

BIG RED FACTOR

2022—Issue 3



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Happy Fall!

It's been a busy season with a lot of wonderful new events and programs. We still have a few remaining programs through 2022 and we hope to see you there.

Please join us for:

- Industry Symposium (November 5)
- Bayer Education Dinner (November 9)
 - PING (December 10th)
- Women's Retreat (December 17th)

We also will be announcing our 2023 calendar shortly. Thank you to everyone who has supported the chapter this year through attending programs, events and fundraisers. You make this community stronger and better. Thank you for welcoming new families with open arms and helping to continue growing our chapter.

Please take a few minutes to fill out our needs assessment to help us best serve you.

We look forward to seeing you in the coming weeks before year end. Stay safe and healthy and in good spirits.



**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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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.

**2022
Events**

Industry Symposium
November 5, 2022

Holiday PING
December 10, 2022

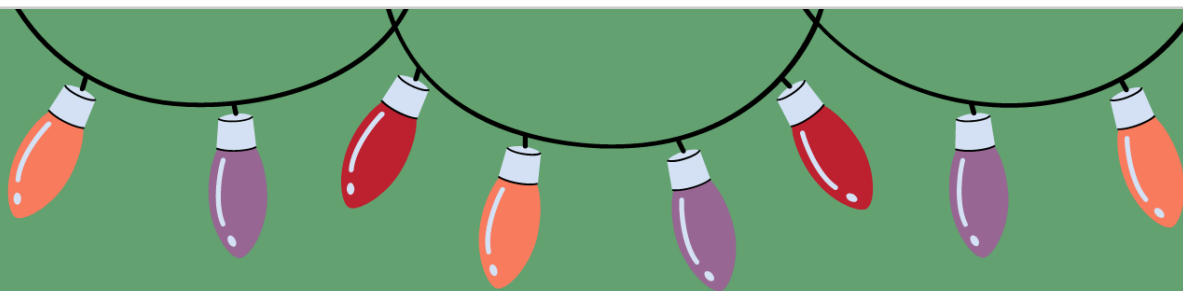
Women’s Retreat
December 17, 2022

We will be planning industry education dinners across Nebraska throughout the rest of 2022. If you want an education dinner in your area, please let us know so we can coordinate.

2023 calendar will be out in the year end newsletter!



**combined health
agencies drive**
MEMBER CHARITY



Holiday PING

(Parent Information Networking Group)

Families with children under 14

December 10

5:30-8:30 pm

Lincoln Children's Museum
1420 P Street, Lincoln, Nebraska

Education, Dinner, Santa and More!
Register at www.nebraskanhf.org



NEBRASKA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION



Research Update

Kevin Mills, PhD, NHF's Chief Scientific Officer

The last few years have been an exciting time for research at NHF! As we look to the future for the bleeding disorders community, research is leading the way. NHF continues to support the scientific research community in their search for new treatments, easier testing, better care, and even the possibility of cures. The ways in which NHF supports, facilitates, and carries out research – by and for the community – have grown by leaps and bounds. Here are just a few exciting updates, and sneak peeks at what's coming next:

The National Research Blueprint. For the last two years, NHF worked closely with the community to evaluate the current state of science for bleeding disorders and to define the most important research priorities. This has been a community led effort. We began with listening sessions and cross-community surveys with patients and their families to ask the question: what's most important to you?

Throughout 2021 community led working groups defined – and refined – the most important research priorities in six (6) areas: hemophilia A&B; von Willebrand disease; rare and ultra-rare bleeding disorders; women, girls, and people who have or had the potential to menstruate; health equity and health services research; and research infrastructure and resources. These community defined research priorities were presented during a four -day, virtual State of the Science Research Summit held in September 2021.

For the last year, NHF has been working with the community to develop a comprehensive National Research Blueprint, to put the research priorities into action. Community led working groups are hard at work developing the detailed plans, the collaboration strategies, the communication channels, and the resources to start tackling the most important scientific and research questions, and to deliver results to the community. This work was kicked off in early 2022 with two amazing workshops, including one in Washington D.C. that brought together patients, families, and others affected by bleeding disorders. It was a powerful day during which people shared their stories, voiced their concerns, and articulated their desires for research. Together with the whole community we are crafting the blueprint and look forward to sharing it with everyone in 2023.

