#### SPRING 2015

#### **Rocky Mountain Hemophilia**

# AA

### & Bleeding Disorders Association

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.

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#### 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

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### **RMHBDA Education Weekend 2015**

A special "Thank you" to our HTC for co-sponsoring our Education Weekend!

Thank you to our generous program funders: Accredo Health, Inc., Bayer Healthcare, Baxter Healthcare, Biogen Idec Hemophilia, CSL Behring, CVS Caremark, Grifols, HF Healthcare, Kedrion USA, Novo Nordisk, Octapharma, Restore RX, Emergent Biosolutions, HFA, Pfizer Hemophilia, and Walgreen Infusion Services.

RMHBDA Education Weekend was held February 27 – March 1 in Bozeman, Montana. Seventeen families attended with 21 youth and 29 adults. Educational sessions during the Weekend included: infusion session, industry/product presentations, Advocacy &

Healthcare Update, HTC Update, and 340 B info session, Communication, and Breakout sessions for our Blood Brotherhood and Sisterhood programs. All chapter members visited with our exhibitors to learn more about each company and their products.

Everyone enjoyed the chapter trip to the bowling alley. Children enjoyed field trips to Spire Climbing Center and the extraordinary programming of Beyond Recreation, sponsored by **Biogen Idec**.

Continued on page 5

### Blood Brotherhood Hemophilia Federation of America – Rocky Mountain & Snake River

#### Hemophilia Association's Men's Retreat

January 9–11, 2015 — West Yellowstone, Montana

Our second annual men's retreat included a discussion about advocacy, numerous experiential activities, and family and friend bonding. We had 10 men attend and the event represented four states: Montana, Idaho, Utah, and Wyoming.

We also enjoyed a snow mobile trip in Yellowstone Park to Old Faithful and back to West Yellowstone, MT. We enjoyed good food and a quality conversation. We hope to grow our group for our next event! Please consider joining us, or if you have some ideas for topics to discuss at a Men's retreat. We also are always looking for unique destinations and activities to include in our Men's retreat.

### Blood Brotherhood August Event

Our next scheduled Blood Brotherhood event will be on **Flathead Lake**,

Continued on page 5









### **From Our Executive Director**

### Welcome to the 2015 Rocky Mountain Bleeding Disorders Walk!

The RMHBDA Bleeding Disorders Walk is about the power of community and hope for a cure. Coming together for a cause empowers us. We are much stronger when we stand together.

Have you registered yet for the 2015 Rocky Mountain Bleeding Disorders Walk? This year, you can win great prizes starting at the \$250 fundraising level. The more your raise, the bigger the prize! You can find the prizes at www.hemophilia.org/walk

*Of course, the Walk is also an amazing way to raise money to fund education, advocacy and research leading to better treatments and a cure.* 

Raising money through the walk isn't hard to do. Friends and family want to help; all you have to do is ask them. Get started by registering today at www.hemophilia.org/walk, click on MT and register your team. You can do even more by forming a team. The more who participate, the more fun we have and the more we raise; come together with your friends and family, and join in on the excitement today.



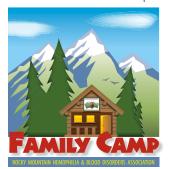
Help get us off to a good start. Join the RMHBDA Walk today!

Be sure to call, text, or email everyone you know and ask for support. Ask 10 people today for a donation — you will be well on your way. Or better yet, ask them to join you at the Walk and start a team — get them to register today to get started!

Graciously, Brad R. Benne

### Family Camp 2015 June 19–21, 2015 | Fairmont Hot Springs | Anaconda, Montana

Each summer, RMHBDA invites affected families living in Montana and Wyoming to attend a weekend retreat. The weekend is packed full of education, bonding, and fun! For more



information, visit www.fairmontmontana.com.

For the parents and teens, we will have teambuilding programming led by our guest, hemophilia leadership expert, Pat Torrey and some time to relax with other families. For youth, Beyond Recreation will provide activities and programming. This is a great opportunity to learn from and share experiences with one another.

We also have many great activities planned for our

campers including arts & crafts projects, field games, and educational sessions for children with bleeding disorders and their siblings. Infusion classes will be offered from our HTC. Call Brad with questions 406.586.4050.

# We Love Donations!

Donations 2015 in honor of Andy Brinkley

Donations Christy & Forrest Berg •Gary & Judith Hughes • Rona Matheson •Oracle

RMHBDA is a 501 (c)(3) nonprofit organization which means that contributions are tax deductible; check with your tax professional to determine how this specifically affects you.

