

Fall  
2018



# HANJournal

***Friendly Reminder: Open Enrollment to purchase 2019 health plans under the Affordable Care Act runs from November 1, 2018 – December 15, 2018. For more information visit websites: <https://www.state.nj.us/dobi/getcovered/index.html> or [www.HealthCare.gov](http://www.HealthCare.gov) Or Call 1(800)318-2596***

# BDRN & HANJ

## 340B Bleeding Disorders Program

In association with:

Rutgers: Robert Wood Johnson Medical School



### Bleeding Disorders Resource Network

BDRN's Mission is to improve the quality of life for people living with bleeding disorders.

At BDRN we are dedicated to serving and making a difference in the bleeding disorders community. We take a team approach to address each set of circumstances. Our commitment to improving the lives of those living with a bleeding disorder is what motivates us and is the essence of everything we do.

### Hemophilia Association of New Jersey

HANJ's mission is to improve the quality of life for persons with a bleeding disorder by providing and maintaining access to highly qualified medical treaters and successfully proven medical regimens.

- Ensure access to care
- Secure more comprehensive insurance coverage
- Ensure the NJ Standards of Care are met
- Provide financial grants to hemophilia and bleeding disorder patients
- Provide financial grants in support of the HTC's
- Provide education programs and reimbursement support to patients of New Jersey

### 340B Program

The 340B Program is a federal drug discount program. It entitles certain safety net providers and clinics, including hemophilia treatment centers, to a discounted price for covered outpatient drugs. Rutgers/RWJ has registered to participate in the 340B Program as a Covered Entity. This will allow Rutgers/RWJ to purchase factor and other drugs at a discount. While other grant fundings suffer cutbacks, Rutgers/RWJ is able to use the cost savings and other program revenues to fund the services it provides to its patients. Rutgers has selected BDRN as one of its contract pharmacies under the 340B Program. BDRN and HANJ have agreed to work together to provide certain services for the Rutgers program, including patient education and financial assistance services.



### Message from ... President of HANJ Joe Markowitz

As the warm weather winds down, and activities go from outdoor to indoor, it's a good time to sit back and reflect on what's important to you. And when you figure that out, are you certain you're taking positive steps to ensure you'll meet those important goals? Just wishing won't get you there. Setting goals isn't just a personal issue, it's good for all areas of your life and your relationships with others.

As I look at the activities that HANJ performs on your behalf, I am confident that we do good work, and work smartly and effectively. Working with legislators, lobbyists, manufacturers, specialty pharmacies and physicians is important to our success. It's a core function. But working with the hemophilia families is our most important job. HANJ is here to help hemophiliacs and their families. Everything we do is in support of that mission.

So the question I'm going to ask you to think about is this: Are we doing what YOU want? Are there additional programs and activities that YOU want HANJ to get involved in?

For example, we have an active Blood Brotherhood program for adult men. But what about adult women, parents, school age boys and girls, and young adults? Should we expand into supporting these groups also? If so, will YOU be willing to volunteer to organize and run these new groups?

With YOUR involvement, we can continue to be the best at helping our membership with meaningful programs.

Best Regards,  
Joe



### Meet the Board... Steven Moersdorf HANJ Trustee



I graduated from the University of Scranton in 1993 with a BS in accounting. My first job after college was with HANJ's accounting firm. When I left that job a few years later, Elena asked me to stop by the office and see her on my way home one night, and the rest as they say is history. I've now been a member of the Board of Trustees for a little over 20 years. While I am currently serving in the position of Vice President, I have spent most of my time on the board serving in the position of Treasurer. I've also served on many of HANJ's committee's but predominantly on the Budget and Finance committee and the Fundraising committee.

I am a Certified Public Accountant and a Principal at the firm Maffei, Masiello & Company, P.A. in Mendham, NJ. We handle accounting, auditing, financial reporting and analysis, tax planning and preparation for small business and individual clients.

Over the years I have enjoyed serving as a volunteer member and leader of a number of organizations. I have been a member of the NJ Society of Certified Public Accountants since 1997. There I have previously served as a member and then the Leader of the Young CPA's Resource Group and as a member, then Treasurer and later Chairman of the Political Action Committee.

Currently, I also serve on the Board of Directors as Treasurer of the Healthcare Chaplaincy Network, an organization that "helps people faced with the distress of illness and suffering to find comfort and meaning." I also currently serve as a member of the Environmental Commission in Chester Township, NJ, where I live.

My wife Marlena and I have been married for six years and we have a two year old daughter named Caitlin who keeps us very busy. In my "spare time" I enjoy, genealogy, bicycle riding, landscaping our yard and traveling.

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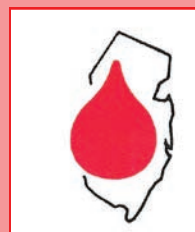
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We welcome all letters and submissions for consideration.

The opinions expressed in HANJournal articles are solely those of the authors and do not necessarily reflect the philosophy of the Hemophilia Association of New Jersey. HANJ makes no recommendations for or against treatments and/or therapies.

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The Hemophilia Association of New Jersey was founded in August 1971 by 10 concerned families, and offers assistance to persons with hemophilia and their families from our office located in East Brunswick, New Jersey.

Our mission is to improve the quality of life for persons with a bleeding disorder by providing and maintaining access to highly qualified medical providers and successfully proven medical regimens.

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**See what's in this Issue :**

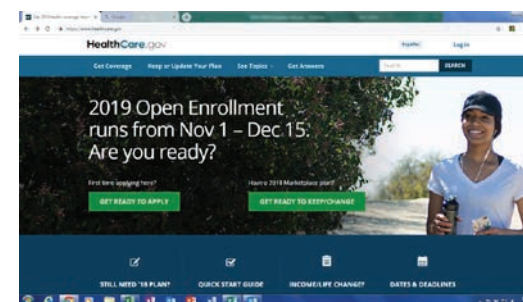
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Money Sense	page 20

**Social Worker Update  
By Neidy Olarte, MSW  
Social Service Coordinator**

**Open Enrollment.  
Are you covered?**

For individuals that are currently in need of health insurance or have insurance through the Marketplace, please be aware that open enrollment for plans under the Health Insurance Marketplace begins November 1, 2018 and ends December 15, 2018 for plans that will become effective January 1, 2019. If you do not elect an insurance plan within this time frame, you will not be able to obtain insurance after this deadline unless you are offered insurance through an employer, qualify for Medicaid, or if you have a qualifying event that makes you eligible for a special enrollment. If you currently have insurance through the Marketplace this is your chance to switch your plan if you are not happy with the plan you currently have. If you like your current plan, you do not have to do anything and will remain on your plan as directed by your insurance carrier.

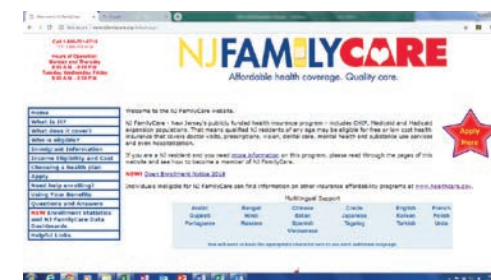
There are several ways to obtain insurance during open enrollment. The most effective way to obtain insurance is to enroll through the marketplace website at [www.healthcare.gov](http://www.healthcare.gov).