Judith Graham Pool Fellowships. NHF continues to fund some of the most promising science – and scientists – at the cutting edge in hematology. We are celebrating the 50th anniversary of our Judith Graham Pool (JGP) fellowships, which have supported some of the most important discoveries in the last five decades. We currently have six (6) actively funded fellows:

Dr. Sean Quinn, PhD (Children's Hospital of Philadelphia) is a postdoctoral fellow working to develop new ways to target Factor V to promote coagulation for people with hemophilia

Dr. Yuan Zhang, PhD (Cleveland Clinic) is a postdoctoral fellow studying how Factor VIII is made inside cells, with the hope of finding improved ways to make FVIII products.

Research Update Continued...

Dr. Vishal Srivastava, PhD (Cleveland Clinic) is a postdoctoral fellow studying how different mutations affect Factor VIII, and how to use this knowledge for personalized medicines.

Dr. Kaushik Das, PhD (University of Texas Health Science Center) is a postdoctoral research associate studying how Factor VII promotes coagulation and prevents inflammation

Dr. Jhansi Magisetty, PhD (University of Texas Health Science Center) is a postdoctoral fellow investigating how Factor VII can be targeted to treat or prevent joint damage in hemophilia.

Dr. Xuejie Chen, PhD (University of North Carolina) is a postdoctoral fellow studying how Factor IX works to promote coagulation and finding new forms of FIX that could be used to better treat hemophilia B

Community Voices in Research (CVR) is one way you can influence research today! Community Voices in Research (CVR) is a one-of-a-kind community-powered registry that seeks to understand what it really means to live with a bleeding disorder. CVR gathers information from those affected by a bleeding disorder: those living with bleeding disorders, parents, siblings, partners, caregivers, and more. This information, gathered confidentially and maintained anonymously, is provided back to participants via a personalized dashboard. You can visualize your own data to see how it compares with the community. The data gathered by CVR also directly impacts research by better informing scientists about the needs, wants, and concerns of those living with bleeding disorders – CVR is a chance to influence what science is done, and how it is done. CVR enables researchers to gain deeper insights into things like: the impact of HTC care on the community; experiences with treatment plans or medications; barriers to health care access; mental health; aging, and more.

In exciting news, CVR has expanded rapidly over the last few years and we are now ready for the next phase. CVR 2.0 will be coming soon! The new CVR will provide an expanded toolkit for participants to visualize and use their personal data; increased numbers of participants, with different diagnoses and from different background; enhanced useability for scientists and researchers; and improved communications by and with the community.

So sign up today for CVR (hemophilia.org/cvr), and make an immediate impact on the research that will deliver tomorrow's medicines!



Scan the
QR Code to
sign up for
CVR today.



FAB Conference 2022

The second annual Females and Bleeding (FAB Conference) took place at Margaritaville in Lake of the Ozarks October 14th-16th bringing together over 60 women from four chapters, Nebraska NHF, Hemophilia of Iowa, Gateway Hemophilia Association and Midwest Hemophilia Association. This event was sponsored by Octapharma. Topics included Treatment Strategies for Heavy Menstrual Bleeding, Mental Health and Positive Outcomes, Anatomy of the Nose and breakouts on Bone Mineralization, Mental health round tables and vWD shared decision making. Saturday afternoon we hosted a period party where we brought together feminine hygiene products and other supplies for people who menstruate that were donated to the Micah House in Council Bluffs, Iowa. We enjoyed a fun pizza party on Saturday night and finished out Sunday morning with a yoga session.

We thank everyone who took the time to drive to our beautiful venue in Lake of the Ozarks and look forward to coming together again in 2023.





NEBRASKA CHAPTER NEEDS ASSESSMENT

- **NEW SURVEY DEVELOPED BY SARAH, MARIA, & MAUREEN**
- **CHANCE FOR THE COMMUNITY TO SHARE THEIR OPINIONS & PREFERENCES**
- **HELP US BETTER UNDERSTAND YOUR NEEDS**
- **IMPROVE PROGRAMS & SERVICES**



We need your feedback!

