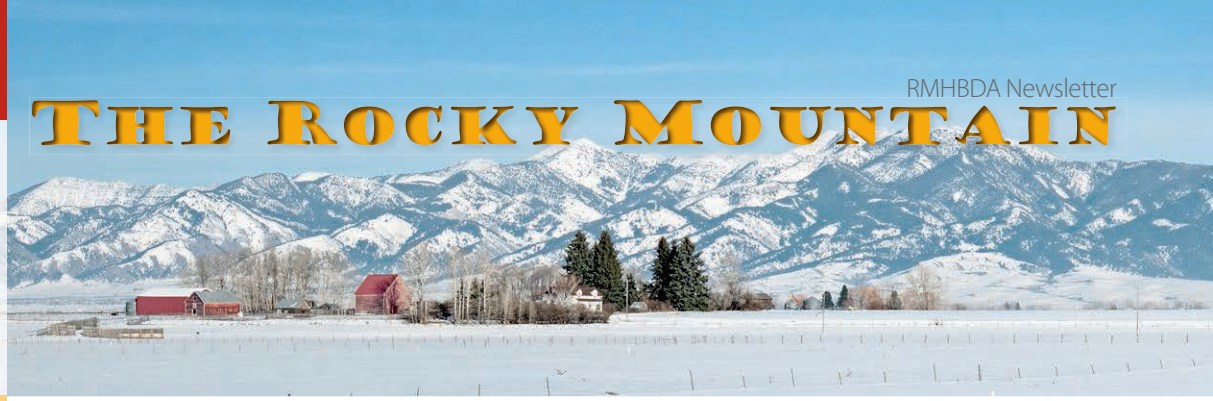
WINTER 2015

Rocky Mountain Hemophilia & Bleeding Disorders Association

RMHBDA Newsletter

The Rocky Mountain



RMHBDA is a 501(c)(3) nonprofit organization founded in 2000 and is a chartered chapter of the National Hemophilia Foundation.

Our mission is to improve the quality of care and life for persons with inherited bleeding disorders, including hemophilia and von Willebrand Disease through education, peer support, resources, and referral.

In This Issue

Rocky Mountain Hemophilia & Bleeding Disorders Association

1627 West Main Street, #142
Bozeman, Montana 59715
406.586.4050

www.rmhbda.org

Brad Benne, *Executive Director*
brad@rmhbda.org

www.facebook.com/rmhbda

RMHBDA Education Weekend & Annual Meeting

February 19 – 21, 2016

Registration Deadline February 1!
Please Register Online

Location: Holiday Inn, 5 East Baxter Lane, Bozeman, MT

Event Host: RMHBDA & the University of Colorado Hemophilia & Thrombosis Center

It's time for the 12th Annual Education Weekend for people affected by bleeding disorders in Montana and Wyoming!

You and your family are invited for a weekend of informative sessions, youth programming for all ages, and an opportunity to connect with others dealing with similar challenges.

University of Colorado Anschutz Medical Campus
Hemophilia and Thrombosis Center

Rocky Mountain Hemophilia & Bleeding Disorders Association

This education weekend and annual meeting of RMHBDA is designed to bring you education, up-to-date information about life with a bleeding disorder, and connect you with other families in our two-state area.

Check-in for the event will be Friday, February 19 from 4–6 p.m. followed by a dinner sponsored by CSL Behring.

On Saturday morning, we will cover topics like Healthcare Reform, State Advocacy efforts, Von Willebrand's Disease, Infusion Education and Product Update presented by Dr. Marilyn Manco-Johnson, Children's programming, and Men and Women's programming.

For our youth, we will have a variety of programming available. Please pack your life-jackets for pool time in the afternoon!

Don't miss your chapter's annual meeting for all members on Saturday — important decisions will be made at this meeting and your input is needed! Lodging and meals will be provided to attending members, so don't hesitate to send your registration off today! Don't miss this opportunity with your Chapter, Industries, HTC Staff, Accredited Speakers, and your family. It will be a special and rewarding weekend for all.

Need assistance to attend Education Weekend?

RMHBDA will provide Patient Assistance applications in all registration packets. Please save all gas, food, and travel expense receipts! If you have any questions, please direct them to Brad Benne, Executive Director at 406.586.4050.