When you log onto the marketplace website, you can review the different plans that are offered as well as compare rates. You will also have a chance to see if you qualify for any subsidies which can lower your

monthly premium rate depending on your family income. On the website there is also a directory of local Navigators that can assist you with your application process should you need any assistance. You may also contact the health insurance plan directly if you do not want to apply through the marketplace website. Please note that by bypassing enrollment through the Marketplace website, you will not be eligible for any subsidies to lower your monthly premium. Those subsidies can only be obtained by submitting your application through the marketplace website.

If you feel like you cannot afford your portion of the premium cost or you feel like your income is too low to purchase a policy through the marketplace, you can contact NJ Family Care at [www.njfamilycare.org](http://www.njfamilycare.org) to see if you qualify for a Medicaid plan.



If you applied through the marketplace and your income is low, they may direct you to contact NJ Family Care. The Hemophilia Association of NJ also offers an Insurance Grant Program that helps with the cost of health insurance premiums as well as any co pays and deductibles. For more information on the Marketplace and for further information on the Insurance Grant Program offered through HANJ, please contact the office at (732) 249-6000 or contact the Social Worker at your Hemophilia Treatment Center.

## WHAT'S HAPPENING

### New Jersey Hemophilia Treatment Centers

#### Rutgers Robert Wood Johnson Medical School Hemophilia Treatment Center



##### **Rutgers RWJ Medical School 340B Program:**

In order for the hemophilia program to maintain comprehensive hemophilia care in an era of increasing health care costs amidst dwindling levels of federal and state funding of hemophilia programs, the Rutgers Robert Wood Johnson Medical School Hemophilia Treatment Center is a 340B covered entity. Participation in the federal 340B program makes it possible for our HTC to continue to serve the hemophilia community with the high level of services and quality of care it expects. If you have questions about this program, please do not hesitate to contact the HTC directly at 732-235-6533.

##### **Studies:**

Currently, the HTC is participating in 2 studies: 1) TAURUS: A Multinational Phase IV Study Evaluating "Real World" Treatment Pattern in Previously Treated Hemophilia A Patients Receiving KOVALTRY (Octocog alfa) for Routine Prophylaxis and 2) A Multicenter Phase 2 Open-Label, Single-Arm, Prospective, Interventional Study of Plasma-Derived Factor VIII/VWF (Alphanate®) in Immune Tolerance Induction Therapy in Subjects with Congenital Hemophilia A. If you are interested in or have questions regarding these studies, please call the HTC.

##### **School & Camp Visits:**

The staff at the HTC continues to provide in-service programs to school and camp personnel about a child's hemophilia. If you are in need of an in-service program at

your child's school or camp, please contact Lisa Cohen, MSW at 732-235-6533. *Please contact Lisa ASAP, as the slots for these visits fill up very quickly!*

##### **Ongoing Training:**

The staff at the HTC continues to provide hands-on training in infusion procedures to parents and their children. A series of thirty minute sessions are held over a period of weeks/months depending on the families' needs, abilities and schedules. Please call Frances Maceren, RN at 732-235-6542, if you are interested in arranging infusion training.



##### **General Information:**

For information regarding women with bleeding disorders and/or a family history of hemophilia, clinical trials, genetic counseling, insurance issues, educational sessions or school visits, please call the **Hemophilia Treatment Center at 732-235-6531.**

## Newark Beth Israel Medical Center and Children's Hospital of New Jersey



As we transition into fall, the staff from the Comprehensive Hemophilia Treatment Center at Newark Beth Israel Medical Center and Children's Hospital of New Jersey would like to share some updates, current programs, and plans with you.

##### **NEWS**

##### **Hemophilia Camp:**

This year, like last year, we had several children attend hemophilia camp at either Double H Ranch or Hole in the Wall Gang Camp. Camp can be an integral part of a patients' journey towards independence. **Both camps offer family camps as well. For more information about camp, or if your child or family is interested in attending camp in the future, please contact Erica, our Social Worker, at the HTC.**

##### **UPCOMING**

##### **Back to School:**

As the school year continues, we know that you might need forms completed, letters for school, or school visits scheduled. School visits are a wonderful opportunity for our HTC to provide education and outreach to your child's school or daycare about hemophilia and other bleeding disorders. Whether the visit is with the staff at your child's school, the daycare staff, or even the child study team, a school visit opens the lines of communication between the child's school or daycare and the HTC. **If you are going to want a school visit scheduled for your child's school or daycare center, or need a letter for school/forms completed, please contact Erica, our Social Worker.** Erica will make sure that we have a release on file, and will coordinate your needs with the school and schedule a visit. **If you will need any forms or letters for your child's school or daycare center, please be mindful that it may take up to two weeks**

**for forms or letters to be completed.** For more information, please contact us at the HTC.

##### **SAVE THE DATE:**

The HTC Annual Holiday Party will be held on Saturday December 15, 2018 from, 2PM to 6PM, at Newark Beth Israel Medical Center; more details to follow.

##### **ONGOING PROGRAMS**

**Hemophilia 340B Program:** Our HTC participates in the Federal 340B Program. As a comprehensive care center, we have been improving the quality of life for individuals with bleeding disorders and providing cost effective care in the long term for many years. In an effort to help HTCs sustain themselves, and provide better care for their eligible patients, Congress created the 340B Program as part of the Veteran's Health Care Act of 1992. Across the United States almost all of the HTCs participate in 340B Programs. Depending on their healthcare coverage, patients may have a variety of pharmacy options to choose from. Our HTC is contracted with four different home care companies; Accredo, BDRN, Bioscrip, and Option Care. Patients who are not currently using one of these four companies may voluntarily switch if their insurance company allows. Participation in the 340B Program is voluntary. Please contact our Program Manager, Phyllis, for further information.

##### **Travel Letters:**

Are you going to be traveling? Are you going to need a travel letter? If you answered yes to either of

those questions, this information is for you. **Please remember to let the HTC staff know if you are going to need a travel letter at least two weeks prior to your scheduled trip** so you can rest assured that your letter is in your hand as you embark on your journey.

**Comprehensive Evaluations:**

It is really important to schedule and attend an annual comprehensive evaluation at the HTC. The annual evaluation is an essential component in the provision of an individual's comprehensive care. Members of the HTC treatment team will complete medical, musculo-skeletal, psychosocial and laboratory evaluations to assess the patient's current health and to develop a treatment plan for the upcoming year. Education and referrals for medical and psychosocial services will also be provided as needed. At the time of an annual evaluation, patients will be asked

to participate in the ATHN (American Thrombosis & Hemostasis Network) Data Set. This is a voluntary program conducted by HTC's with support from ATHN to improve the health of people with coagulation disorders. Patients will also be educated about any other available studies that they might be eligible to participate in. **Please note that any individual receiving medication through the HTC to treat their bleeding disorder must be seen by the HTC on an annual basis.**

**Manufacturer Programs:**

Manufacturers have programs available to help patients continue to receive products during a lapse of insurance coverage. They also offer co-pay assistance programs. Each program has enrollment requirements and many require yearly re-enrollment. Enrollment in these programs can be beneficial. For more information, please contact the HTC.

