CHAPTER Factors

SUMMER/FALL 2016

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access solutions

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Free Trial Program*

- Enroll today for up to 6 free doses†
- Delivered to your home free of charge

Access to Therapy

We might be able to provide treatment at no cost if you‡:

- Experience challenges getting insurance coverage for a Bayer product
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- Are between jobs and are experiencing a gap in insurance coverage

$0 Co-pay Program§

If you have private insurance, you may be eligible for the $0 Co-pay Program.

- You may be able to receive up to **$12,000 in assistance** per year, regardless of income
- **Assistance is awarded per patient.** Multiple members of the same household can apply
- Enrollment can be completed in **one short phone call**

Live Helpline Support

- Consult with an expert in insurance
- Spanish-speaking Case Specialists are also available

CALL

1-800-288-8374

8:00 AM-8:00 PM (ET) Monday-Friday. Spanish-speaking Case Specialists are also available.

*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.

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News and Notes

Most of our days are spent where we live, eat and work. We have family and friends, go to movies, sports activities and generally "live our lives." Occasionally we are presented with opportunities to expand our horizons. Such an opportunity arose at the NHF Annual Meeting and World Federation of Hemophilia Conference in Orlando this past July. There were two sessions at the meeting where we were able to meet and interact with other hemophilia associations/societies from around the world. Many of the world societies gave presentation on how their groups deal with hemophilia and the difficulties that they have to deal with. Some are similar to ours, most are not. I met people from Nigeria, Egypt, New Zealand, France who deal with bleeding disorders everyday…just like we do. Many countries have limited access to diagnosis and treatment. Representatives from the World Federation listed out some of the issues. They are: Isolation and lack of education: Limited access to medical expertise and diagnostic display; People with Von Wille Brands, Rare Bleeding Disorders and women under represented; Governments demanding more evidence to justify costs; Product safety and adverse events; Little evidence, data to make the case. However, they did stress that with the introduction of new products and the advancement of gene therapy that we are ushering in a new era. They also reiterated that the new era would have to have committed stakeholders, partners and volunteers.

I came away with a whole new perspective. We will continue to plan education and fundraising events here at MHA, but while we are doing that we will remember that there are organizations all around the world doing the same thing. The ultimate goal is to provided treatment for all people with bleeding disorder be it in the United States and around the world.

Mark Cox
Executive Director

twitter @MidwestHemo

QUICK NOTES

Message from the President

Even though MHA already hosts a variety of great programs throughout the year, including Family Fun Fair, Summer Camp and various one-day educational events, we continually strive to improve our presence in the community. Our current endeavor involves the creation of a first-ever true Youth Program.

Scheduled launch in 2017, this program will help develop the next generation of leaders for MHA. Not only will it provide a way for teens to gain confidence and work toward independence, it will also build trust between teens and their parents. The program will tackle career counseling, along with relationship counseling, like how to tell someone close to you about your bleeding disorder.

Education modules will be created, providing continuity for youth education, not just at camp or Family Fun Fair, but throughout the year. Program goals include learning about bleeding disorders, increasing confidence, and becoming better self-advocates. Career choices and interests will be topics of exploration which will include investigating interests, training for leadership, and learning how to build a resume and to complete college applications. The program will also provide teens with a look at duties of the MHA Board of Directors.

We plan to work with teens throughout this development process to ensure we stay on track with programs and activities that are of keen interest to them. A meeting was held with the teens at this year's Summer Camp to get the ball rolling and to hear their ideas.

This program will be a collaborative effort between a youth program committee and teens. It is vital that everyone work together to build a successful youth program.

The structure is still being developed but we are excited for this new endeavor. We believe that this program will lead to a stronger organization.

— Aimee Tempera, President

Remembering Fathers in Hemophilia: Samuel Appleton

I search for intriguing stories about people with bleeding disorders. By discovering those stories, including historical ones, I always learn something valuable. Often, I find inspiration in the stories of other family members, as in the case of the Appletons, who were connected with the powerful origins of our country.

One father of a child with hemophilia was Major Samuel Appleton (1625–1696). His son, Oliver Appleton, was the first person identified with hemophilia to be born in the American colonies.[1] Samuel spent a lifetime in public service fulfilling legislative, judicial, and military roles. He stuck to his principles about the illegality of improper taxation, and he remained calm in times of distress—during battle, and during the infamous Salem witch trials.