We appreciate your consideration.

# amazonsmile

You shop. Amazon gives. AmazonSmile (smile.amazon.com) Amazon's way of letting Amazon customers enjoy their convenient online shopping plus the benefit of the AmazonSmile Foundation donating 0.5% of the price of eligible purchases to the charitable organizations selected bu customers.

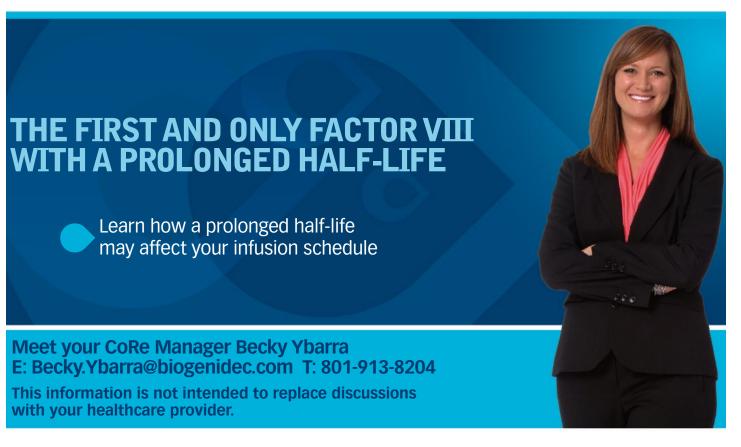


Safe and secure donation at no cost to RMHBDA or the donor — just visit **www.rmhbda.org** on the Donate/Join page.

### **, ⊙** goodsearch

Search the internet with the patent-protected, Yahool-powered search engine (just like you'd search on any other search engine, and we'll donate about a penny for nearly all searches to your selected cause. www.goodsearch.com





### 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.

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#### **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

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ELOCTATE<sup>™</sup> is a trademark of Biogen Idec.

Issued June 2014

### **Washington Days**

Jodi & Hannah Rudell, representing the great State of Wyoming traveled to Washington, DC to represent RMHBDA. Lisa Maxwell, hailing from the great State of Montana represented RMHBDA, as well. The House bill HR 460 we were lobbying for was asking for increased funding for research as well as some much needed adjustments in the prescription tiers that could lower our prescription costs for factor concentrates. We lobbied with our Senators directly to ask them to introduce a Senate bill as a companion bill to HR 460. Our team was able to meet Senator John Barrasso from Wyoming, two years in a row! Thank you, Senator Barrasso!

One of our talking points focused on continued funding for the HTCs. With all three states facing low-density populations and massive acreage with long drives, we had no problem explaining why these specialty doctors are so important. Also on our list to present was the Specialty Tier Drug pricing. Even though we live with these dollar amounts every day, staffers and congressmen are still amazed to find out what it costs. We continue to advocate with the National Hemophilia Foundation and the Hemophilia Federation of America. Other Federal priorities for the bleeding disorders community include: the Federal Hemophilia programs, federally-funded research, blood and blood product safety, access to care, and access to skilled nursing facilities.







From page 1: Blood Brotherhood

August 1, 2015. We will have a discussion about "Exercise & Physical Therapy." Followed by a chartered fishing trip in hopes to land a *large* Lake Trout!

From page 1: Education Weekend 2015

Raffle Winners Avery Amende, Lane Maxwell, Beldon Savage, Jaime Gronley, Mike Magone, and Ron Fiene.









# UNLOCKING YOUR SELF-POTENTIAL



# ADVATE SUPPORTS YOU BY IMPROVING YOUR PERSONAL INFUSION EXPERIENCE WITH THE BAXJECT III SYSTEM

The reconstitution process with the BAXJECT III system is easier, faster,

- and designed for you\*
- An all-in-one, connected design<sup>1</sup>
- Broad selection of doses, providing opportunities for single-vial options<sup>1</sup>
- One-step activation with fewer steps for faster reconstitution—just press, swirl, flip and withdraw\*1.2
  - Straightforward pooling process if more than 1 vial is needed—no additional supplies required<sup>1</sup>



Reconstitute ADVATE in about half the time\*<sup>2</sup>

As compared with the BAXJECT II needleless transfer device.

- Watch the ADVATE with BAXJECT III system reconstitution video and see how it all comes together at **ADVATE.com**
- Share your experience using the A DVATE with BA XJECT III system at www.BAXJECT3Survey.com

# ADVATE [Antihemophilic Factor (Recombinant)] Important Information Indications

ADVATE is a medicine used to replace clotting factor (factor VIII or antihemophilic factor) that is missing in people with hemophilia A (also called "classic" hemophilia).