**Please contact us at the Hemophilia Treatment Center to sign up for one of the above programs or to request further information about available groups or services for children and adults. We can be reached at (973) 926-6511.**

**St. Michael's Medical Center**



**School Visits:**

School is certainly back in session and we want to remind you that we are available for school visits. Our main goal is to educate school staff about the different types of bleeding disorders and new treatments. You may call The Blood Research Institute at (973) 877-5342 for more information.

**Scholarships:**

Feel free to call us at (973) 877-5342 for information on scholarships. We know a lot of our patients are now entering college and might be in need of financial assistance. Please do not hesitate to call and ask for information, help, and assistance.

**Patient Education:**

Our patients are always welcome to ask questions about new therapies and insurance updates. If any of you have any questions or concerns, please give us a call and we will provide you with the most up to date medical

and insurance information. You may call Dominique Joseph, Nurse at (973) 877-5340 or Social Worker, Joanne Rodriguez, at (973) 877-2967.

**End of Year Celebration:**

Our Psychosocial gathering will be taking place at St. Michael's Medical Center on December 22, 2018 from 12:30pm to 2:30pm. Please call our center at (973) 877-5342 to RSVP and be on Santa's List. We are looking forward to having a day of fun.

We will continue providing the care that we have provided to our patients for years and hope to continue providing the same care for more years to come.

From all of us at St. Michael's Medical Center we wish you all a beautiful and healthy Fall Season!!!



HemMobile® Striiv Wearable—

**GET THE MOST OUT OF ACTIVITY TRACKING**

 **HemMobile® App + Striiv Wearable**

 **TRACK ACTIVITY**

Track your heart rate, steps, distance, calories, and duration

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Photograph, map, and log each bleed

 **TRACK INFUSIONS**

Record the date, time, and location of every infusion

 **SHARE REPORTS**

Create consolidated reports to share with your treatment team

To begin tracking, the HemMobile® Striiv Wearable must be paired with the HemMobile® app.

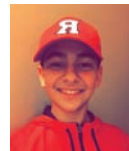


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## My Hemophilia Journey...

By Andrew Michael DiGiovanni

My name is Andrew Michael DiGiovanni. I am 15 years old and in the 10th grade. I love staying active and hanging out with my friends.

When I was a baby, my mom noticed that I was getting lots of bruises. She took me to the doctors who asked if anyone was hurting me or if she knew of anyone that would abuse me. The doctor even said that if I were to go to the hospital that they would call child protective services. My mom was very worried and took me back to the doctors for the 3rd time and insisted that I get blood work done. That's when I was diagnosed with Hemophilia B Severe. I was nine months old.

Hemophilia is a life threatening bleeding disorder in which I have no clotting factor, which means I can bleed spontaneously internally or externally. There is no cure for Hemophilia, but I am protected with the protein of Factor IX which I infuse intravenously directly into my veins. YES, I can inject myself. My Mom taught me how important it was for me to learn. So, I learned, and at the age of 5 years old, I actually did my 1st infusion!!! I'm so proud of that!

I have to be really careful. I have to watch my surroundings and make sure I am in safe locations. I don't like to be around large crowds. I am scared sometimes and have anxiety. Sometimes I get nervous when I get into a vehicle. When I do get hurt sometimes I have to go to the hospital, be in a wheelchair, crutches, braces, do physical therapy and most importantly make sure I do my Factor. It's extremely painful when I have a bleed. Sometimes I want to run away from all my problems. I have missed a lot of school. I have spent many days in the hospital. I have missed many parties and events that I should've have went to. It hurts me when other kids make fun of me or don't want

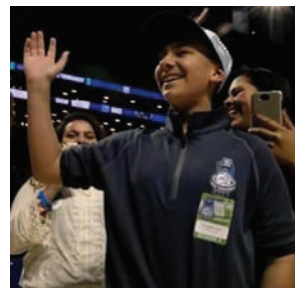
to play with me because they think I'm contagious or are afraid of me. Even Adults. I wish I could live a more normal life.

But I have Amazing news!!! I'm not alone!!! There are so many people who love me, care for me and support me. With the support of my Mom, Milinda, my sister, Gabriella, my Hemophilia family and friends I'm not alone. I have met so many friends in this Community through different organizations such as: The Hemophilia Association of New Jersey, The Coalition for Hemophilia B, Gut Monkey, Hole in the Wall Gang Camp, Double H Ranch, my treatment center and a few other organizations. I found many friends that go through the same thing I do and are there for me. When I'm with my Hemophilia family I feel free!! I'm loved and cared for. They are my family. I actually have too many friends now!!! Lol..

They helped me overcome many obstacles. I believe in myself and have more confidence. I'm not afraid anymore because I know I will always have my Hemophilia Family. All my troubles go away when I'm with my Hemophilia Family. I'm a new Me Now! I'm better, I'm stronger!, I'm more caring and more understanding to others feelings. I'm a kinder person because of the bond this Community has. I learned so much. I can do anything I really want to do because I believe in myself, my dreams, my future. I'm going out to the big world out there and be all I can be! I'm going to be me, Andrew Michael DiGiovanni.

I know this Community will always be here for me through all my journeys ahead. I couldn't do this on my own before, but I have this strong Community by my side with me now and forever!!!

Thank you all for your support. You changed my life forever.



# FACTOR REPLACEMENT REFLECTS THE PROTECTION WITHIN

*For people with hemophilia, Factor treatment temporarily replaces what's missing.<sup>1,2</sup> With a long track record of proven results, Factor treatment works with your body's natural blood clotting process to form a proper clot.<sup>2-6</sup>*

*Brought to you by Shire, dedicated to pursuing advancements in hemophilia for more than 70 years.<sup>7</sup>*

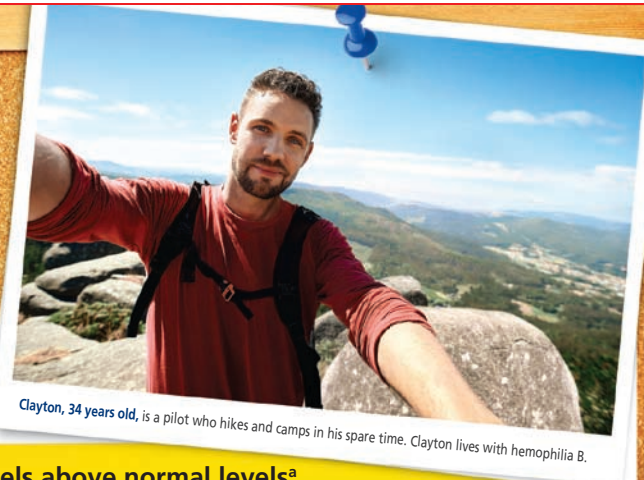
## Stay empowered by the possibilities.