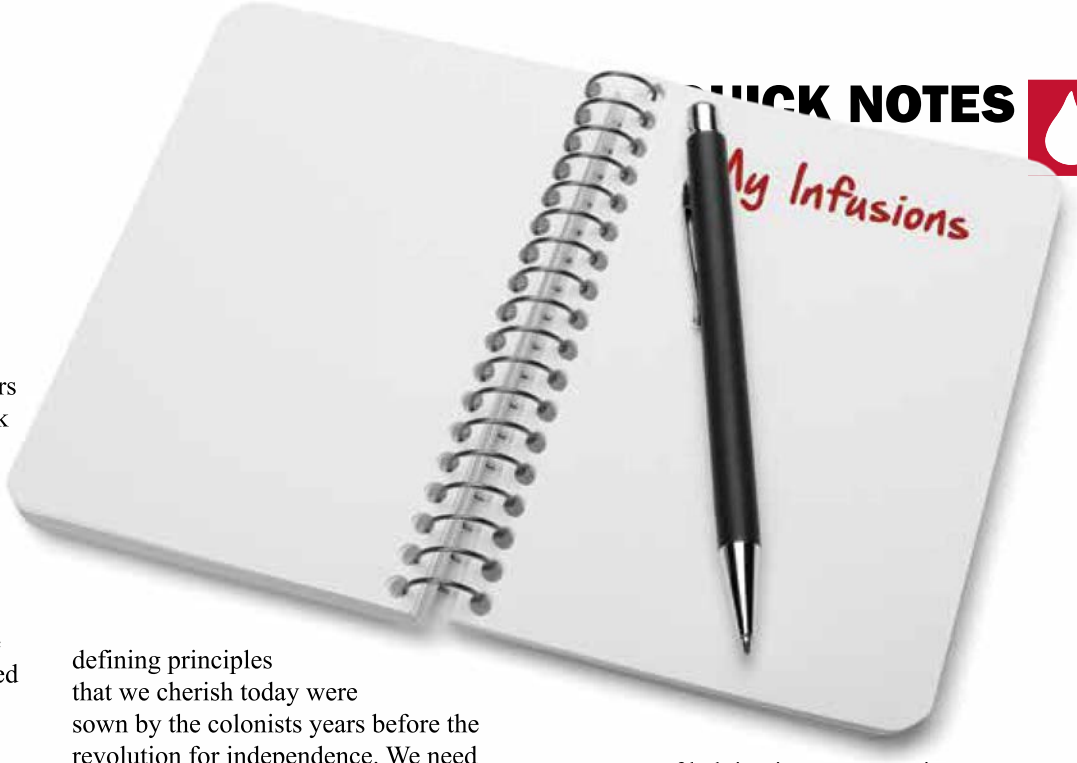
Photo courtesy of www.thetrustees.org.

Samuel was only 11 when his family left England to settle in the Massachusetts Bay Colony in 1636. His father, also named Samuel, was one of the original settlers of historic Ipswich. The family owned a house and eight acres in town, and a 400-acre farm on the Ipswich River.[2]

One of five children, Samuel grew up to help run the family farm and businesses. He married Hannah Paine in 1651, and they had three children. After his wife's death, in 1656 he married Mary Oliver (1640–1698), a hemophilia carrier, and had eight more children, including Oliver in 1677. Oliver's bleeding disorder was noted by family members, but probably not as a genetic condition. Only later, in retrospect, did family members realize the distinctness of the bleeding.

Due to periodic threats of Indian attacks, Samuel Appleton led the local militia. From lieutenant in 1668, he rose to the rank of captain during King Philip's War, and commanded an infantry of 100 men. At the decisive battle near Hatfield along the Connecticut River in 1675, Samuel was commander-in-chief of more than 500 men. A turning point for the colonists, this battle proved that the Indian warriors could be defeated. During the fighting, a bullet passed through Samuel's hair. If he had died then, his son Oliver with hemophilia would never have been born.

Samuel held several elected offices. As a legislator, he was a commissioner of Essex County in 1668. He was a representative of the General Court from 1669 to 1680. And he served on the Governor's Council from 1681 to 1692. Appleton opposed the government of the colonial governor, Sir Edmond Andros. When in 1687 Andros levied a tax of one penny on a pound, the town of Ipswich refused to collect the tax, stating that it was against the rights of



Englishmen for any taxes to be levied without consent of an assembly chosen by landowners, or "freeholders." An arbitrary and illegal warrant was issued for the arrest of Samuel and other leaders in the opposition to the tax. Samuel took refuge in Saugus, where he stood on a rock and denounced the government. A Massachusetts historical marker now acknowledges the site as "Appleton's Pulpit." Refusing to apologize, Samuel was imprisoned in November 1687. He petitioned in January for his release due to his age and weakness, but wasn't freed until March 1688, when he posted a 1,000-pound bond.