**SCAN QR CODE OR VISIT
OUR WEBSITE TO COMPLETE**

Your voice matters and
will help shape the future of NENHF

Family Education Weekend 2022

This year, the Family Education Weekend was held at the Downtown DoubleTree in the Old Market in Omaha on August 6th and 7th. Our keynote speaker, Pat Torrey, the CEO and founder of Gutmonkey, kicked off the event with a discussion about fixed vs. growth mindset. Gutmonkey is an adventure education company that provides life changing experiences for communities with chronic health conditions. Pat led the teen track in which the teens practiced “finding fun”, accepting change, and connecting with others. We also held a teen council meeting, and welcomed new members Steven Taylor, Ava Foster, and Hunter Quintana. We began working on our upcoming service project with the HTC.

An important topic of the weekend was learning about the importance of advocating for bleeding disorders and sharing your story. We also had sessions about gene therapy, the new VWD guidelines, aging with hemophilia, and raising a child with hemophilia. Program Manager, Sarah Arrieta, also presented about the research opportunities at NHF, including the Nebraska Needs Assessment, the Community Voices in Research (CVR) Registry, and the National Research Blueprint (NRB). Saturday evening, families enjoyed a few lively rounds of bingo. On Sunday morning, community members learned Tai Chi and Qi Gong 5 Animals techniques from teacher, Tracy Risch. We hope you enjoyed the 2022 Family Education Weekend as much as we did, and we were so happy to see everyone who came to join us.



Unite for Bleeding Disorders Walk

The weather was beautiful on September 24th, 2022, at the Unite Walk at Chalco Hills in Omaha. Many friends and community members showed their support to raise awareness about bleeding disorders. Walkers enjoyed facepainting, a bounce house, and pancakes flipped by The Pancake Man. This year we raised almost \$35,000. A big congrats to our top fundraising team, Team Elliott! It's always a great time at the Unite Walk, and this year did not disappoint.

Thank you to everyone that helped make this fundraising event such a hit!

The Unite for Bleeding Disorders Walk is our largest, community driven fundraising event and we cannot do it without our amazing teams and attendees.

We can't wait to see you next year for another great walk!





LIVING!
with HEMOPHILIA

We cordially invite you to join us
for an educational session.



// Attendees are encouraged to actively participate in the discussion.

// Attendees can learn from one another and focus on problem-solving approaches to the day-to-day challenges posed by living with hemophilia.

Please feel free to extend this invitation to anyone whom you think will benefit from this experience.

Please join us

Date: November 9, 2022

Time: 6:00pm Central Time

Location: Misty's Steakhouse and Brewery
200 N 11th St
Lincoln, NE 68508

Speaker: Mya Anderson, HNE/ONE

Topic: Being Prepared for a Hemophilia Emergency PP-UN-HEM-US-0244-1

Please RSVP by: 11/4/2022

To RSVP, or for any questions or additional details, please contact:

Register online at www.nebraskanhf.org by November 7th

We look forward to seeing you!





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[JiviExtensionStudy.com](https://www.jiviestensionstudy.com)