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In hemophilia B  
**TAKE CONTROL TO A  
 HIGH LEVEL**  
 WITH REBINYN®

**NOW AVAILABLE**



Clayton, 34 years old, is a pilot who hikes and camps in his spare time. Clayton lives with hemophilia B.

Rebiny® elevates factor levels above normal levels<sup>a</sup>

**+94%** Factor IX (FIX) levels achieved immediately after an infusion<sup>b</sup>

**17%** FIX levels sustained after 7 days<sup>a</sup>

With a single dose of Rebiny® 40 IU/kg in adults with ≤2% FIX levels<sup>a</sup>

<sup>a</sup>In two phase 3 studies, factor levels were evaluated for 1 week after the first dose of Rebiny® 40 IU/kg. The average levels after 7 days were 16.8% in 6 adults, 14.6% in 3 adolescents, 10.9% in 13 children ages 7 to 12 years, and 8.4% in 12 children up to age 6 years.

<sup>b</sup>Based upon a 2.34% increase in factor levels per IU/kg infused in adults.

Image of hemophilia B patient shown is for illustrative purposes only.

**INDICATIONS AND USAGE**

**What is Rebiny® Coagulation Factor IX (Recombinant), GlycoPEGylated?**

Rebiny® is an injectable medicine used to replace clotting Factor IX that is missing in patients with hemophilia B. Rebiny® is used to treat and control bleeding in people with hemophilia B. Your healthcare provider may give you Rebiny® when you have surgery. Rebiny® is not used for routine prophylaxis or for immune tolerance therapy.

**IMPORTANT SAFETY INFORMATION**

**What is the most important information I need to know about Rebiny®?**

- Do not attempt to do an infusion yourself unless you have been taught how by your healthcare provider or hemophilia treatment center. Carefully follow your healthcare provider's instructions regarding the dose and schedule for infusing Rebiny®.

**Who should not use Rebiny®?**

Do not use Rebiny® if you:

- are allergic to Factor IX or any of the other ingredients of Rebiny®.
- are allergic to hamster proteins.

**What should I tell my health care provider before using Rebiny®?**

Tell your health care provider if you:

- have or have had any medical conditions.
- take any medicines, including non-prescription medicines and dietary supplements.
- are nursing, pregnant, or plan to become pregnant.
- have been told you have inhibitors to Factor IX.

**How should I use Rebiny®?**

- Rebiny® is given as an infusion into the vein.
- Call your healthcare provider right away if your bleeding does not stop after taking Rebiny®.
- Do not stop using Rebiny® without consulting your healthcare provider.

**What are the possible side effects of Rebiny®?**

- Common side effects include swelling, pain, rash or redness at the location of the infusion, and itching.
- Call your healthcare provider right away or get emergency treatment right away if you get any of the following signs of an allergic reaction: hives, chest tightness, wheezing, difficulty breathing, and/or swelling of the face.
- Tell your healthcare provider about any side effect that bothers you or that does not go away.
- Animals given repeat doses of Rebiny® showed Polyethylene Glycol (PEG) inside cells lining blood vessels in the choroid plexus, which makes the fluid that cushions the brain. The potential human implications of these animal tests are unknown.

**Please see Brief Summary of Prescribing Information on the following page.**

Rebiny® is a prescription medication.

You are encouraged to report negative side effects of prescription drugs to the FDA.

Visit [www.fda.gov/medwatch](http://www.fda.gov/medwatch), or call 1-800-FDA-1088.

**Learn more at [rebiny.com](http://rebiny.com)**



Novo Nordisk Inc., 800 Scudders Mill Road, Plainsboro, New Jersey 08536 U.S.A.

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**rebiny®**  
 Coagulation Factor IX  
 (Recombinant), GlycoPEGylated

**rebiny®**

Coagulation Factor IX  
 (Recombinant), GlycoPEGylated

**Brief Summary Information about:  
 REBINYN® Coagulation Factor IX  
 (Recombinant), GlycoPEGylated**

**Rx Only**

This information is not comprehensive.

- Talk to your healthcare provider or pharmacist
- Visit [www.novo-pi.com/REBINYN.pdf](http://www.novo-pi.com/REBINYN.pdf) to obtain FDA-approved product labeling
- Call 1-844-REB-INYN

**Read the Patient Product Information and the Instructions For Use that come with REBINYN® 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 REBINYN® after reading this information, ask your healthcare provider.

**What is the most important information I need to know about REBINYN®?**

Do not attempt to do an infusion yourself unless you have been taught how by your healthcare provider or hemophilia treatment center.

You must carefully follow your healthcare provider's instructions regarding the dose and schedule for infusing REBINYN® so that your treatment will work best for you.

**What is REBINYN®?**

REBINYN® is an injectable medicine used to replace clotting Factor IX that is missing in patients with hemophilia B. Hemophilia B is an inherited bleeding disorder in all age groups that prevents blood from clotting normally.

REBINYN® is used to treat and control bleeding in people with hemophilia B.

Your healthcare provider may give you REBINYN® when you have surgery.

REBINYN® is not used for routine prophylaxis or for immune tolerance therapy.

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- are allergic to Factor IX or any of the other ingredients of REBINYN®
  - if you are allergic to hamster proteins
- If you are not sure, talk to your healthcare provider before using this medicine.

Tell your healthcare provider if you are pregnant or nursing because REBINYN® might not be right for you.

**What should I tell my healthcare provider before I use REBINYN®?**

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 IX.

**How should I use REBINYN®?**

Treatment with REBINYN® should be started by a healthcare provider who is experienced in the care of patients with hemophilia B.

REBINYN® is given as an infusion into the vein.

You may infuse REBINYN® 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 B learn to

infuse the medicine by themselves or with the help of a family member.

Your healthcare provider will tell you how much REBINYN® to use based on your weight, the severity of your hemophilia B, and where you are bleeding. Your dose will be calculated in international units, IU.

**Call your healthcare provider right away if your bleeding does not stop after taking REBINYN®.**

If your bleeding is not adequately controlled, it could be due to the development of Factor IX inhibitors. This should be checked by your healthcare provider. You might need a higher dose of REBINYN® or even a different product to control bleeding. Do not increase the total dose of REBINYN® to control your bleeding without consulting your healthcare provider.

**Use in children**

REBINYN® can be used in children. Your healthcare provider will decide the dose of REBINYN® you will receive.

**If you forget to use REBINYN®**

If you forget a dose, infuse the missed dose when you discover the mistake. Do not infuse a double dose to make up for a forgotten dose. Proceed with the next infusions as scheduled and continue as advised by your healthcare provider.

**If you stop using REBINYN®**

Do not stop using REBINYN® 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 REBINYN®?**

Always take REBINYN® exactly as your healthcare provider has told you. You should check with your healthcare provider if you are not sure. If you infuse more REBINYN® than recommended, tell your healthcare provider as soon as possible.