In 1689, during the coup of crown-appointed Governor Andros, Samuel and other leaders in the Massachusetts Bay Colony put Andros on a boat to the island prison in Boston Harbor. Colonial revolutionaries 100 years later simplified the opposition to taxes with the slogan "No taxation without representation." But it's important to remember that the ideas for the American Revolution began long before 1776: to be properly recognized, Ipswich adopted the motto "The Birthplace of American Independence 1687."

Samuel Appleton served on the judiciary. He was a deputy to the Massachusetts General Court from 1668 to 1681. As a member of the Council of Assistants from 1681 to 1686, Samuel attended the examination of accused witches in Salem on April 11, 1692. His role may have been minor; he isn't always listed as one of the seven judges. And apparently he did not serve as a judge in any of the trials that executed 20 alleged witches in 1692. On May 2, 1693, the first Supreme Court convened in Ipswich to try Andover residents charged with witchcraft. As a judge at that hearing, Samuel cleared everyone accused of witchcraft, ending the infamous witch trials and demonstrating his rationality. During the hysterical witchcraft proceedings in Salem, Oliver Appleton was a 15-year-old with hemophilia living at home in Ipswich.

The story of Major Samuel Appleton reveals essential information about colonial America. Some of our defining principles that we cherish today were sown by the colonists years before the revolution for independence. We need to honor those colonial leaders for their contributions, and remember that Major Samuel Appleton also raised a son with hemophilia.

[1] "The Appletons: America's 'First Family' with Hemophilia." PEN, Nov. 2002.
[2] That farm still exists today. Called Appleton Farms, it is the second oldest continuously run farm in America, now administered by the Trustees of Reservations, a nonprofit conservation organization in Massachusetts.

Why is it important to keep a log of factor infusions?

Keeping a log of factor infusions and bleeds helps you communicate with your HTC. Logs help your medical provider see how factor is being used in real life (not just what we prescribe) and it helps keep track of how many bleeds have occurred and where. Keeping track can also help you to honestly look at your consistency with factor infusions and understand how bleeds can start to add up over the course of a year. Finally, logs can also help you to know which lot numbers you infused in case there's ever a recall.

More and more, insurance providers are requesting logs to ensure the factor they are paying for is being used as its intended. Keeping a log can help your insurance provider understand that you are using factor appropriately and it is effective in preventing bleeds. A log is one part of helping insurance carriers understand the need for new factor products and how they are used. Many people expect that this requirement will become more common in the future, so start logging now to be prepared!

Even 3-4 bleeds per year (or sometimes just 1-2), if they occur in the same joint, can cause permanent damage, leading to pain or disability. Without a log, our patients cannot reliably remember how frequently, and where, bleeds have occurred. This means their health care provider has to use a best guess to determine therapy, which is often not optimal. It might also mean missing important information, like bleeds only happen after a missed dose or bleeds happen on Sunday after dosing on a Friday. Every piece of the puzzle is important when trying to prevent bleeds while finding an infusion schedule that works for each person.

There are many options for keeping records. My favorite for my patients is the ATHN Advoy website or app as well as our home grown app Hemotool. Both of these apps are able to email me infusion information and lets our team know when a patient has a bleed. But there are many apps that can communicate with you HTC directly via email or notifications. Paper logs are great too! I recom mend using a yearly calendar and using the stickers from your factor vials.

Any way you keep them, logs help you and your doctor better understand and treat your bleeding disorder!

— By Andrew Wilson, RN, FNP-C

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

David, 22 years old, *lives with hemophilia A.*

Novoeight® is ready when you are

UP TO **86°F** **FOR 12 MONTHS**

Highest storage temperature for the longest time[a]

Because you seek out new experiences, you need a treatment that is ready when you are. Designed to fit into your world, Novoeight® can be stored at up to 86°F for 12 months and up to 4 hours after being mixed.

Visit **Novoeight.com** to learn about additional features and see how Novoeight® can fit into your world.

Please see Prescribing Information for complete storage instructions.