Continued on page 2

Message from the Executive Director

Dear RMHBDA Supporter,

For over 15 years, RMHBDA has been honored to support the bleeding disorders community of Montana and Wyoming by offering quality educational programs and providing critical assistance services for many families. Many folks involved with RMHBDA are thriving and we are proud to apart of your success!

Yes, another letter asking for your money. 'Tis the time of year when our mailboxes overflow with them. A perfect storm of year-end planning coupled with the season of generosity and good will converge into a blizzard of requests for our assets! So many good homes for our cash make for difficult choices. Difficult decisions to be sure, yet for me, a much easier one since I have become involved with RMBHDA. I realize many of you give your unconditional time, love, and money already, and for that we are deeply grateful. For those of you that haven't or who would consider another a small donation to our chapter, we ask that you deeply consider what RMHBDA means to you and your family.

With gratitude and appreciation,
Brad Benne,
Executive Director

From page 1: **Education Weekend**

RMHBDA Education Weekend Schedule *(tentative)* February 19 – 21

Friday, February 19

4:00 – 6:00 pm Registration & Exhibits
6:00 – 6:15 pm Welcome
6:15 – 7:30 pm Dinner & Program, sponsored by CSL Behring

Saturday, February 20

7:00 – 8:00 am Breakfast
8:00 – 11:00 am Sessions: Infusion, Dr. Marilyn Manco-Johnson, Advocacy & Healthcare Update
10:30 – 12:00 pm Exhibits/Break
12:00 – 1:00 pm Lunch sponsored by Baxalta
1:00 – 3:00 pm Session (Men's & Women's Sessions)
3:00 – 7:00 pm Free Time
6:00 pm – ? Bowling & Pizza

Sunday, February 21

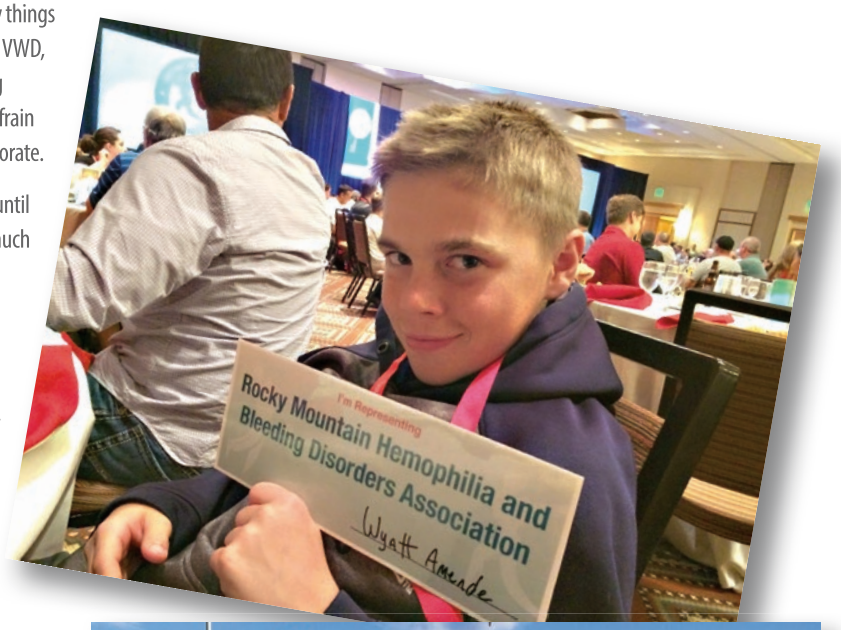
8:00 – 9:30 am Biogen Session & Breakfast
10:30 am – ? Check out/Good Byes

Safe Travels! Hope to see you there!

Holiday Inn
5 East Baxter Lane
Bozeman, MT

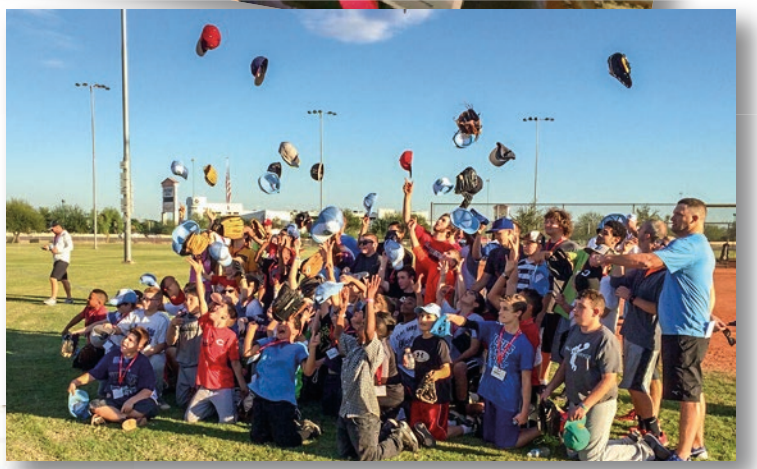
"What lessons have you learned through your experience of having a bleeding disorder?"