ADVATE is used to prevent and control bleeding in adults and children (0-16 years) with hemophilia A. Your healthcare provider may give you ADVATE when you have surgery.

ADVATE can reduce the number of bleeding episodes in adults and children (0-16 years) when used regularly (prophylaxis).

ADVATE is not used to treat von Willebrand disease.

### **DETAILED IMPORTANT RISK INFORMATION**

- You should not use ADVATE if you:
- Are allergic to mice or hamsters.
- Are allergic to any ingredients in ADVATE.

Tell your healthcare provider if you are pregnant or breastfeeding because ADVATE 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 ADVATE 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 ADVATE 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 ADVATE.

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.

Side effects that have been reported with ADVATE include: cough, headache, joint swelling/aching, sore throat, fever, itching, unusual taste, dizziness, hematoma, abdominal pain, hot flashes, swelling of legs, diarrhea, chills, runny nose/congestion, nausea/vomiting, sweating, and rash.

Tell your healthcare provider about any side effects that bother you or do not go away or if your bleeding does not stop after taking ADVATE.

# 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 Brief Summary of ADVATE full Prescribing Information.

References: 1. ADVATE Prescribing Information. Westlake Village, CA: Baxter Healthcare Corporation; April 2014. 2. Data on file.

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#### ADVATE [Antihemophilic Factor (Recombinant)] Lyophilized Powder for Reconstitution for Intravenous Injection Brief Summary of Prescribing Information: Please see package insert for full Prescribing Information.

#### INDICATIONS AND USAGE

ADVATE [Antihemophilic Factor (Recombinant)] is a recombinant antihemophilic factor indicated for use in children and adults with hemophilia A (congenital factor VIII deficiency or classic hemophilia) for:

- Control and prevention of bleeding episodes.
- Perioperative management.
- · Routine prophylaxis to prevent or reduce the frequency of bleeding episodes.
- ADVATE is not indicated for the treatment of von Willebrand disease.

#### CONTRAINDICATIONS

ADVATE is contraindicated in patients who have life-threatening hypersensitivity reactions, including anaphylaxis, to mouse or hamster protein or other constituents of the product (mannitol, trehalose, sodium chloride, histidine, Tris, calcium chloride, polysorbate 80, and/or glutathione).

#### WARNINGS AND PRECAUTIONS

#### Hypersensitivity Reactions

Allergic-type hypersensitivity reactions, including anaphylaxis, have been reported with ADVATE. Symptoms include dizziness, paresthesia, rash, flushing, facial swelling, urticaria, dyspnea, and pruritus. ADVATE contains trace amounts of mouse immunoglobulin G (MulgG)  $\leq$  0.1 ng/IU ADVATE, and hamster proteins  $\leq$  1.5 ng/IU ADVATE. Patients treated with this product may develop hypersensitivity to these non-human mammalian proteins.

Discontinue ADVATE if hypersensitivity symptoms occur and administer appropriate emergency treatment. Neutralizing Antibodies

Neutralizing antibodies (inhibitors) have been reported following administration of ADVATE predominantly in previously untreated patients (PUPs) and previously minimally treated patients (MTPs). Monitor all patients for the development of factor VIII inhibitors by appropriate clinical observation and laboratory testing. If expected plasma factor VIII activity levels are not attained, or if bleeding is not controlled with an expected dose, perform an assay that measures factor VIII inhibitor concentration. [see *Warnings and Precautions*]

#### **Monitoring Laboratory Tests**

- Monitor plasma factor VIII activity levels by the one-stage clotting assay to confirm the adequate factor VIII levels have been achieved and maintained when clinically indicated. [see *Dosage and Administration*]
- Perform the Bethesda assay to determine if factor VIII inhibitor is present. If expected factor VIII activity
  plasma levels are not attained, or if bleeding is not controlled with the expected dose of ADVATE, use
  Bethesda Units (BU) to titer inhibitors.
- If the inhibitor titer is less than 10 BU per mL, the administration of additional antihemophilic factor concentrate may neutralize the inhibitor and may permit an appropriate hemostatic response.
- If the inhibitor titer is above 10 BU per mL, adequate hemostasis may not be achieved. The inhibitor titer may rise following ADVATE infusion as a result of an anamnestic response to factor VIII. The treatment or prevention of bleeding in such patients requires the use of alternative therapeutic approaches and agents.