[a]Compared with other recombinant factor VIII products.

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.

SATISFACTION GUARANTEED

Terms and conditions apply.

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, 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® (NŌ-vō-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.

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Plainsboro, NJ 08536, USA

Manufactured by:
Novo Nordisk A/S
DK-2880 Bagsvaerd, Denmark

1214-00024657-1 12/14

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NUWIQ®

Antihemophilic Factor (Recombinant)

Want to Learn More?

Contact your
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PHONE | 682-712-3777

EMAIL | Amanda.Matthews@octapharma.com

Date of preparation: 8/2016. NUW-017-CAD-cr

octapharma®
For the safe and optimal use of human proteins

TO INFINITY AND BEYOND!

2016 SUMMER CAMP

My name is Luke Saulsberry and I had the wonderful pleasure of being MHA Summer Camp Director for this past year. I was asked to write a summary of camp, and I also want to write about the exciting future Camp.

This year we had 70 campers and 65 volunteers attend. We had a ton of fun, and we also learned quite a bit. If you are familiar with camp, most of the daily activities were similar in years past. However, we did add a couple new things! The older campers went zip lining and also camped out in the woods. The entire camp received one-on-one time with golf professional Perry Parker. Everyone also played a new game where the campers built boats out of cardboard, duct tape and gallon jugs. The results were fantastically amazing! I think this year went well and I hope you and/or your camper did too.

We are so excited from this past year, we are already planning camp for next year. It sounds crazy, but it is true. We learned a lot from our campers and volunteers that will help make camp even better. For starters, we really want to expand our camp. We would love to reach 100 campers and that also means we would need more volunteers as well. If you have not had a camper attend or if you have not volunteered at camp, we would love the opportunity to discuss getting you or your camper to attend camp.

The second thing we learned this year is that change is good. Our goal is to keep campers attending year after year and eventually become active members of MHA. To encourage campers returning from age seven to 17 we are going to make changes. Although, we do not know exactly what that entails, but the few changes we made this year were refreshing and thoroughly enjoyed. Any changes will not be arbitrary but thoughtfully and extensively discussed with due diligence before implementation. Before things get out of hand, though, one thing is very clear. We are going to keep the staples of what makes MHA Summer Camp the "best week of the year" for all of those that attend.

It is a lot to digest but simply put, we are in a very exciting time for MHA Summer Camp. Great things are ahead and we hope that you will be a part of what is to come. Join us on this adventure, farewell my friends, to infinity and beyond!

ALPROLIX®
[Coagulation Factor IX
(Recombinant), Fc Fusion Protein]

Casey, a MyALPROLIX Peer,™ started on a once-every-10-day prophylaxis infusion schedule and adjusted to once every 14 days.

Learn more at www.alprolix.com/findyourfit

The recommended starting prophy regimens are either 50 IU/kg once weekly, or 100 IU/kg once every 10 days. Dosing regimen can be adjusted based on individual response.

Children under 12 years of age may have higher Factor IX body weight-adjusted clearance, shorter half-life, and lower recovery. Higher dose per kilogram body weight or more frequent dosing may be needed in these children.

Extended protection* from bleeds

ALPROLIX is the first factor IX offering prophylaxis infusion schedules starting every 7 or 10 days with the potential to extend based on your response.

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

Indications and Important Safety Information

Indications

ALPROLIX [Coagulation Factor IX (Recombinant), Fc Fusion Protein] is a recombinant DNA derived, coagulation factor IX concentrate indicated in adults and children with hemophilia B for:

- On-demand treatment and control of bleeding episodes
- Perioperative management of bleeding
- Routine prophylaxis to reduce the frequency of bleeding episodes

ALPROLIX is not indicated for induction of immune tolerance in patients with hemophilia B.

Important Safety Information

Do not use ALPROLIX if you are allergic to ALPROLIX or any of the other ingredients in ALPROLIX.

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 and all your medical conditions, including if you are pregnant or planning to become pregnant, are breastfeeding, or have been told you have inhibitors (antibodies) to factor IX.

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

ALPROLIX may increase the risk of formation of abnormal blood clots in your body, especially if you have risk factors for developing clots.

Common side effects of ALPROLIX include headache and abnormal sensation of the mouth. These are not all the possible side effects of ALPROLIX. Talk to your healthcare provider right away about any side effect that bothers you or does not go away, and if bleeding is not controlled using ALPROLIX.

