotting behavior in blood samples from 3 of the 21 known carriers.

The study’s important finding that individual carriers vary in their bleeding and clotting patterns was wholly overlooked in 1951. The authors of the study deemed the results “too indefinite and inconsistent to be of diagnostic value” and “disappointing.” The authors’ hope had been that their laboratory tests would show some subtle difference in coagulation in the blood of all known carriers. Then, tests could be used to definitively identify carriers among woman of uncertain carrier status (for example, women with a brother or uncle who had hemophilia). This specific focus can be understood from a historical perspective: most males born with severe hemophilia in the 1940s did not live to adulthood. Prognosis was so poor that identifying carriers was seen as vital for only one reason: carriers would “probably elect to remain childless.”1

Of course, times have changed. Testing the blood of carriers is now seen as vital for a second reason: to meet the healthcare needs of carriers who may have reduced clotting ability themselves. In the age of recombinant factor and prophylaxis, severe hemophilia in the US is more manageable than ever. It is perhaps only against this modern backdrop that the priorities of both the medical field and the hemophilia community have expanded to allow greater attention to be given to less severe cases.

We understand today that as many as one-half of hemophilia carriers may have a mild form of the disorder, yet most are not diagnosed as having hemophilia. In 2010, National Hemophilia Foundation’s Medical and Scientific Advisory Council (NHF’s MASAC) issued Recommendation 197 concerning girls and women with inherited bleeding disorders. This includes the recommendation that all females with a family history of bleeding disorders have their factor levels tested, and that females with factor levels lower than 50%—those with mild hemophilia—be given factor under certain circumstances, such as bleeding episodes.2

Why Are Some Women “Bleeders”?

The scenario just outlined describes women who are often called “symptomatic carriers,” and who typically meet two separate criteria. First, these women show abnormal bleeding symptoms, frequently supported by lab results showing factor VIII or IX levels less than 50%. Second, they are known as carriers because one of the two copies of their factor-producing gene has a mutation, while the other is normal. This genetic carrier status is often determined by a family pedigree. So, why are some carriers symptomatic while others are not?

The most common explanation is skewed X-inactivation (see “Devil in the Details,” page 8). Briefly, females have two X chromosomes (XX) and males have just one (XY), yet only one X chromosome can be active in a cell. Nature has a way of leveling the playing field by shutting off one of the two X chromosomes in each cell of a female’s body. The process of X-inactivation ensures expression of just one copy of many genes on the X chromosome in females—which occurs by default in males, who have only one X. The decision of which X to shut off in each cell is usually random, so in some cases, female carriers by chance will end up with more cells

Clearing a Path: Women Need a New Diagnosis

In other rare cases, a woman may also have a mutation on both of her X chromosomes, for example if her mother is a carrier for hemophilia A or B and her father has the same disorder. In this instance, the daughter could have hemophilia with a range of possible degrees of severity, like that seen in males.

There are several other causes of abnormal bleeding in women. Most women with bleeding issues have von Willebrand disease (VWD), the most common bleeding disorder in both men and women, affecting 1% to 2% of the population. VWD is caused by a mutation in the gene responsible for the production of von Willebrand factor (VWF). Unlike factors VIII and IX, the gene for VWF is located on chromosome 12 and is inherited identically in males and females, so the disorder occurs equally in men and women and can be passed on from either (or both) parents. There are several different types of VWD, and they can vary in severity.

Several other factor deficiency or platelet disorders also affect both sexes, including factor VII deficiency and factor XI deficiency (hemophilia C). These bleeding disorders are generally inherited recessively, meaning that the mutated copy of the gene must be passed on by both parents, which

is exceedingly rare. However, shared ancestry can increase the incidence of rare recessive genetic diseases in certain ethnic groups.

Identifying and Treating Bleeding Symptoms in Women

Many of the symptoms that women with bleeding disorders experience are similar to those of men with hemophilia. These may range from milder symptoms, such as prolonged bleeding following dental procedures or bruising, to more serious bleeds, including joint bleeding and intracranial hemorrhage.