Winter

WOMEN'S RETREAT

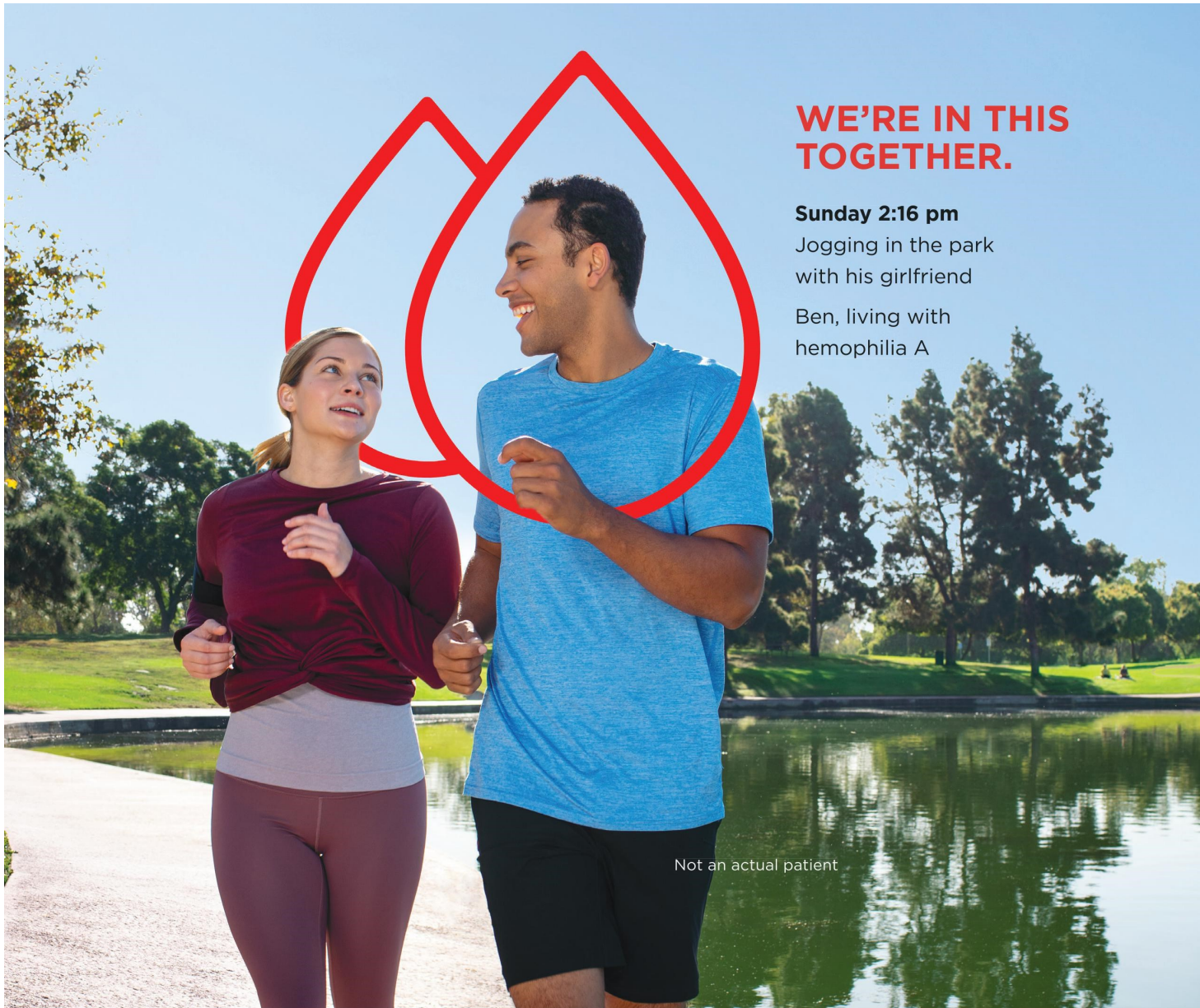
Saturday, December 17

9:30 AM-3:30 PM

NENHF OFFICE

Education, Crafts, Connection





WE'RE IN THIS TOGETHER.

Sunday 2:16 pm

Jogging in the park with his girlfriend

Ben, living with hemophilia A

Not an actual patient

Let's make today brilliant.

Takeda is here to support you throughout your journey and help you embrace life's possibilities. Our focus on factor treatments and educational programs, and our dedication to the bleeding disorders community, remain unchanged. And our commitment to patients, inspired by our vision for a bleed-free world, is stronger than ever.

bleedingdisorders.com



Six Facts about Women and Hemophilia

CONVERSATION STARTERS: HEAVY PERIODS

Have you ever had a heavy period?

Do heavy periods run in your family?

Have you ever seen a doctor about your heavy periods?

Do you want me to send you some resources about heavy periods?

