

HFMD MISSION

To meet the needs and to enhance the quality of life for persons living with hemophilia, related inherited bleeding disorders and their complications

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Magic, Music, and Important Information HFMD Annual Meeting 2018

HFMD Members, Families, HTC Caregivers, and Sponsors came together on April 20th & 21st to share stories, hear riveting speakers, and have some fun with our Friday evening activities at the airport Marriott in Bloomington, MN.

Our event began with a taco buffet and entertaining performance from Magician Tom Anderson and his daughter Nicole. Children and parents were on the edge of their seats as Tom dazzled our group with some impressive magic acts so slight of hand. There were no shortage of child and adult volunteers to come up on stage to participate in some of Tom's hijinx.

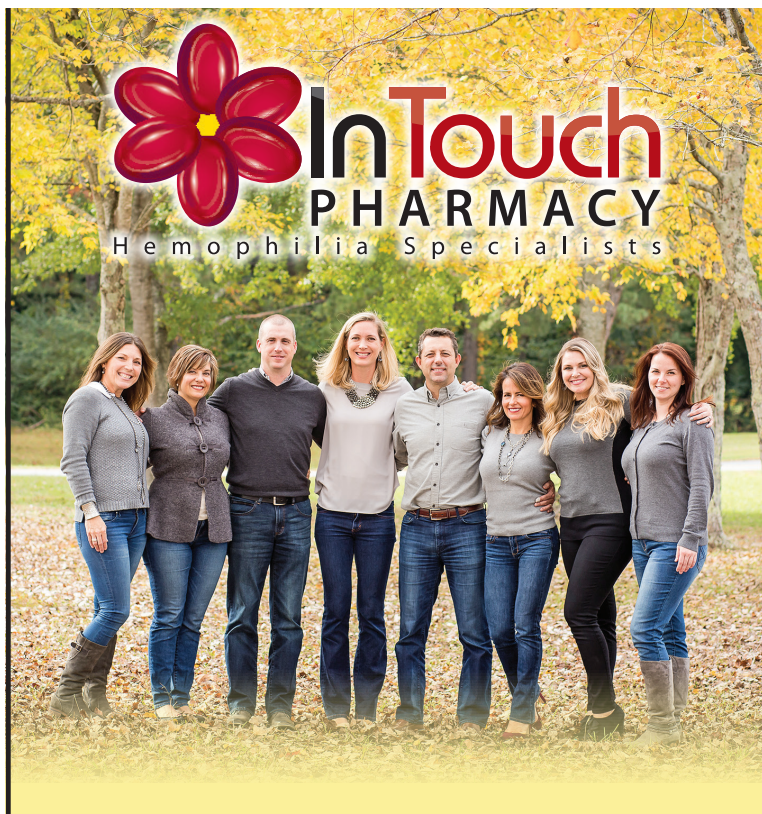
Next, it was time for our musical chairs Cakewalk led by Nathan Anderson, MSW Sanford Children's who share his wit and many costumes as the emcee. Controlled chaos

could be one description of what ensued once the music started and stopped each time. The last member (child or adult) standing in our 3 rings of chairs each won a DQ or other cake gift certificate. It was both fun and exhausting; just to watch. Our group, especially the kids really enjoyed this classic game for groups.

While the cakewalk was in full swing, we hosted a special wine and cheese reception for Women with bleeding disorders, and carriers. Sue Curoe, RN, University of MN Health led the call for the purse bingo, which also featured announcements from Sonji Wilkes of HFA who shared updates on the Blood Sisterhood program. Kerry Budinger of HFMD did a super job in organizing this very special reception. We were told by many of the attendees it was well received and hope we do it again next year.

Saturday morning opened at 8:00 a.m. with a hearty breakfast and time to visit all of our exhibitor booths. Jim Paist led off the programming with a look back on the past year for HFMD with emphasis on all of our public policy advocacy efforts. It was another busy year with strong member turnout at so many of our events; including at the state Capitol on March 22nd Bleeding Disorders Awareness Day, Minnesota.