Significantly, women with bleeding disorders experience some symptoms that are distinct from those experienced by men: prolonged or heavy bleeding during menstruation (menorrhagia), and bleeding complications related to pregnancy and childbirth. The stigma that most cultures place on discussing menstrual bleeding can present a particular challenge to identifying women with bleeding disorders, especially those with mild symptoms or who lack a family history. It's common for a woman to be unsure if the amount of bleeding she experiences is—or is not—normal, and the problem may be missed if she doesn't bring it up with her physician. On the other hand, some bleeding disorders, such as VWD, may actually be more often diagnosed in women than in men, even if they occur at a similar rate. This can be attributed to the challenges of excessive menstrual bleeding in affected females once they reach puberty, compared to affected males, who may not be diagnosed unless they have a serious injury or surgery. Increasingly, new resources, such as the website betteryouknow.org and the Victory for Women initiative developed by NHF, are available to help both men and women assess whether they are symptomatic and open dialogues with their physicians.

Diagnosis and treatment of bleeding symptoms in women should be comparable to what men receive when reporting similar symptoms or factor levels. Yet some women with bleeding disorders have been challenged when sharing their concerns with physicians and seeking treatment. This may be due in part to the rare incidence of many bleeding disorders. In the case of potential carriers of hemophilia A and B, there may be an additional hurdle: the common misconception among primary care providers that such X-linked recessive bleeding disorders affect only males. Additionally, because some physicians are more familiar with autosomal recessive disorders in which carriers usually do not have symptoms, they may wrongly assume that a female carrier of an X-linked recessive disorder must also be asymptomatic. Even experts at some hemophilia treatment centers (HTCs) may have work to do: some carriers of hemophilia A and B have reported being told by HTC personnel that they were hypersensitive to the possibility of bleeding symptoms because of their family history, or that "only males can be affected"…only to be later diagnosed. Identifying carriers with low factor levels as having hemophilia is key to countering this persistent misconception.

Clearing a Path: Women Need a New Diagnosis

Through NHF's program My Life, Our Future, potential carriers can now be genotyped (a process of identifying the specific gene mutation causing a person's bleeding disorder) for free or at low cost through one of the participating HTCs to find out whether they carry the gene for hemophilia. In fact, most HTCs are willing to test women and girls who want to know their carrier status, or find out whether they have a low factor level. The National Hemophilia Program Coordinating Center (NHPCC), funded through the American Thrombosis and Hemostasis Network (ATHN) by the Health Resources and Services Administration (HRSA), has also funded a project of national significance at Children's Hospital of Philadelphia to develop a "Genetic Education Toolkit for Female Relatives at Risk of Carrier Status" to support education on this issue. What's more, groups such as the Foundation for Women and Girls with Bleeding Disorders focus on advocacy for women with all types of bleeding disorders by educating their healthcare providers. Similarly, Healthy People 2020, a 10-year agenda launched in 2010 to improve the nation's health, is helping to raise providers' awareness of the importance of diagnosing bleeding disorders in women. The group is tracking progress in identifying women with VWD and getting them into treatment by age 21, listing this among the indicators of quality healthcare in the US.

Stand Up and Be Counted!

How can we measure the success of these initiatives to ensure that women and girls with bleeding disorders are diagnosed and treated? In short—data! Diane Aschman, president and CEO of ATHN, and Barbara Konkle, MD, of Bloodworks Northwest and the University of Washington, point to several projects that ATHN is involved in to collect data about women who are carriers of hemophilia—those who have abnormal factor levels (less than 50%) as well as those whose factor levels fall within the normal range. For example, if a woman is confirmed as a carrier of hemophilia A or B through the My Life, Our Future project, HTCs will document her factor activity levels, and may also document her standardized bleed score, a survey used by physicians to help diagnose the type and severity of a bleeding disorder.3 This project builds on the primary ATHN dataset, in which HTCs can enroll women with bleeding disorders, as well as carriers, to record baseline factor level and other demographic and clinical information. In addition, Community Counts is a Centers for Disease Control and Prevention Public Health Surveillance for Bleeding Disorders project. HTCs submit (through ATHN) an HTC Population Profile, which counts all patients with specified bleeding and clotting disorders, including women whose levels fall either within or outside the normal range. These numbers will be tracked over time.