**What are the possible side effects of REBINYN®?**

**Common Side Effects Include:**

- swelling, pain, rash or redness at the location of infusion
- itching

**Other Possible Side Effects:**

You could have an allergic reaction to coagulation Factor IX products. Call your healthcare provider right away if you get any of the following signs of an allergic reaction: hives, chest tightness, wheezing, difficulty breathing, and/or swelling of the face.

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

You may be at an increased risk of forming blood clots in your body, especially if you have risk factors for developing blood clots. Call your healthcare provider if you have chest pain, difficulty breathing, leg tenderness or swelling.

Animals given repeat doses of REBINYN® showed Polyethylene Glycol (PEG) inside cells lining blood vessels in the choroid plexus, which makes the fluid that cushions the brain. The potential human implications of these animal tests are unknown.

These are not all of the possible side effects from REBINYN®. 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.

**What are the REBINYN® dosage strengths?**

REBINYN® comes in three different dosage strengths. The actual number of international units (IU) of Factor IX in the vial will be imprinted on the label and on the box. The three different strengths are as follows:

Cap Color Indicator	Nominal Strength
Red	500 IU per vial
Green	1000 IU per vial
Yellow	2000 IU per vial

Always check the actual dosage strength printed on the label to make sure you are using the strength prescribed by your healthcare provider.

**How should I store REBINYN®?**

**Prior to Reconstitution** (mixing the dry powder in the vial with the diluent):

Store in original package in order to protect from light. Do not freeze REBINYN®.

REBINYN® vials can be stored in the refrigerator (36-46°F [2°C-8°C]) for up to 24 months until the expiration date, or at room temperature (up to 86°F [30°C]) for a single period not more than 6 months.

If you choose to store REBINYN® 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 be more than 6 months. Do not return the product to the refrigerator.
- Do not use after 6 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:**

The reconstituted (the final product once the powder is mixed with the diluent) REBINYN® should appear clear without visible particles.

The reconstituted REBINYN® should be used immediately.

If you cannot use the reconstituted REBINYN® immediately, it should be used within 4 hours when stored at or below 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 REBINYN® and hemophilia B?**

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

**More detailed information is available upon request.**

Available by prescription only.

For more information about REBINYN®, please call Novo Nordisk at 1-844-REB-INYN.

Revised: 11/2017

REBINYN® is a trademark of Novo Nordisk A/S.

For Patent Information, refer to: <http://novo nordisk-us.com/patients/products/product-patents.html>

Manufactured by:

Novo Nordisk A/S  
 Novo Allé, DK-2880 Bagsværd, Denmark

For information about REBINYN® contact:

Novo Nordisk Inc.  
 800 Scudders Mill Road  
 Plainsboro, NJ 08536, USA

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 USA17BI003951 12/2017



## Ask the Expert

Kim Isenberg  
Vice President, Policy and Advocacy,  
Hemophilia Federation of America (HFA)

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**Q: I'm hearing more and more about accumulator adjuster programs (AAPs). As we move into open enrollment this fall, how do I find out if my health insurance plan has an AAP?**

**A:** Accumulator adjuster programs are part of a strategy to drive patients to a generic drug in order to contain costs that pharmacy benefit managers (PBMs) are implementing around the country. AAPs are part of the benefit design that PBMs provide to health insurance plans, and apply to patients who use drug copay cards and other forms of manufacturer copay assistance. AAPs are still applied to patients who are prescribed specialty products such as clotting factor even though there are no generics available. Under an AAP, a PBM accepts the manufacturer copay assistance for out-of-pocket costs associated with a prescribed drug, but then *doesn't credit that amount toward the patient's overall deductible*. This means that patients with chronic and expensive disorders will still be required to personally pay deductibles, copays, and other out-of-pocket expenses up to the yearly out-of-pocket maximum, even as the health plan draws down the full amount of the copay card. This creates a huge financial burden for patients and their families.

So how do you find out if your health insurance plan has an AAP? Many employers provide a choice of health insurance plans during open enrollment. Prior to enrolling in your 2019 health insurance plan, review the policies for each plan offered and all plan documents. Make sure you have copies of the summary of benefits and coverage, drug formularies, and provider network. Most of this information is available online. Fully understand your options. Ask your HR department or call the insurance plan directly if you think you need more guidance or can't find information on AAPs in

**If you are experiencing a problem with Accumulator Adjuster Programs (AAPs) please contact the HANJ Office for assistance.**

your plan options—and keep pressing for clear answers. Note that there is no industry standard name for AAPs, and some plans use euphemistic titles such as “Out of Pocket Protection Program.” This can make it hard to detect an AAP in your plan. Finally, don't wait until the last minute to enroll. Start researching as early as you can.

Throughout your plan year, closely watch your Explanation of Benefits (EOB) notifications. You should be able to track whether the copay assistance payment is being applied to your deductible and/or out-of-pocket maximum. If your plan has an AAP, this means you'll be billed for your copay after your copay assistance is depleted. You may need to budget for that unanticipated out-of-pocket cost or seek additional financial assistance.

**Q: My health insurance plan is provided by my employer, so how can I find resources to help with the financial hardship an AAP creates?**

**A:** Before enrolling in your employer's health insurance plan, explore your options. For example, compare your employer's plan to your spouse's plan. Or find out if your state has a chronic disease assistance program that provides assistance with out-of-pocket costs.

AAPs can leave people who live with expensive chronic conditions, like bleeding disorders, with unanticipated barriers to treatment when an individual or a family can't pay the out-of-pocket cost. If this happens to you, check out the options in HFA's Resource Library: Navigating Patient Assistance Programs.<sup>1</sup> Or contact HFA directly at [advocacy@hemophiliafed.org](mailto:advocacy@hemophiliafed.org). You may also want to see if your specialty pharmacy provider can suggest any sources of assistance. A new patient assistance fund<sup>2</sup> may be able to help with expenses if you're faced with an AAP.

HFA and National Hemophilia Foundation (NHF) are working to educate health plans and PBMs about the dangers posed by AAPs. If you have received a letter from your employer or benefits manager stating that your copay cards will no longer be applied to your deductible, HFA needs to hear from you. Please share your story with Project CALLS.<sup>3</sup> Collecting data about these issues is the only way to fight them.

1. [www.hemophiliafed.org](http://www.hemophiliafed.org) (search “navigating patient assistance programs”).
2. [panfoundation.org/index.php/en/about-us/media-room/patient-access-network-foundation-opens-new-hemophilia-patient-assistance-fund](http://panfoundation.org/index.php/en/about-us/media-room/patient-access-network-foundation-opens-new-hemophilia-patient-assistance-fund) (accessed July 17, 2018).
3. [www.hemophiliafed.org](http://www.hemophiliafed.org) (search “Project CALLS”).