Hello, my name is Wyatt Amende, I am 13 years old, and am interested in representing our chapter in CSL Behring's Gettin' in the Game national competition. I have learned many things about life and sports through my bleeding disorder. With VWD, I have to overcome challenges that kids without bleeding disorders don't even think about. I have been forced to refrain myself from doing things that normal kids can do in a blink of an eye. Allow me to elaborate.



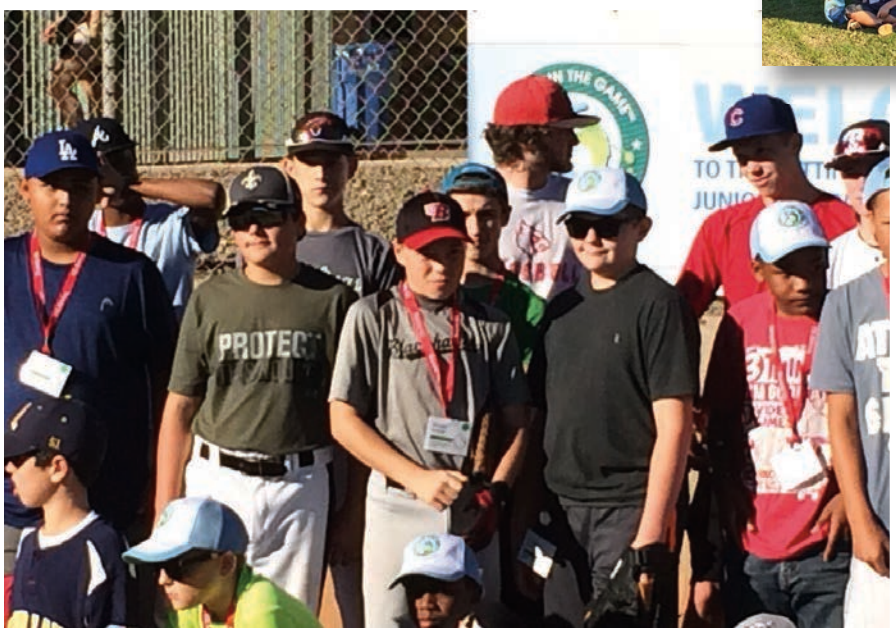
I have been playing baseball since I was five years old. The game felt so natural to me, until this season. In past years, injuries had never really bothered me, as I was playing at a much lower level. This year however, was different. In the league I now play in, players wore metal spikes, the base paths were 20 feet longer, and many of the players had hit their growth spurt. It was a struggle for me to keep up with the game. I would often roll my ankles, scrape myself in the dirt, and bruise easily if the ball hit me, fielding or batting. To help myself keep up with the game I love I took it upon myself to learn to self infuse.

I was tired of coming home sore and beaten up. I asked my mom to take me into my pediatrician to help me learn about sticking myself safely. I met with my doctor 5 times before I felt confident with home infusions. Once I started infusing before, and sometimes after tournaments, I felt much better. I was healing from injuries that would normally take me a week or two to come back from in two to three days. I felt great.



Since I have started home infusions, I have been able to keep up with the competitive level of play that was expected of me. This year I would like to compete in CSL Behring's Gettin' in the Game to work with the professional athletes to help me gain a cutting edge for next season. I attended this tourney as an 11-year-old in 2012 and am looking forward to returning. Thank you for this opportunity!

Sincerely,
Wyatt Amende



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 Becky Ybarra
E: becky.ybarra@biogen.com T: 801-913-8204

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?
Common side effects of ELOCTATE are joint pain and general discomfort.

Allergic reactions may occur. 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, which may stop ELOCTATE from working properly. Your healthcare provider may give you blood tests to check for inhibitors.

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.

Manufactured by:
Biogen Idec Inc.
14 Cambridge Center, Cambridge, MA 02142 USA
U.S. License # 1697

44279-01

Issued June 2014

Mile High Colorado Camp

July 10–15, 2016

Leadership Pre-Camp Retreat
July 8–10, 2016

Camp forms will be available in mid-March 2016! Stay Tuned!