#### ADVERSE REACTIONS

The serious adverse reactions seen with ADVATE are hypersensitivity reactions and the development of high-titer inhibitors necessitating alternative treatments to factor VIII.

The most common adverse reactions observed in clinical trials (frequency  $\geq$ 10% of subjects) were pyrexia, headache, cough, nasopharyngitis, vomiting, arthralgia, and limb injury.

#### **Clinical Trial Experience**

Because clinical trials are conducted under widely varying conditions, adverse reaction rates observed in the clinical trials of a drug cannot be directly compared to rates in clinical trials of another drug and may not reflect the rates observed in clinical practice.

ADVATE has been evaluated in five completed clinical trials in previously treated patients (PTPs) and one ongoing trial in previously untreated patients (PUPs) with severe to moderately severe hemophilia A (factor VIII  $\leq$ 2% of normal). A total of 234 subjects have been treated with ADVATE as of March 2006. Total exposure to ADVATE was 44,926 infusions. The median duration of participation per subject was 370.5 (range: 1 to 1,256) days and the median number of exposure days to ADVATE per subject was 128 (range: 1 to 598).<sup>3</sup>

The summary of adverse reactions with a frequency ≥5% (defined as adverse events occurring within 24 hours of infusion or any adverse event causally related occurring within the trial period) is shown in Table 3. No subject was withdrawn from a clinical trial due to an adverse reaction. There were no deaths in any of the clinical trials.

Table 3 Summary of Adverse Reactions<sup>a</sup> with a Frequency >5% (N = 234 Treated Subjects<sup>a</sup>)

|      |                |        | Numbor           | Der    |
|------|----------------|--------|------------------|--------|
| mara | i i oquolioj _ | -0/0 ( | <br>loutou oubje | ,000 ) |

| MedDRA° System Organ Class                           | MedDRA<br>Preferred Term             | Number<br>of ADRs | Number<br>of<br>Subjects | Percent<br>of<br>Subjects |
|--|--------------------------------------|-------------------|--------------------------|---------------------------|
| General disorders and administration site conditions | Pyrexia                              | 78                | 50                       | 21                        |
| Nervous system disorders                             | Headache                             | 104               | 49                       | 21                        |
| Respiratory, thoracic, and mediastinal disorders     | Cough                                | 75                | 44                       | 19                        |
| Infections and infestations                          | Nasopharyngitis                      | 61                | 40                       | 17                        |
| Gastrointestinal disorders                           | Vomiting                             | 35                | 27                       | 12                        |
| Musculoskeletal and connective tissue disorders      | Arthralgia                           | 44                | 27                       | 12                        |
| Injury, poisoning, and procedural complications      | Limb injury                          | 55                | 24                       | 10                        |
| Infections and infestations                          | Upper respiratory<br>tract infection | 24                | 20                       | 9                         |

| Respiratory, thoracic, and mediastinal disorders     | Pharyngolaryngeal<br>pain | 23 | 20 | 9 |
|--|---------------------------|----|----|---|
| Respiratory, thoracic, and mediastinal disorders     | Nasal congestion          | 24 | 19 | 8 |
| Gastrointestinal disorders                           | Diarrhea                  | 24 | 18 | 8 |
| Gastrointestinal disorders                           | Nausea                    | 21 | 17 | 8 |
| General disorders and administration site conditions | Pain                      | 19 | 17 | 8 |
| Skin and subcutaneous tissue disorders               | Rash                      | 16 | 13 | 6 |
| Infections and infestations                          | Ear infection             | 16 | 12 | 5 |
| Injury, poisoning, and procedural complications      | Procedural pain           | 16 | 12 | 5 |
| Respiratory, thoracic, and mediastinal disorders     | Rhinorrhea                | 15 | 12 | 5 |

<sup>a</sup> Adverse reactions are defined as all adverse events that occurred (a) within 24 hours after being infused with investigational product, or (b) all adverse events assessed related or possibly related to investigational product, or (c) adverse events for which the investigator's or sponsor's opinion of causality was missing or indeterminate.

<sup>b</sup> The ADVATE clinical program included 234 treated subjects from 5 completed studies in PTPs and 1 ongoing trial in PUPs as of 27 March 2006.

<sup>c</sup> MedDRA version 8.1 was used.