## Seasonal Affective Disorder

U.S. Depart. Of Health and Human Services,  
National Institute of Mental Health,  
<https://www.nimh.nih.gov/health/topics/seasonal-affective-disorder/index.shtml>

### Overview

Seasonal Affective Disorder (SAD) is a type of depression that comes and goes with the seasons, typically starting in the late fall and early winter and going away during the spring and summer. Depressive episodes linked to the summer can occur, but are much less common than winter episodes of SAD.

### Signs and Symptoms

Seasonal Affective Disorder (SAD) is not considered as a separate disorder. It is a type of depression displaying a recurring seasonal pattern. To be diagnosed with SAD, people must meet full criteria for major depression coinciding with specific seasons (appearing in the winter or summer months) for at least 2 years. Seasonal depressions must be much more frequent than any non-seasonal depressions.

### Symptoms of Major Depression

- Feeling depressed most of the day, nearly every day
- Feeling hopeless or worthless
- Having low energy
- Losing interest in activities you once enjoyed
- Having problems with sleep
- Experiencing changes in your appetite or weight
- Feeling sluggish or agitated
- Having difficulty concentrating
- Having frequent thoughts of death or suicide.

Symptoms of the Winter Pattern of SAD include:

- Having low energy
- Hypersomnia
- Overeating
- Weight gain
- Craving for carbohydrates
- Social withdrawal (feel like “hibernating”)

Symptoms of the less frequently occurring summer seasonal affective disorder include:

- Poor appetite with associated weight loss
- Insomnia
- Agitation
- Restlessness
- Anxiety
- Episodes of violent behavior

### Risk Factors

Attributes that may increase your risk of SAD include:

- **Being female.** SAD is diagnosed four times more often in women than men.
- **Living far from the equator.** SAD is more frequent in people who live far north or south of the equator. *For example, 1 percent of those who live in Florida and 9 percent of those who live in New England or Alaska suffer from SAD.*
- **Family history.** People with a family history of other types of depression are more likely to develop SAD than people who do not have a family history of depression.
- **Having depression or bipolar disorder.** The symptoms of depression may worsen with seasons if you have one of these conditions (but SAD is diagnosed only if seasonal depressions are the most common).



- **Younger Age.** Younger adults have a higher risk of SAD than older adults. SAD has been reported even in children and teens.

The causes of SAD are unknown, but research has found some biological clues:

- **People with SAD may have trouble regulating one of the key neurotransmitters involved in mood, serotonin.** One study found that people with SAD have 5 percent more serotonin transporter protein in winter months than summer months. Higher serotonin transporter protein leaves less serotonin available at the synapse because the function of the transporter is to recycle neurotransmitter back into the pre-synaptic neuron.
- **People with SAD may overproduce the hormone melatonin.** Darkness increases production of melatonin, which regulates sleep. As winter days become shorter, melatonin production increases, leaving people with SAD to feel sleepier and more lethargic, often with delayed circadian rhythms.
- **People with SAD also may produce less Vitamin D.** Vitamin D is believed to play a role in serotonin activity. Vitamin D insufficiency may be associated with clinically significant depression symptoms.

#### Treatments and Therapies

There are four major types of treatment for SAD:

- Medication
- Light therapy
- Psychotherapy
- Vitamin D

These may be used alone or in combination.

#### Medication

Selective Serotonin Reuptake Inhibitors (SSRIs) are used to treat SAD. The FDA has also approved the use of bupropion, another type of antidepressant, for treating SAD.

As with other medications, there are side effects to SSRIs. Talk to your doctor about the possible risks of using this medication for your condition. You may need to try several different antidepressant medications before finding the one

that improves your symptoms without causing problematic side effects. For basic information about SSRIs and other mental health medications, visit NIMH's Medications webpage. Check the FDA's website for the latest information on warnings, patient medication guides, or newly approved medications.

#### Light Therapy

Light therapy has been a mainstay of treatment for SAD since the 1980s. The idea behind light therapy is to replace the diminished sunshine of the fall and winter months using daily exposure to bright, artificial light. Symptoms of SAD may be relieved by sitting in front of a light box first thing in the morning, on a daily basis from the early fall until spring. Most typically, light boxes filter out the ultraviolet rays and require 20-60 minutes of exposure to 10,000 lux of cool-white fluorescent light, an amount that is about 20 times greater than ordinary indoor lighting.

#### Psychotherapy

Cognitive behavioral therapy (CBT) is type of psychotherapy that is effective for SAD. Traditional cognitive behavioral therapy has been adapted for use with SAD (CBT-SAD). CBT-SAD relies on basic techniques of CBT such as identifying negative thoughts and replacing them with more positive thoughts along with a technique called behavioral activation. Behavioral activation seeks to help the person identify activities that are engaging and pleasurable, whether indoors or outdoors, to improve coping with winter.

#### Vitamin D

At present, vitamin D supplementation by itself is not regarded as an effective SAD treatment. The reason behind its use is that low blood levels of vitamin D were found in people with SAD. The low levels are usually due to insufficient dietary intake or insufficient exposure to sunshine. However, the evidence for its use has been mixed. While some studies suggest vitamin D supplementation may be as effective as light therapy, others found vitamin D had no effect. ●

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## Hemophilia Association of New Jersey **FALL** Educational Symposium

Our Association held its Fall Educational Symposium on September 13, 2018 at The Madison Hotel in Morristown, NJ. We encourage our members to attend our Educational Symposia to learn more about important topics affecting their life with a bleeding disorder and to meet and network with others in the community.

Miriam Goldstein, Association Director of Policy for the Hemophilia Federation of America (HFA), presented "Can I get a Witness? Legal Rights for Bleeding Disorders" and Clarissa Robles, Senior Community Specialist for WellCare Health Plans of New Jersey presented "Everything you need to know about New Jersey Family Care". Both presentations were a hit!

We encourage members to submit topics of interest you would be interested in learning about. Please feel free to contact us with your suggestions.



# MONEY SENSE

## Planning for Health Care Costs

*Discussing worst-case scenarios with family is never easy. These tips from Merrill Lynch Wealth Management outline four conversations every family should have right now.*

"When my mom and dad started having health problems about a decade ago, my wife, Maddy, and I said, 'Do we want to have a discussion about our own long-term care?'" recalls Dr. Ken Dychtwald. "And we both realized we did not want to talk about it, because it is a horrible discussion to have. You know—what happens if you have a stroke, or you can no longer walk?"

Not even experts in the field of aging, like Dychtwald and his wife, Maddy, co-founders of Age Wave, an organization that studies the challenges of aging, want to think about frightening health-related "what-ifs" when it comes to their personal lives.

"My generation—the boomers—prefer to think of ourselves as indestructible," Dychtwald says. "But, you know what? We said to ourselves, 'It is not fair to either of us or our kids not to have this discussion.'" So the Dychtwalds did their homework. "We made some important decisions. For one, we decided to buy long-term-care insurance."

Talking about how you will pay for your future health needs is just one of several critical conversations related to health and wealth that family members should be having. "For many, it is the missing piece of the retirement puzzle," says Dychtwald.