Then it was time for our keynote speaker; HFMD Board Member and Board President of BDAND (Bleeding Disorders Alliance of North Dakota). Carson spoke of his experience being involved with HFMD since he was a young child and how he has embraced his hemophilia his entire life. He shared stories and pictures with his wife Emily and of his work in the US Senate office of Tina Smith. Carson's presentation was informative and uplifting. We are so proud of Carson!



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Then Dr. Susan Kearny, and Nicole Hart, RN took the stage to share their amazing experience in going to Ethiopia earlier in the year as a critical part of the Twinning Project Children's HTC has embarked upon to help establish and strengthen the Hemophilia Clinic in Addis Ababa Ethiopia where they lack so many resources and funding to treat their patient population. They surely do their best to treat patients with what little resources they have. The WFH is doing so much in sponsoring Twinning Projects like this in third world countries.

Jennifer Lissick, Pharm D presented important information and facts about the unsettled landscape of health

insurance today in Minnesota and nationwide. She shared helpful information in how our members can maintain the best healthcare available for their families.



During lunch, we had a Blood Brotherhood session (sponsored by HFA) where Mike Zlotniwiski, PT shared strategies in good health and strength training with 14 of our Blood Brothers who attended the annual meeting. While all of these education session are happening Saturday, Vicki Neis Child Life Program Manager from Children's and her team held another fantastic all-day program for over 50 of our kids. Vicki's theme was Ethiopia as she and her Team presented information about the country and its culture. The kids got to feel desert sand, make straw huts, and wooden drums. We extend a special thanks to Craig Looney and NC-HS Specialty Care for hosting the drum making workshop. These drums are very cool and compact with a distinct sound that the kids truly enjoyed making with them. We are so fortunate to have Vicki Neis and her talented child-life programming team who take such care of our children with an amazing blend of learning and fun.

We then featured 3 very important afternoon breakout sessions:

Opioid Addiction Panel led by HFMD member Jeff Kunkel & Georgia Panopoulos, PhD. Attendees in this session were truly moved in hearing Jeff's personal story, while Dr. Panopoulos focused on non-medication alternative therapies to deal with pain.

We had a break-out session for Women with Bleeding Disorders "In the Driver's Seat of Your Health" led by Sonji Wilks of HFA.

We also featured a session on Concussions in youth sports led by expert Katie Slifco, RN.

The final general session of our Annual Meeting was the ever-popular Ask the Provider Panel Featuring Dr. Mark Reding, Dr. Susan Kearny, and Jennifer Lissick, Pharm D. We had just over 200 attendees on Saturday. HFMD appreciates the effort from all of our presenters.

This event was all made possible by our generous sponsors:

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Opioid Addiction Session

I had the honor of attending an excellent break out session at the HFMD Annual Meeting on April 21, 2018.

The topic was Opioid Addiction. Jeff Kunkel, a member of the hemophilia community with severe Hemophilia, bravely told his story. As with many men with Hemophilia, Jeff shared his history of painful joints from bleeds and chronic damage. He was able to easily, and legitimately, get pain medication prescribed when he experienced flares of pain. Over time his use of these meds increased and his attempts to get these medications changed. He ended up abusing narcotics and ultimately was using heroin. His family was present at the session and spoke of their challenges of trying to support him in his pain but also not enable his addictive behaviors.

There were tears in Jeff's eyes as he spoke. There were tears in the audience as we listened. Tears of empathy and tears from those undergoing the same struggles. And there were shout-outs of support for Jeff and his telling of his story. Jeff eloquently said, "I hit rock bottom, but did not realize that rock bottom had a basement."

Through much effort and strength, Jeff is now sober, and working daily to keep that sobriety. He spoke of needing to make his sobriety his first focus each day, then his relationship with God, then his family. He said that if he is not sober, and right with his higher power, he cannot be the devoted husband, father, and son that he needs to be.