#### Immunogenicity

The development of factor VIII inhibitors with the use of ADVATE was evaluated in clinical trials with pediatric PTPs (<6 years of age with >50 factor VIII exposures) and PTPs (>10 years of age with >150 factor VIII exposures). Of 198 subjects who were treated for at least 10 exposure days or on study for a minimum of 120 days, 1 adult developed a low-titer inhibitor (2 BU in the Bethesda assay) after 26 exposure days. Eight weeks later, the inhibitor was no longer detectable, and *in vivo* recovery was normal at 1 and 3 hours after infusion of another marketed recombinant factor VIII concentrate. This single event results in a factor VIII inhibitor fequency in PTPs of 0.51% (95% Cl of 0.03 and 2.91% for the risk of any factor VIII inhibitor development).<sup>34</sup> No factor VIII inhibitors were detected in the 53 treated pediatric PTPs.

In clinical trials that enrolled previously untreated subjects (defined as having had up to 3 exposures to a factor VIII product at the time of enrollment), 5 (20%) of 25 subjects who received ADVATE developed inhibitors to factor VIII.<sup>3</sup> Four subjects developed high titer (>5 BU) and one patient developed low-titer inhibitors. Inhibitors were detected at a median of 11 exposure days (range 7 to 13 exposure days) to investigational product.

Immunogenicity also was evaluated by measuring the development of antibodies to heterologous proteins. 182 treated subjects were assessed for anti-Chinese hamster ovary (CHO) cell protein antibodies. Of these subjects, 3 showed an upward trend in antibody titer over time and 4 showed repeated but transient elevations of antibodies. 182 treated subjects were assessed for mulgG protein antibodies. Of these, 10 showed an upward trend in anti-mulgG antibody titer over time and 2 showed repeated but transient elevations of antibodies. Four subjects who demonstrated antibody elevations reported isolated events of urticaria, pruritus, rash, and slightly elevated eosinophil counts. All of these subjects had numerous repeat exposures to the study product without recurrence of the events and a causal relationship between the antibody findings and these clinical events has not been established. Of the 181 subjects who were treated and assessed for the presence of anti-human von Willebrand Factor (WWF) antibodies, none displayed laboratory evidence indicative of a positive serologic response. The detection of antibody formation is highly dependent on the sensitivity and specificity of the assay. Additionally, the observed incidence of antibody (including neutralizing antibody) positivity in an assay may be influenced by several factors including assay methodology, sample handling, timing of sample collection, concomitant medications, and underlying disease. For these reasons, comparison of the incidence of antibodies to ADVATE with the incidence of antibodies to other products may be misleading.

#### **Post-Marketing Experience**

The following adverse reactions have been identified during post-approval use of ADVATE. Because these reactions are reported voluntarily from a population of uncertain size, it is not always possible to reliably estimate their frequency or establish a causal relationship to drug exposure.

Among patients treated with ADVATE, cases of serious allergic/hypersensitivity reactions including anaphylaxis have been reported and factor VIII inhibitor formation (observed predominantly in PUPs). Table 4 represents the most frequently reported post-marketing adverse reactions as MedDRA Preferred Terms.

| Table          | 4          |
|----------------|------------|
| Post-Marketing | Experience |

| Organ System [MedDRA Primary SOC]                    | Preferred Term                        |
|--|---------------------------------------|
| Immune system disorders                              | Anaphylactic reaction <sup>a</sup>    |
|  | Hypersensitivity <sup>a</sup>         |
| Blood and lymphatic system disorders                 | Factor VIII inhibition                |
| General disorders and administration site conditions | Injection site reaction               |
|  | Chills                                |
|  | Fatique/Malaise                       |
|  | Chest discomfort/pain                 |
|  | Less-than-expected therapeutic effect |

<sup>a</sup>These reactions have been manifested by dizziness, paresthesias, rash, flushing, face swelling, urticaria, and/or pruritus.

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Patented: see www.baxter.com/productpatents/

Baxter Healthcare Corporation, Westlake Village, CA 91362 USA

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### **Industry News**

### **Biogen Scholarship**

Biogen Idec is proud to enable students with hemophilia to pursue their passions through a wide range of academic scholarships, including awards for vocational/ technical schools, community colleges, and four-year colleges and universities. The deadline to apply for the 2015-16 Biogen Idec Hemophilia Scholarship Program is April 15, 2015.

### **RMHBDA Scholarship**

The Rocky Mountain Hemophilia and Bleeding Disorder Association is a chapter located in Bozeman, Montana that is dedicated to representing, educating, supporting, and helping those patients with bleeding disorders and their families in Montana and Wyoming.