When and Where?

The Hemophilia and Thrombosis Center (HTC) is proud to once again sponsor the summer camp program:

- July 10–15, 2016
- Rocky Mountain Village, Empire Colorado.

Who Should Attend?

- Children with hemophilia or other bleeding disorders
- Siblings of the above groups
- Mile High Colorado Camp is for ages 7–18. Check back with us soon to learn about the different programs we offer at camp!

Why Attend Camp?

The purpose of camp is to learn about bleeding disorders, develop skills, and have fun! Campers will have the opportunity to meet new friends and participate in a variety of traditional camp activities. As always, we have included educational components with the goal of encouraging self-confidence and independence.

Many campers have learned to perform self-infusion, experienced teamwork, and discovered new skills during the week of camp. Staff at the Hemophilia & Thrombosis Center (HTC) and Rocky Mountain Village wants this to be a wonderful experience that creates a wealth of fond memories for your camper.

What does it cost?

Each family is required to pay only a non-refundable $75 deposit. The remainder of the camp cost, approximately $1,000 per camper, is underwritten by other sources. If you have questions or need additional information, please call Brad Benne at 406.586.4050. **Scholarship forms are available.** Scholarships will be granted on an individual basis.

Help send a child to camp!

Make a dream come true this summer! Your contribution will send a youth to hemophilia summer camp at Mile High Camp in Colorado. Your support makes a lasting difference in the lives of children with a bleeding disorder.

2016 Calendar

January
20 Jackson Community Night, Jackson
29-31 NACCHO Camp Conference

February
19-21 RMHBDA Education Weekend & Annual Meeting, Bozeman
25-27 NHF Washington DC Days

March
1-31 Hemophilia Awareness Month!
27-29 HFA Annual Symposium

April
17 World Hemophilia Day

May
TBD Biogen Education Series

June
6-8 HTC Clinic, Billings
TBD Blood Brotherhood/Dads in Action Float Trip, Kalispell

July
8-10 Mile High Summer Camp, Leadership Pre-Camp Retreat, Empire, CO
10-15 Mile High Summer Camp, Rocky Mountain Village, Empire, CO
21-23 NHF Annual Meeting, Orlando, FL
24-28 World Federation of Hemophilia Congress, Orlando, FL
29-31 RMHBDA Family Camp, Flathead Lake Methodist Camp, Rollins, MT

August
TBD Educational Programs/Walk Call to Action

September
10 RMHBDA Walk for Hemophilia, Billings
30-10/1 Men's Retreat, Chico Hot Springs

October
TBD CSL Behring "Getting In the Game"

November
4-6 Women's Retreat, Chico Hot Springs

Now Approved!