Yet as important as these conversations are, the vast majority of people are not having them. Seven out of 10 couples age 50 and older have not discussed how much they will need to save for health care in retirement; and only one in five people age 50+ has talked about long-term-care plans with their adult children, according to a 2015 Merrill Lynch study conducted in partnership with Age Wave.

Here are four questions that can help you start having these important family conversations. Sit down with your spouse, your children, your parents and your siblings. Talk about your expectations. Make plans together. Then, should one of you become ill, you can all concentrate on one another instead of worrying about the finances and whether you are doing the right thing for everyone concerned.

### 1. Where will the money come from?

It is never too early to talk about the potential costs and other consequences of medical care for yourself, your children or your parents. The considerations should include possible outlays for such expenses as home health care or changes to your house to accommodate a disability.

"Once Maddy and I had our talk, we felt better," Dychtwald says. "We may not be able to wave a magic wand and make ourselves perfectly healthy for the rest of our lives, but at least we know that we are covered should one of these things happen to either of us."

Though long-term-care insurance was an appropriate choice for the Dychtwalds, it is not right for everyone. There are a

number of other financial choices you can consider, from hybrid forms of life insurance and Health Savings Accounts to simply saving and investing more for eventual medical costs.

A logical next step, after you discuss these issues with your family, is to review your choices with a financial advisor to help ensure that your retirement and any legacy you hope to pass on will not be threatened.

### 2. Will our parents have the care they need as they grow older?

In addition to considering their own future, many people struggle with aging parents' unwillingness to face their limitations. The best response is to ask specific questions: At what point would it make sense for you to stop driving, or to have a caretaker come in to help with meals?

Cynthia Hutchins, director of Financial Gerontology at Bank of America Merrill Lynch, advises bringing these issues up long before safety concerns arise, and then positioning yourself as your loved ones' ally.

"Often when you first broach the topic, you will be rebuffed," says Kate Wilber, professor of gerontology at the University of Southern California Davis School of Gerontology. "That is normal. It does not mean the door is closed. This will likely take more than one conversation."

### 3. Who will provide the caregiving, if it is needed?

Taking care of aging parents—or paying for their care—can be a large responsibility, and yet it is a responsibility that often falls unevenly in families.

Hutchins recommends that siblings talk first among themselves about how they

will share the caregiving role. "You want to be sure that both your parents' and your own needs are considered," she says. "Sometimes it makes sense to cobble together a combination of in-home and outside care." That way, siblings can at least share the costs, if not the hands-on responsibilities.

### 4. What about end-of-life issues?

Having this conversation can help ensure that a loved one's (or your own) wishes will be honored. Among the things to consider: Which medical treatments do you want to be used or avoided at the end of your life? Whom do you want to be your health-care proxy if you are unable to communicate your wishes? You can use a health-care power of attorney and a living will to document your choices.

Once you have discussed these tough subjects with your family, it is important to keep talking as years go by and circumstances change. "No one can predict their health future," Dychtwald says. "But you can put plans in place to help prepare yourself for what might come."

Having these important conversations is the first step to getting there.

**For more information, contact your Merrill Lynch Financial Advisor Cono T. Spinelli of the Paramus, N.J. office at 201.967.2730 or [cono\\_spinelli@ml.com](mailto:cono_spinelli@ml.com).**

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## Hemophilia Association of New Jersey 2018 Fall Educational Symposium Exhibitors

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**We would like to Thank all the Exhibitors at our  
Fall Educational Symposium this year.  
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**Wednesday - December 5th, 2018 6:30pm**

Seasons 52: 217 Lafayette Ave, Edison, NJ

Hemophilia Association of New Jersey

RSVP: [chansen561@comcast.net](mailto:chansen561@comcast.net) or 732-249-6000

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# Blood Brotherhood For Adult Men with Hemophilia



The NJ Blood Brotherhood program holds free events for men with bleeding disorders. This group is open to anyone over the age of 21 who has a bleeding disorder. Each of our events incorporates a bit of education, socializing and a physical activity, but we typically use the time to get to know other guys in the community. The events are completely free and there is no commitment to attend every event.

If you'd like to join the Blood Brotherhood group and attend one of our events, please reach out to Joe Markowitz (Joe.Markowitz@gmail.com, 201-650-0335) or Peter Marciano (petermarcano@gmail.com, 201-401-7080) or HANJ directly.

HANJ has partnered with the Hemophilia Federation of America (HFA) to offer the Blood Brotherhood program. Blood Brotherhood is a men's group open to adult men (21+) with bleeding disorders. The purpose of this group is to provide an opportunity for older men with bleeding disorders to connect with their peers in a fun, relaxed setting. There is NO COST to attend any Blood Brotherhood event and once you sign up, there is no obligation to attend every event.

## DONATE! DONATE! DONATE!

Please show your support by donating to The Hemophilia Association of New Jersey. Every single dollar counts!

Your donations go towards providing crucial programs to support persons with hemophilia in New Jersey.

Please make your check out to The Hemophilia Association of New Jersey or HANJ. We are a non-profit 501(c) organization. You will receive a receipt when we receive your donation for tax purposes.

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Amount of Donation: \_\_\_\_\_

You can always donate on our website at [www.hanj.org](http://www.hanj.org)  
Thank You! Your Donations Make A Big Difference!

### A ONCE-WEEKLY SUBCUTANEOUS (GIVEN UNDER THE SKIN) INJECTION FOR PEOPLE WITH HEMOPHILIA A WITH FACTOR VIII INHIBITORS

We extend our appreciation to the individuals, families, and healthcare providers who participated in the clinical trials that led to the approval of HEMLIBRA®. We thank you and celebrate with the community who made it a reality.

Discover [HEMLIBRA.com](http://HEMLIBRA.com)

#### WHAT IS HEMLIBRA?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children with hemophilia A with factor VIII inhibitors.

#### WHAT IS THE MOST IMPORTANT INFORMATION I SHOULD KNOW ABOUT HEMLIBRA?

HEMLIBRA increases the potential for your blood to clot. Discontinue prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent, and the dose and schedule you should use.

HEMLIBRA may cause the following serious side effects when used with aPCC (FEIBA®), including:

- **Thrombotic microangiopathy (TMA).** This is a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs. Get medical help right away if you have any of the signs and symptoms of TMA during or after treatment with HEMLIBRA.
- **Blood clots (thrombotic events).** Blood clots may form in blood vessels in your arm, leg, lung or head. Get medical help right away if you have any of the signs or symptoms of blood clots during or after treatment with HEMLIBRA.

If aPCC (FEIBA®) is needed, talk to your healthcare provider in case you feel you need more than 100 U/kg of aPCC (FEIBA®) total.



#### HOW SHOULD I USE HEMLIBRA?

See the detailed "Instructions for Use" that comes with your HEMLIBRA for information on how to prepare and inject a dose of HEMLIBRA, and how to properly throw away (dispose of) used needles and syringes.

HEMLIBRA may interfere with laboratory tests that measure how well your blood is clotting and may cause a false reading. Talk to your healthcare provider about how this may affect your care.