Why it often goes misdiagnosed, the most common symptoms, and more

1. Women with hemophilia are often undiagnosed or misdiagnosed

Historically hemophilia was thought of as a “man’s disease,” and for many years the belief was that women in families with hemophilia could only be carriers of the disease, meaning they could pass the affected gene on to their children. But we now know that some women who carry the hemophilia gene have low enough levels of factors VIII or IX that they also have hemophilia, and that women with hemophilia will often experience similar symptoms and complications as men with hemophilia. Nevertheless, a lack of awareness on the part of primary care doctors means that many women with hemophilia today still go undiagnosed or misdiagnosed.

2. Women are more likely to have mild hemophilia

According to a [2021 study of nearly 30,000 people](#) conducted by researchers at the Centers for Disease Control and Prevention, nearly one-fifth of patients with [mild hemophilia](#) admitted to treatment centers in the US are female. The percentage of women and girls with severe or moderate hemophilia is thought to be somewhere in the range of less than 0.5% to a little more than 1%.

A much more common bleeding disorder in women is [von Willebrand disease](#), which affects more than 3 million Americans—about 1 percent of the population, or approximately 1 in every 100 people. This inherited bleeding disorder occurs equally in men and women.

Six Facts about Women and Hemophilia Continued

3. One of the most common signs of hemophilia in women is heavy menstrual bleeding

[Heavy menstrual periods](#) are defined as:

- Bleeding for more than seven days, from the time it began until it stopped
- Flooding or gushing of blood
- Passing clots that are bigger than a quarter
- Changing a tampon and/or pad every two hours or less on the heaviest day
- Other common signs and symptoms of hemophilia in women include:
- Being told you are “low in iron” or have anemia
- Heavy bleeding from dental surgery, other surgery or childbirth
- Frequent nosebleeds that last longer than 10 minutes
- Bleeding from cuts lasting longer than five minutes
- Easy bruising (weekly, raised and larger than a quarter)

4. Making the diagnosis can be complicated

There’s no one simple diagnostic test to confirm that a woman has hemophilia or another type of bleeding disorder, so providers often have to piece together various symptoms, multiple lab results and timing of the lab testing to confirm the diagnosis. One of the challenges for providers is to determine whether heavy periods are related to normal variation or a sign of an underlying bleeding disorder.

To help women prepare for diagnostic tests and understand their results, the National Hemophilia Foundation (NHF), in cooperation with the CDC, produced a brochure called [“What Women and Girls Should Know About Getting Tested for Bleeding Symptoms: Your Guide to Lab Tests, Screening Tools and Health Exams.”](#)

5. Pregnant women with hemophilia require special care

[Pregnant women with hemophilia](#) are at an increased risk for serious bleeding after delivery because the high levels of factor during pregnancy can fall back to lower levels after delivery. That’s why most women with a bleeding disorder need treatment with clotting factor or another treatment to prevent excessive bleeding at the time of delivery. All pregnant women with hemophilia should be cared for by a maternal-fetal medicine physician, which is a doctor who specializes in high-risk pregnancy.

6. There are specialized centers for women and girls with bleeding disorders

Women and girls with hemophilia can seek care at one of the [approximately 141 hemophilia treatment centers \(HTCs\)](#) across the country, a nationwide network of centers established in the 1970s to diagnose and treat hemophilia and other bleeding disorders. But many HTCs have established special designated clinics to diagnose and treat women and girls with bleeding disorders. To locate a center near you, consult [this map](#) created by the Foundation for Women & Girls with Blood Disorders.

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Thank you to our Industry Sponsors who support our programming, advocacy and outreach efforts throughout Nebraska for all bleeding disorders.



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Rural Outreach and VWD

Blue Cross and Blue Shield of Nebraska (BCBSNE) has awarded the Combined Health Agencies Drive (CHAD) and its statewide umbrella of 23 health care agencies the company's Health of Nebraska Sponsorship, which is dedicated to supporting programs and services for Nebraskans affected by a medical diagnosis.

For more than 80 years, BCBSNE has offered security and stability to its members faced with medical expenses. Through its Health of Nebraska initiative, BCBSNE seeks to support programs that address social determinants of health and health equity, BCBSNE's sponsorship will directly benefit the missions of the various CHAD organizations, helping them to continue to offer meaningful, vital programming for communities across the state.