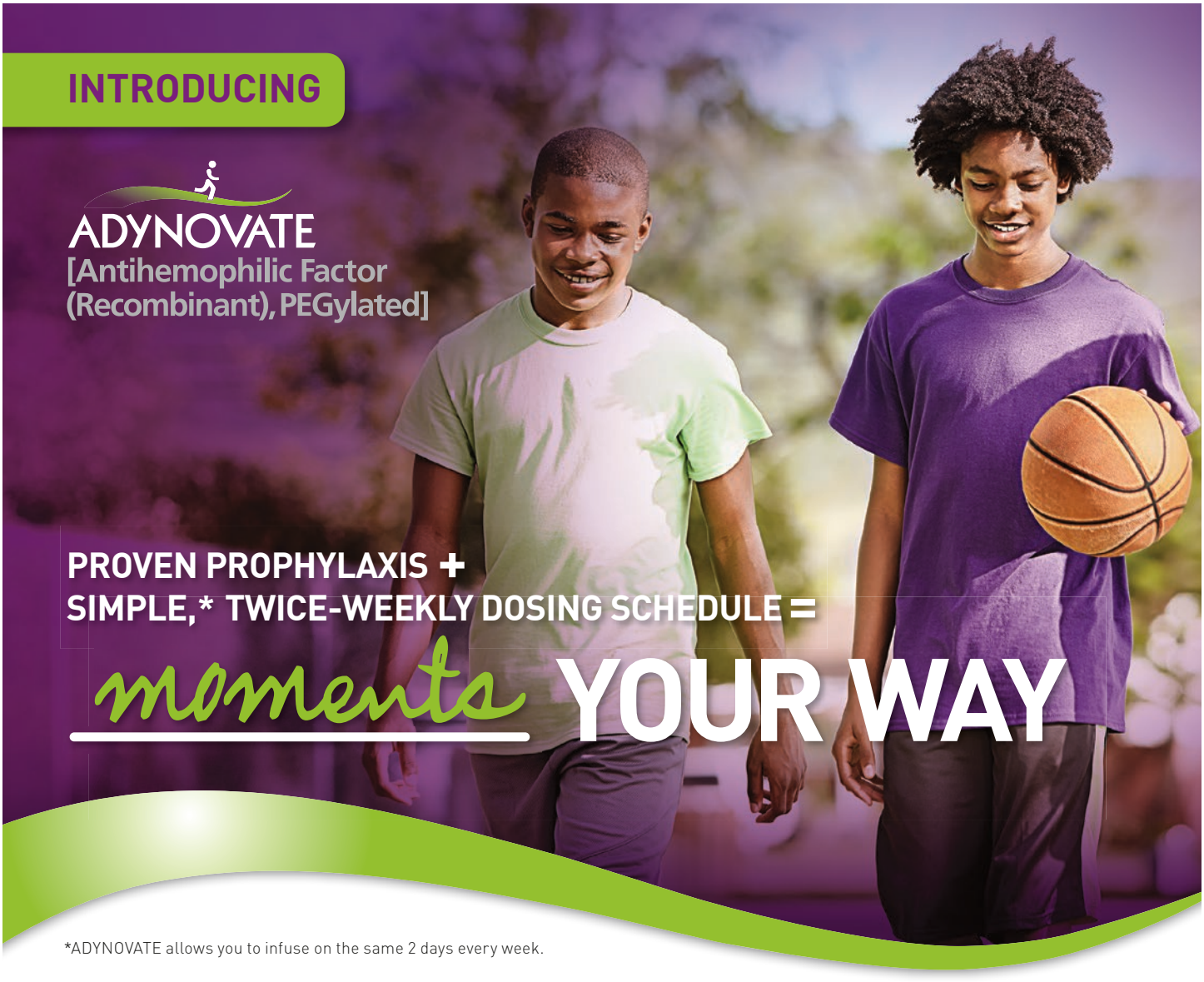
NUWIQ®

Antihemophilic Factor (Recombinant)

Available **EARLY 2016**

Date of preparation: 9/2015. NUW-005-CAD

octapharma®
For the safe and optimal use of human proteins



*ADYNOVATE allows you to infuse on the same 2 days every week.

ADYNOVATE [Antihemophilic Factor (Recombinant), PEGylated] Important Information

Indication

ADYNOVATE is used on-demand to control bleeding in patients 12 years of age and older with hemophilia A. ADYNOVATE can reduce the number of bleeding episodes when used regularly (prophylaxis).

ADYNOVATE is not used to treat von Willebrand disease.

DETAILED IMPORTANT RISK INFORMATION

You should not use ADYNOVATE if you:

- Are allergic to mice or hamster protein
- Are allergic to any ingredients in ADYNOVATE or ADVATE [Antihemophilic Factor (Recombinant)]

Tell your healthcare provider if you are pregnant or breastfeeding because ADYNOVATE may not be right for you.

You should tell your healthcare provider if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Have been told that you have inhibitors to factor VIII (because ADYNOVATE may not work for you).

Your body may form inhibitors to Factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop ADYNOVATE from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to Factor VIII.

You can have an allergic reaction to ADYNOVATE.
Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.

The common side effects of ADYNOVATE are headache and nausea. Tell your healthcare provider about any side effects that bother you or do not go away.

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 following page for ADYNOVATE Important Facts.

For full Prescribing Information visit www.ADYNOVATE.com.

Reference: 1. ADYNOVATE Prescribing Information. Westlake Village, CA: Baxalta US Inc.

Baxalta

ADYNOVATE [Antihemophilic Factor (Recombinant), PEGylated]

Important facts about

ADYNOVATE [Antihemophilic Factor (Recombinant), PEGylated]

This leaflet summarizes important information about ADYNOVATE. Please read it carefully before using this medicine. This information does not take the place of talking with your healthcare provider, and it does not include all of the important information about ADYNOVATE. If you have any questions after reading this, ask your healthcare provider.

What is the most important information I need to know about ADYNOVATE?