#### WHAT ARE THE OTHER POSSIBLE SIDE EFFECTS OF HEMLIBRA?

**The most common side effects of HEMLIBRA include:** redness, tenderness, warmth, or itching at the site of injection; headache; and joint pain. These are not all of the possible side effects of HEMLIBRA.

You may report side effects to the FDA at (800) FDA-1088 or [www.fda.gov/medwatch](http://www.fda.gov/medwatch). You may also report side effects to Genentech at (888) 835-2555.

Please see Brief Summary of Medication Guide on the following page for more important safety information, including **Serious Side Effects**.

#### Medication Guide Brief Summary HEMLIBRA® (hem-lee-bruh) (emicizumab-kxwh) injection, for subcutaneous use

#### WHAT IS THE MOST IMPORTANT INFORMATION I SHOULD KNOW ABOUT HEMLIBRA?

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- **Thrombotic microangiopathy (TMA).** This is a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs. Get medical help right away if you have any of the following signs or symptoms during or after treatment with HEMLIBRA:
  - confusion
  - weakness
  - swelling of arms and legs
  - yellowing of skin and eyes
  - stomach (abdomen) or back pain
  - nausea or vomiting
  - feeling sick
  - decreased urination
- **Blood clots (thrombotic events).** Blood clots may form in blood vessels in your arm, leg, lung or head. Get medical help right away if you have any of these signs or symptoms of blood clots during or after treatment with HEMLIBRA:
  - swelling in arms or legs
  - pain or redness in your arms or legs
  - shortness of breath
  - chest pain or tightness
  - fast heart rate
  - cough up blood
  - feel faint
  - headache
  - numbness in your face
  - eye pain or swelling
  - trouble seeing

**If aPCC (FEIBA®) is needed, talk to your healthcare provider in case you feel you need more than 100 U/kg of aPCC (FEIBA®) total.**

See "What are the possible side effects of HEMLIBRA?" for more information about side effects.

#### WHAT IS HEMLIBRA?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children with hemophilia A with factor VIII inhibitors.

- Hemophilia A is a bleeding condition people can be born with where a missing or faulty blood clotting factor (factor VIII) prevents blood from clotting normally.
- HEMLIBRA is a therapeutic antibody that bridges clotting factors to help your blood clot.

#### BEFORE USING HEMLIBRA, TELL YOUR HEALTHCARE PROVIDER ABOUT ALL OF YOUR MEDICAL CONDITIONS, INCLUDING IF YOU:

- are pregnant or plan to become pregnant. It is not known if HEMLIBRA may harm your unborn baby. Females who are able to become pregnant should use birth control (contraception) during treatment with HEMLIBRA.
- are breastfeeding or plan to breastfeed. It is not known if HEMLIBRA passes into your breast milk.

**Tell your healthcare provider about all the medicines you take,** including prescription medicines, over-the-counter medicines, vitamins, or herbal supplements. Keep a list of them to show your healthcare provider and pharmacist when you get a new medicine.

#### HOW SHOULD I USE HEMLIBRA?

**See the detailed "Instructions for Use" that comes with your HEMLIBRA for information on how to prepare and inject a dose of HEMLIBRA, and how to properly throw away (dispose of) used needles and syringes.**

- Use HEMLIBRA exactly as prescribed by your healthcare provider.
- HEMLIBRA is given as an injection under your skin (subcutaneous injection) by you or a caregiver.
- Your healthcare provider should show you or your caregiver how to prepare, measure, and inject your dose of HEMLIBRA before you inject yourself for the first time.

- Do not attempt to inject yourself or another person unless you have been taught how to do so by a healthcare provider.
- Your healthcare provider will prescribe your dose based on your weight. If your weight changes, tell your healthcare provider.
- If you miss a dose of HEMLIBRA on your scheduled day, you should give the dose as soon as you remember. You must give the missed dose before the next scheduled dosing day and then continue with your normal weekly dosing schedule. Do not double your dose to make up for a missed dose.
- HEMLIBRA may interfere with laboratory tests that measure how well your blood is clotting and may cause a false reading. Talk to your healthcare provider about how this may affect your care.

#### WHAT ARE THE POSSIBLE SIDE EFFECTS OF HEMLIBRA?

- See "What is the most important information I should know about HEMLIBRA?"

#### The most common side effects of HEMLIBRA include:

- redness, tenderness, warmth, or itching at the site of injection
- headache
- joint pain

These are not all of the possible side effects of HEMLIBRA.

Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

#### HOW SHOULD I STORE HEMLIBRA?

- Store HEMLIBRA in the refrigerator at 36°F to 46°F (2°C to 8°C). Do not freeze.
- Store HEMLIBRA in the original carton to protect the vials from light.
- Do not shake HEMLIBRA.
- If needed, unopened vials of HEMLIBRA can be stored out of the refrigerator and then returned to the refrigerator. HEMLIBRA should not be stored out of the refrigerator for more than 7 days at 86°F (30°C) or below.
- After HEMLIBRA is transferred from the vial to the syringe, HEMLIBRA should be used right away.
- Throw away (dispose of) any unused HEMLIBRA left in the vial.

**Keep HEMLIBRA and all medicines out of the reach of children.**

#### GENERAL INFORMATION ABOUT THE SAFE AND EFFECTIVE USE OF HEMLIBRA.

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use HEMLIBRA for a condition for which it was not prescribed. Do not give HEMLIBRA to other people, even if they have the same symptoms that you have. It may harm them. You can ask your pharmacist or healthcare provider for information about HEMLIBRA that is written for health professionals.

#### WHAT ARE THE INGREDIENTS IN HEMLIBRA?

**Active ingredient:** emicizumab

**Inactive ingredients:** L-arginine, L-histidine, poloxamer 188, and L-aspartic acid.

Manufactured by: Genentech, Inc., A Member of the Roche Group,  
1 DNA Way, South San Francisco, CA 94080-4990  
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For more information, go to [www.HEMLIBRA.com](http://www.HEMLIBRA.com) or call 1-866-HEMLIBRA.  
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# **SUPER BOWL LIII**



## **RAFFLE**



**\$20.00 per ticket**

**Drawing to be held on January 13, 2019 at 7pm.  
Miller's Woodbridge Ale House  
350 US Highway 9 North, Woodbridge, NJ 07095  
(You do not have to be present to win.)**

### **Grand Prize\***

**2 TICKETS TO SUPER BOWL LIII  
FEBRUARY 3, 2019**

**5 DAYS/4 NIGHTS HOTEL  
ACCOMMODATIONS FOR TWO**

**ROUND TRIP AIRFARE FOR TWO to ATLANTA, GA  
(\*ALL OTHER EXPENSES ARE RESPONSIBILITY OF THE WINNER)**

### **Second Prize**

**GIFT CERTIFICATE FROM BEST BUY  
(Value \$500)**

**Proceeds go to:**

**Hemophilia Association of New Jersey  
197 Route 18 South, Suite 206 North  
East Brunswick, NJ 08816**