"Our goal with community funding is to cultivate lasting relationships and give back to our communities in ways that directly advocate for the health of Nebraskans," said Kathy Nellor, health transformation leader at BCBSNE. "Nebraskans count on support from all CHAD member agencies, and it is a privilege to help them help others for the second year in a row."

In 2020, CHAD's 23 member agencies collectively assisted more than 37,133 Nebraskans with professional care or resources, ensured access to specialized or long-term support for over 9,625 patients and invested approximately \$518 million in medical research alongside their national affiliates. Since the onset of the COVID-19 pandemic, CHAD and its member agencies have continued to find impactful, innovative alternatives to get and stay connected to the people they help across the state.

CHAD is a local organization raising funds with and for Nebraska's health agencies across Nebraska since 1972.

"As we approach our 50th year serving Nebraska, CHAD is so pleased to have an outstanding community leader like BCBSNE to work with on what matters to the constituents of our health agencies across the state. March of Dimes, American Lung Association, JDRF and so many more are going to have the funding to support Nebraskans with new or expanded programming," said Michelle Grossman, president and chief executive officer of CHAD. "We sincerely thank BCBSNE for investing in the health and well-being of all Nebraskans."

Nebraska NHF received a grant through CHAD and BCBS focused on rural outreach and VWD Guideline distribution to providers. We are working to host educational outreach dinners across the State of Nebraska while hosting community connection dinners. If you are interested in having a program in your area, please let us know. We are excited to get more bleeding disorders awareness and VWD treatment and diagnostic guidelines out to all Nebraskans. We would like thank CHAD and BCBS for their support in these endeavors.



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1.6

**MEDIAN OVERALL
BLEEDS PER YEAR†**

0

**MEDIAN JOINT
BLEEDS PER YEAR†**

#1

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FOR PROPHYLAXIS IN US‡**

*ELOCTATE has been proven to help patients prevent bleeding episodes using a prophylaxis regimen.

†In the A-LONG study, 164 previously treated adults and adolescent males with severe Hemophilia A ages 12-65 received Eloctate either every 3 to 5 days, once weekly, or on demand.

‡#1 prescribed based on HTC reported data as of September 2020.

A CONNECTION YOU CAN COUNT ON

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INDICATION

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- Do not use ELOCTATE if you have had an allergic reaction to it in the past.
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- 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.
- Additional common side effects of ELOCTATE are headache, rash, joint pain, muscle pain and general discomfort.
- If you have risk factors for developing abnormal blood clots in your body, such as an indwelling venous catheter, treatment with Factor VIII may increase this risk.
- 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, or if bleeding is not controlled after using ELOCTATE.

Please see [full Prescribing Information](#).

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MAT-US-2020798-v2.0-02/2021

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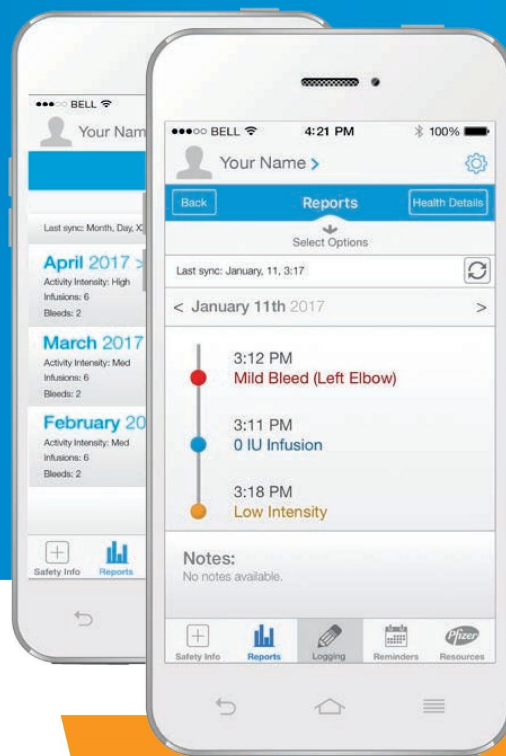
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from 8:00 AM to 8:00 PM Eastern Time.

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