Each of these data projects will shed light on the number of women with bleeding disorders, differentiating the number of women and girls from males with each disorder and

categorizing each individual based on severity. Once published, the data on the number and severity of these disorders in women will provide evidence of need, often the first step in designing appropriate strategies to prevent complications. Such data will also help inform providers, payers, and patients about bleeding disorders in women.

Could This Apply to Me?

Whether you are a known carrier, a woman with a family history of bleeding disorders, or a woman who has experienced unusual bleeding—your first step is to have your symptoms assessed. You can contact your local HTC, but you may prefer to start with a self-assessment (betteryouknow.org) or reach out to your primary care physician. Either way, keep records of your symptoms. Don't hesitate to ask to have your factor levels tested, even if you encounter some skepticism. Keep in mind that it may take more than one discussion or appointment to be properly diagnosed. It's also important to remember that factor VIII in particular can be elevated during times of stress or pregnancy, so multiple blood draws at different times may be necessary to establish an accurate baseline.

Clearing a Path: Women Need a New Diagnosis

Once your results are in, ask a hematologist to put a treatment plan in place based on your lab results, symptoms, and lifestyle. Remember—just as with hemophilia in males, bleeding tendency in females doesn't always perfectly correlate with factor level, and members of the same family may have different bleeding patterns. You may want to encourage other women in your extended family to consider being assessed. Carefully consider enrolling in an ATHN study, where your data may contribute to a broader understanding of bleeding disorders in women. Above all, be your own advocate!

Pfizer dinner at Fireworks

November 17, 2016, Pfizer hosted an educational dinner at Fireworks restaurant in Lincoln. We had the opportunity to learn from Gladis Murllo, RN about over coming challenges while enjoying some time together with our Hemo Family. She helped us to recognize some of the challenges everyone may face with a bleeding disorder and in particular helped out our teenage crowd by giving extra attention to the young adults and their unique life challenges. By looking at other people's challenges through videos and slides, we found new ways to deal with some of the things that may come up in our day to day life.

We are thankful to Pfizer for giving our community another educational opportunity and a great dinner out in Lincoln.

Thanks to you, the thousands who have said yes to progress, we have achieved our goal of enrolling 5,000 people in the *My Life, Our Future* research repository, making it the largest resource of its kind in the world

ELOCTATE®
[Antihemophilic Factor (Recombinant), Fc Fusion Protein]

THE FIRST FACTOR VIII WITH A PROLONGED HALF-LIFE

Learn how a prolonged half-life may affect your infusion schedule

Meet your CoRe Manager Brenda Adamson
E: brenda.adamson@biogen.com T: 402-686-0666

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, 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

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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Ties That Bond

Cristina de la Riva, 23, has always been close to her younger brother, Jorge. In fact, she says they are best friends. Jorge was diagnosed with severe hemophilia A at birth. His hemophilia immediately became a family affair. “When Jorge was diagnosed, our family was diagnosed,” Cristina says. “We became a team that was going to figure this out together.”
Although she was only 2 years old when Jorge was born, Cristina’s parents told her the truth as soon as she was able to understand it. The family got involved right away with the Lone Star Chapter of the National Hemophilia Foundation (NHF) in Houston.

“When I was little, all I remember of hemophilia was my brother crying because he had a shot, so I related to hemophilia very negatively,” Cristina says. “But later, as my mom became the director of the Lone Star Chapter, then I associated hemophilia with the community, going to bowl-a-thons, going to walks and doing fun stuff.”

“Jorge only lets a few people experience his hemophilia with him, so I think it’s made us closer,” she says. “That’s kind of a gift to the siblings in our community, something that is shared and can be a bonding experience within the family.”