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

FIX-US-0573 V2 03/2016

ALPROLIX [Coagulation Factor IX (Recombinant), Fc Fusion Protein], Lyophilized Powder for Solution For Intravenous Injection.

FDA Approved Patient Information

ALPROLIX® /all' pro liks / [Coagulation Factor IX (Recombinant), Fc Fusion Protein]

Please read this Patient Information carefully before using ALPROLIX 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 ALPROLIX?

ALPROLIX is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia B. Hemophilia B is also called congenital Factor IX deficiency.

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

Who should not use ALPROLIX?

You should not use ALPROLIX if you are allergic to ALPROLIX or any of the other ingredients in ALPROLIX. Tell your healthcare provider if you have had an allergic reaction to any Factor IX product prior to using ALPROLIX.

What should I tell my healthcare provider before using ALPROLIX?

Tell your healthcare provider about all of the medicines you take, including all prescription and non-prescription medicines, such as over-the-counter medicines, supplements, or herbal medicines.

Tell your doctor about all of your medical conditions, including if you:

- are pregnant or planning to become pregnant. It is not known if ALPROLIX may harm your unborn baby.
- are breastfeeding. It is not known if ALPROLIX passes into breast milk or if it can harm your baby.
- have been told that you have inhibitors to Factor IX (because ALPROLIX may not work for you).

How should I use ALPROLIX?

ALPROLIX should be administered as ordered by your healthcare provider. You should be trained on how to do infusions by your healthcare provider. Many people with hemophilia B learn to infuse their ALPROLIX by themselves or with the help of a family member.

See the **Instructions for Use** for directions on infusing ALPROLIX. The steps in the **Instructions for Use** are general guidelines for using ALPROLIX. Always follow any specific instructions from your healthcare provider. If you are unsure of the procedure, please ask your healthcare provider. Do not use ALPROLIX as a continuous intravenous infusion.

Contact your healthcare provider immediately if bleeding is not controlled after using ALPROLIX.

What are the possible side effects of ALPROLIX?

Common side effects of ALPROLIX include headache and abnormal sensation in the mouth.

Allergic reactions may occur. Call your healthcare provider or get emergency treatment right away if you have any of the following symptoms: hives, chest tightness, wheezing, difficulty breathing, or swelling of the face.

ALPROLIX may increase the risk of forming abnormal blood clots in your body, especially if you have risk factors for developing blood clots.

Your body can also make antibodies called, "inhibitors," against ALPROLIX, which may stop ALPROLIX from working properly. Your healthcare provider may need to test your blood for inhibitors from time to time.

These are not all the possible side effects of ALPROLIX. Talk to your healthcare provider about any side effect that bothers you or that does not go away.

How should I store ALPROLIX?

Store ALPROLIX vials at 2°C to 8°C (36°F to 46°F). Do not freeze.

ALPROLIX vials may also be stored at room temperature up to 30°C (86°F) for a single 6 month period.

If you choose to store ALPROLIX at room temperature:

- Note on the carton the date on which the product was 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 product or diluent after the expiration date printed on the carton, vial or syringe.

After Reconstitution:

- Use the reconstituted product as soon as possible; however, you may store the reconstituted product at room temperature up to 30°C (86°F) for up to 3 hours. Protect the reconstituted product from direct sunlight. Discard any product not used within 3 hours after reconstitution.
- Do not use ALPROLIX if the reconstituted solution is cloudy, contains particles or is not colorless.

What else should I know about ALPROLIX?

Medicines are sometimes prescribed for purposes other than those listed here. Do not use ALPROLIX for a condition for which it was not prescribed. Do not share ALPROLIX with other people, even if they have the same symptoms that you have.