The session was to include presentations by Dr. Georgia Panopoulos, a health psychologist who has worked for many years with people with chronic pain, including many members of the hemophilia community. She has also been involved at the national level as a speaker at the inhibitor summits. She was prepared to present further information but the people gathered were hungry to hear more details of Jeff's story. Jeff suggested that we should talk about this topic at every annual meeting and it certainly seems timely with the national push to reduce opioid addiction.

We look forward to hearing more from Jeff and Georgia in the future. Thanks to both of them for an excellent session!

By Vicky Hannemann, RN, BSN Nurse Clinician

NHF's Chapter Leadership Seminar in San Francisco

HFMD's Administrative Assistant, Kerry Budinger, spent 4 days in San Francisco in April to attend the National Hemophilia Foundation's (NHF) Chapter Leadership Seminar. The Seminar kicked off with a general assembly of staff from 51 Chapters from around the United States. Staff gathered for an overview of the programs and services NHF offers to assist Chapters with goals and challenges they face with programming and fundraising in their home states.

For the next two and a half days the group broke into smaller session where a number of programming and service topics were explored and discussed. These

included disaster planning, social media outreach, and cultural guidance.

At the end of each day there was some time to explore the sites that San Francisco has to offer, because you can't visit this city by the bay without seeing the Painted Ladies, riding a street car, visiting the Golden Gate Bridge, and of course visiting Alcatraz. All-in-all it was a fun and informative seminar.

By Kerry Budinger.



*Photos by Kerry Budinger:
Painted Ladies, top right.
Golden Gate Bridge,
center. Trolley, right top.*



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St. Paul Saints Baseball in Full Swing

The HFMD partnered with CSL Behring on June 24th at CHS Field to host a group education outing at a baseball game. The keynote speaker was Jessie Schrader, a former minor-league baseball pitcher who happens to have hemophilia.

Our event began one hour before the first pitch with our group of 46 huddled together to hear Jessie's story. Kids and their parents listened closely as Jessie spoke of his love for playing baseball, and overcoming an occasional bleed. Jessie would not let his bleeding disorder dissuade him from advancing to the professional level of baseball.

Jessie's story was exciting and inspirational! He then signed a new baseball for every one of our attendees, before the game began between the Saints and the Winnipeg Golden-Eyes. HFMD would like to thank Jason Clarin, Lori Kunkel, Mark Wiener, and CSL Behring for sponsoring, planning, and co-hosting such fun family event.



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A Community Education Program with Sides of Salsa

HFMD partnered with Shire and Richa Sastry on May 17th to co-host a Hello Talk program entitled Journey of Factor, presented by April Litrell. This was a fascinating presentation with some excellent visuals of how blood-clotting factor works inside of our bodies. April answered a number of thoughtful questions from our group. The event was held at the Rojo Mexican Restaurant in the Southdale mall, Edina. *Thank you Shire!*