Visit www.rmhbda.org for more information.

### Nate Slack Scholarship – HF Healthcare

The Nate Slack Scholarship award, presented by HF healthcare, wants to honor memory and a giving spirit of Nate Slack by providing two (2) \$1,000 educational scholarships.

The scholarships are made available to people with hemophilia (or a related bleeding disorder) or to a person within the immediate family who is attending (or has been accepted to) an accredited Junior College, University, College, or Trade School.

Apply by filling out an application and writing about your experience with hemophilia or a related bleeding disorder, involvement in the bleeding disorder community and educational goals. For more info about this scholarship, visit www.hfhealthcare.com/scholarship and submit your application by May 15, 2015

### Baxter Scholarship

applications are

available as at

Education Advantage scholarship program

Baxter

www.scholarsapply.org/baxteredge, or by calling Scholarship America at 877-544-3018, or emailing baxter@scholarshipamerica.org.

Applicants can apply online, download the application and mail it in, or request a paper application. Completed applications for scholarship renewals are due to Scholarship America by February 15, 2015, while the deadline for new applications is April 15, 2015.

Grifols will launch a new and improved copay card program for patients on ALPHANATE and AlphaNine SD.

#### **Program Information:**

Patients may be eligible for up to \$20,000 in coverage annually for the cost of their ALPHANATE or AlphaNine SD

### **Novo Nordisk**

Novo Nordisk is pleased to announce it is launching a new, comprehensive patient support program specifically designed

specifically designed **NOVO nordisk** for and inspired by the bleeding disorders community—NovoSecure<sup>™</sup>. The program will replace SevenSECURE<sup>®</sup>, which has been an integral part of the company's offering for

NovoSecure<sup>™</sup> enrollees can apply for a variety of programs, including:

- A competitive scholarship program
- Life coaching with HeroPath™
- Career counseling

several years.

Insurance support

HTCUpdate Inversity of Colorado Anschutz Medical Campus Hemophilia and Thrombosis Cent

### **Montana Clinic Dates**

- Billings Clinic, St. Vincent's Hospital, June 1–3
- Missoula Clinic, Community Medical, July 27–29

### **RMHBDA 2015 Program & Event Calendar**

As of March 31, 2015. The chapter is still determining exact dates for several programs and events for the community.

#### April

17 World Hemophilia Day

#### May

TBD Biogen Idec Education Series/Walk Kickoff TBD Pfizer Education Series/Walk Kickoff

#### **June**

20-22 RMHBDA Family Camp at Fairmont Hot Springs, MT

#### July

10-12 Mile High Summer Camp Leadership Pre-camp Retreat12-17 Mile High Summer Camp, Rocky Mountain Village, Empire, CO

#### August

TBD Baxter Facts First/ Walk Call to Action 13-16 NHF Annual Meeting

#### September

2 RMHBDA Walk for Bleeding Disorders, Billings

#### October

TBD CSL Behring "Getting in the Game"

#### November

6-8 Chico Hot Springs



Biotherapies for Life<sup>™</sup> **CSL Behring** 



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### Save the Date! Mile High Colorado Camp

# Mile High Colorado CampJuly 12-17, 2015

July 10-12, 2015

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

Leadership Pre-Camp Retreat

### When and Where?

The Hemophilia and Thrombosis Center (HTC) is proud to once again sponsor the summer camp program at Rocky Mountain Village from July 10-17, 2015.

### Who Should Attend?

Children with hemophilia or other bleeding disorders

#### Siblings of the above groups

Mile High Colorado Camp is for ages 7-18. Programming is determined by age. 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

### World Hemophilia Day — April 17, 2015 Building A Family of Support

Join us on April 17 to raise awareness about bleeding disorders and the need to build a family of support for those living with them.

Families come in many forms but they all share the ability to support and advocate. World Hemophilia Day provides an opportunity to talk to your extended family and friends, colleagues, and caregivers to raise awareness and increase support for those living with an inherited bleeding disorder.

You can also go one step further and have a local landmark, a light in your home or office, or your front porch light lit in red on April 17 to show your commitment to the bleeding disorder community.

This year connect the global bleeding disorder family on the World Federation of Hemophilia social media network and encourage your online community to join the global family.



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 a non-refundable \$75.00 deposit. The remainder of the camp cost, approximately \$1000.00 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!

This summer make a dream come true. 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.





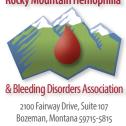
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# commitment, leadership & innovation

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