Do not attempt to do an infusion to 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 ADYNOVATE so that your treatment will work best for you.

What is ADYNOVATE?

ADYNOVATE is an injectable medicine used to replace clotting factor (factor VIII or antihemophilic factor) that is missing in people with hemophilia A (also called "classic" hemophilia). Hemophilia A is an inherited bleeding disorder that prevents blood from clotting normally.

ADYNOVATE is used on-demand to control bleeding in patients 12 years of age and older with hemophilia A. ADYNOVATE can reduce the number of bleeding episodes when used regularly (prophylaxis).

ADYNOVATE is not used to treat von Willebrand disease.

Who should not use ADYNOVATE?

You should not use ADYNOVATE if you:

- Are allergic to mice or hamster protein
- Are allergic to any ingredients in ADYNOVATE or ADVATE

Tell your healthcare provider if you are pregnant or breastfeeding because ADYNOVATE may not be right for you.

How should I use ADYNOVATE?

ADYNOVATE is given directly into the bloodstream.

You may infuse ADYNOVATE 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 healthcare provider or hemophilia treatment center. Many people with hemophilia A learn to infuse their ADYNOVATE by themselves or with the help of a family member.

Your healthcare provider will tell you how much ADYNOVATE to use based on your individual weight, level of physical activity, the severity of your hemophilia A, and where you are bleeding.

Reconstituted product (after mixing dry product with wet diluent) must be used within 3 hours and cannot be stored or refrigerated. Discard any ADYNOVATE left in the vial at the end of your infusion as directed by your healthcare professional.

How should I use ADYNOVATE? (cont'd)

You may have to have blood tests done after getting ADYNOVATE to be sure that your blood level of factor VIII is high enough to clot your blood.

Call your healthcare provider right away if your bleeding does not stop after taking ADYNOVATE.

What should I tell my healthcare provider before I use ADYNOVATE?

You should tell your healthcare provider if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Are breastfeeding. It is not known if ADYNOVATE passes into your milk and if it can harm your baby.
- Are pregnant or planning to become pregnant. It is not known if ADYNOVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADYNOVATE may not work for you).

What are the possible side effects of ADYNOVATE?

You can have an allergic reaction to ADYNOVATE.

Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.

The common side effects of ADYNOVATE are headache and nausea. Tell your healthcare provider about any side effects that bother you or do not go away.

These are not all the possible side effects with ADYNOVATE. You can ask your healthcare provider for information that is written for healthcare professionals.

What else should I know about ADYNOVATE and Hemophilia A?

Your body may form inhibitors to Factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop ADYNOVATE from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to Factor VIII.

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

The risk information provided here is not comprehensive. To learn more, talk with your health care provider or pharmacist about ADYNOVATE. The FDA approved product labeling can be found at www.ADYNOVATE.com or 855-4-ADYNOVATE.

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.

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Westlake Village, CA 91362 USA
U.S. License No. 2020
Issued 11/2015

15E001-ADY-US

Baxalta

Leadership begins with U.

Bayer HealthCare

Apply for a summer internship with Bayer Healthcare! Application Deadline is Friday, February 12 at 11.59 p.m. ET

Introducing Bayer 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.

CSL Behring Presents Phase III Data

for Its Long-Acting Recombinant Factor IX Albumin Fusion Protein for Hemophilia B at the 57th ASH Annual Meeting & Exposition

CSL Behring

Global biotherapeutics leader CSL Behring today presented data from its Phase III PROLONG-9FP clinical program evaluating the efficacy and long-term safety of its investigational long-acting fusion protein linking recombinant coagulation factor IX with recombinant albumin (rIX-FP). The data, from an ongoing extension study and two pivotal Phase III studies, assessed rIX-FP for routine prophylaxis in previously-treated adults with hemophilia B, at dosing intervals of up to 14 days. The findings were presented during an oral presentation at the American Society of Hematology's (ASH) 57th ASH Annual Meeting and Exposition in Orlando, along with a second abstract reporting efficacy and safety results of rIX-FP in patients undergoing surgical procedures.

New Data Presented at ASH Show for Elocta and Alprolix

May Help Control Target Joint Bleeds in People with Haemophilia A and B

Biogen

New data demonstrate Elocta (efmoroctocog alfa) [recombinant human coagulation factor VIII, Fc fusion protein]) (marketed as Eloctate in the USA) and Alprolix (rFIXFc) may effectively manage target joint bleeding and maintain low annualised bleeding rates (ABRs) in people with severe haemophilia A and B. The data, which were presented by Biogen and Swedish Orphan Biovitrum AB at the 57th American Society of Hematology (ASH) Annual Meeting and Exposition in Orlando, Florida.