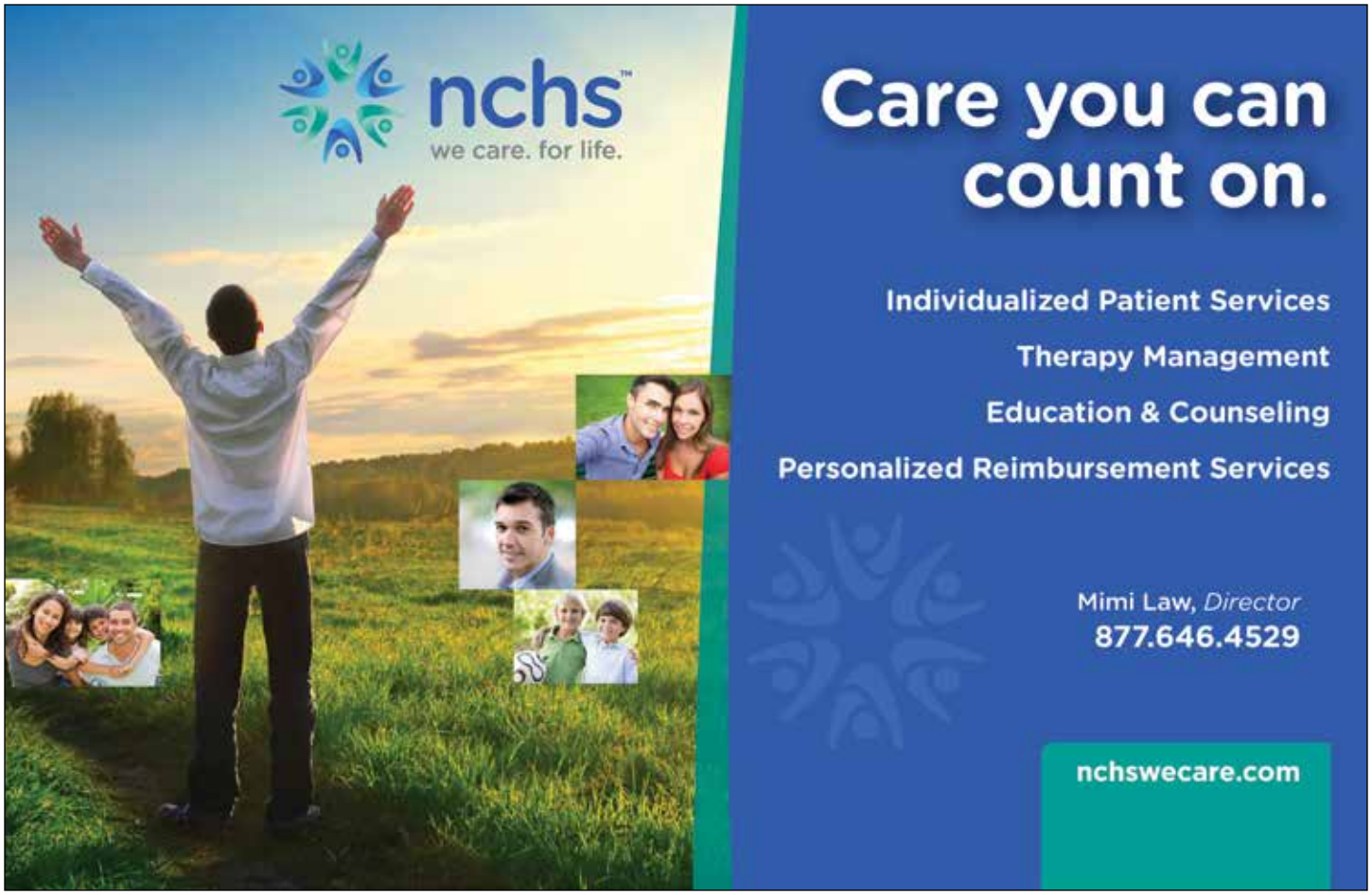
Manufactured by
Biogen Inc.
Cambridge, MA 02142 USA
U.S. License #1697

HELPFUL NUMBERS

KANSAS CITY REGIONAL HEMOPHILIA CENTER
1-816-302-6869 • 1-800-236-1713
Dr. Shannon Carpenter • Dr. William Jennings
Dr. Brian Wicklund • Dr. Jill Moormeier • Katie Foote, LMSW
Andrew Wilson, RN, CFNP • Melissa Armanees, RN, CPNP

UNIVERSITY OF MISSOURI HOSPITAL AND CLINICS
HEMOPHILIA TREATMENT CENTER
1-573-882-9355
Dr. Barbara Gruner • Dr. Carl Freter
Dr. Tamara Hopkin • Lauren Grana, MSW

NATIONAL HEMOPHILIA FOUNDATION (NHF)
1-800-42-HANDI • www.hemophilia.org



MOVING? New Address

Name

Address

City State ZIP

(Area Code) Phone Number

E-Mail Address

MAIL TO: MHA • PO Box 412866 • Kansas City, MO 64141
E-MAIL TO: *info@midwesthemophilia.org*

Midwest Hemophilia Association
PO Box 412866
Kansas City, MO 64141