Open communication
For Cristina, being the unaffected sibling of someone with a bleeding disorder has been a positive experience overall. In fact, she appreciates the opportunities it has created, such as the chance to advocate and participate in NHF’s National Youth Leadership Institute (NYLI), a three-year leadership training program for young adults ages 18 to 24.

But this is not always the case, according to Jeanne Safer, PhD, a psychotherapist and author of *The Normal One* (Delta, 2003). The title, she says, came from the unaffected siblings in families of children with disabilities or other challenges who self-identify as “the normal one” in the family.

According to Safer, it’s important to let unaffected siblings talk about their frustrations and fears. “You can’t make somebody feel certain things. You have to allow them to feel what they feel,” she says. Parents should avoid telling unaffected siblings to “count your blessings” if they express negativity about their sibling’s condition. “That squelches normal responses,” says Safer.

Family members should avoid referring to the sibling with a bleeding disorder as having “special needs.” After all, Safer says, all children have special needs of some sort. Consistently treating the sibling with a bleeding disorder as special can make unaffected siblings feel that they’re not special or that their needs don’t count.

Education, observation
Hiding the facts about bleeding disorders from unaffected siblings will only breed fear and uncertainty.
Cristina’s parents let her be present for Jorge’s clotting factor infusions, so she could see exactly what was involved. “I was in on it,” she says. “Otherwise, it would have been this private thing between my father or mother and my brother. I would have felt left out. I would have seen hemophilia as an experience that was separate and foreign to my own.”

What’s more, Cristina’s parents were candid with her about her risk of being a carrier of hemophilia, especially because her mother is a symptomatic carrier. Cristina was tested at age 19 and is not a carrier.

Let them shine
Safer points out that not all siblings will be naturally close. In fact, some aren’t comfortable being part of their brother’s or sister’s care. She urges parents not to force camaraderie in these relationships. She also suggests spending some one-on-one time with unaffected siblings.

“Let them be the center of attention regularly,” Safer says. “And let them have their own friends, activities and moments to shine.”

“Your family bleeding disorder doesn’t have to be something negative in your life. In our family, we became closer because of our bleeding disorder,” says Cristina.

Kid's Corner

When Your Sibling has a Bleeding Disorder

Illustration by John Haslam

If you have a brother or sister with a bleeding disorder, you probably have a lot of questions. You may wonder if you will get a bleeding disorder, too. If you have a small bruise or bleed and worry it might mean you have a bleeding disorder, ask your parents about it.

You may also wonder what it's like to have a bleeding disorder. Does your sister have a special doctor? Do those needles hurt? Maybe you worry about what games are safe to play with your brother or sister.

The more you know about your sibling's bleeding disorder, the less you will feel afraid or anxious.

Here are some other ideas that may help you and your family:

- **Learn more.** Find out about your sibling's treatment. Or just be there when your brother or sister wants to talk about it.
- **Share your feelings.** Talk to your parents if you're scared or if you feel like you don't get much attention. Those feelings are normal. Usually it feels better to share your feelings with others than to bottle them up inside.
- **Do things you enjoy.** Your parents may encourage you to do things with your brother or sister, as long as they're safe. But it's also OK to want to do things your sibling can't, like play basketball or ice skate. Talk to your mom or dad about trying a new hobby or sport—just for you.

At times, your brother or sister will need extra attention. Sometimes it may even seem as if your sibling gets all the attention. But remember that your parents are doing their best to love and support everyone in your family, including you.

Leadership Begins With U

Introducing Leadership U, a paid summer internship* for full-time college students whose lives have been touched by hemophilia. Work alongside leaders at Bayer, while learning how to become a future leader in the hemophilia community.

*Includes lodging and transportation costs

Now Accepting 2017 Summer Internship Applications at the NEW

LivingWithHemophilia.com/Lead

Applications are due no later than:
Tuesday, January 31, 2017 at 11:59 p.m. ET

Bayer

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