"As the first therapies to offer prolonged protection from bleeds, Elocta and Alprolix continue to show low rates in both joint bleeding and overall annualised bleeding episodes," said Kate Dawson, M.D., vice president, U.S. Medical at Biogen. "Their ability to reduce bleed rates, which may translate into the potential for reducing some joint disease, continues to reaffirm their clinical value for people living with haemophilia A and B."

FDA OKs Baxalta's Drug for Von Willebrand Bleeding Disorder

Baxalta

The U.S. Food and Drug Administration today approved Vonvendi, von Willebrand factor (Recombinant), for use in adults 18 years of age and older who have von Willebrand disease (VWD). Vonvendi is the first FDA-approved recombinant von Willebrand factor, and is approved for the on-demand (as needed) treatment and control of bleeding episodes in adults diagnosed with VWD.

VWD is the most common inherited bleeding disorder, affecting approximately 1% of the U.S. population. Men and women are equally affected by VWD, which is caused by a deficiency or defect in von Willebrand factor, a protein that is critical for normal blood clotting. Patients with VWD can develop severe bleeding from the nose, gums, and intestines, as well as into muscles and joints. Women with VWD may have heavy menstrual periods lasting longer than average and may experience excessive bleeding after childbirth.

"Patients with heritable bleeding disorders should meet with their health care provider to discuss appropriate measures to reduce blood loss," said Karen Midthun, M.D., director of the FDA's Center for Biologics Evaluation and Research. "The approval of Vonvendi provides an additional therapeutic option for the treatment of bleeding episodes in patients with von Willebrand disease."

The safety and efficacy of Vonvendi were evaluated in two clinical trials of 69 adult participants with VWD. These trials demonstrated that Vonvendi was safe and effective for the on-demand treatment and control of bleeding episodes from a variety of different sites in the body. No safety concerns were identified in the trials. The most common adverse reaction observed was generalized pruritus (itching).

The FDA granted Vonvendi orphan product designation for these uses. Orphan product designation is given to drugs intended to treat rare diseases in order to promote their development.

Vonvendi is manufactured by Baxalta U.S., Inc., based in Westlake Village, California.

The FDA, an agency within the U.S. Department of Health and Human Services, protects the public health by assuring the safety, effectiveness, and security of human and veterinary drugs, vaccines and other biological products for human use, and medical devices. The agency also is responsible for the safety and security of our nation's food supply, cosmetics, dietary supplements, products that give off electronic radiation, and for regulating tobacco products.

Update from HTC-UC

University of Colorado Anschutz Medical Campus
Hemophilia and Thrombosis Center

Recently, the CDC has been working to update their website and provide access to data from both the Community Counts project as well as the older surveillance project, the UDC. Below is a compilation that Judith Baker, my colleague in the Western States Region, assembled for HTC staff use.

- Division of Blood Disorders' expanded bleeding disorders website for the Community Counts surveillance project: http://www.cdc.gov/ncbddd/hemophilia/communitycounts/index.html
- You can learn more about the project, its history, glossary, and obtain national level data reports on the population profile: http://www.cdc.gov/ncbddd/hemophilia/communitycounts/data-community-counts.html.
- The legacy UDC surveillance project website contains the project's history and major findings: http://www.cdc.gov/ncbddd/blooddisorders/udc/aboutus.html, articles published using the UDC data: http://www.cdc.gov/ncbddd/blooddisorders/udc/articles.html data reports: https://www2a.cdc.gov/ncbddd/htcweb/UDC_Report/UDC_Report.asp how to submit research proposals: http://www.cdc.gov/ncbddd/blooddisorders/udc/udc-hemophilia.html
- The CDC continues to highlight our full length documentary, *Bloodroots – Hemophilia Treatment Center Pioneers in Comprehensive Care*: http://www.cdc.gov/ncbddd/hemophilia/video.html A collaboration of Regions VIII, IX and X.
- The CDC continues to host the US HTC Directory: https://www2a.cdc.gov/ncbddd/htcweb/Dir_Report/Dir_Search.asp

Rocky Mountain Hemophilia
& Bleeding Disorders Association
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WINTER 2015