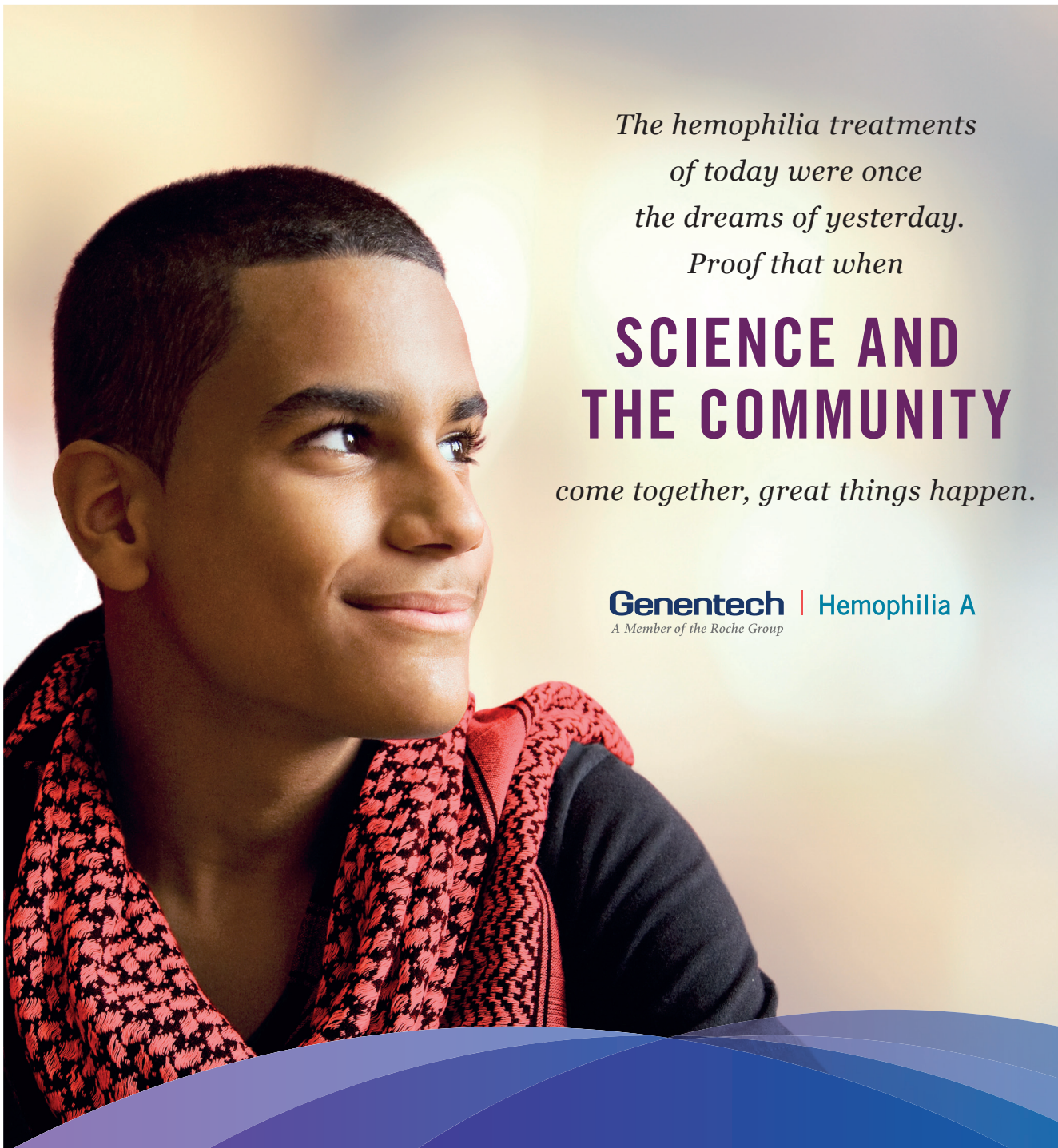


Post-Secondary Scholarships Awarded for 2018-2019 School Year

This year HFMD received a number of wonderful candidate applications for the HFMD Post-Secondary Scholarship Awards. In total six scholarship recipients were awarded \$1,666 each to assist with tuition expenses for the 2018-2019 school year at the college or vocational school they attend.

HFMD awards scholarships annually. Please note, the amount awarded varies with the number of eligible applicants.

Congrats! 



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These are donations received from January 1, 2018 through June 30, 2018.

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Current Calendar of Events

July 8-13, 2018	HFMD Summer Hemophilia Camp Camp Courage North, Lake George, MN
July 28, 2018	South Dakota Summer Event (For SD Patients) Wild Water West Waterpark, Sioux Falls, SD
August 5, 2018	Annual Walk Fundraiser Como Park, St. Paul, MN
August 19, 2018	Blood Brotherhood and Blood Sisterhood Twins Game Target Field, Minneapolis, MN
August 25, 2018	Saint Croix River Boat Cruise Hudson, WI
October 6, 2018	Women's Education Event The Machine Shed, Lake Elmo, MN
October 11-13, 2018	70th Annual NHF Bleeding Disorders Conference Orlando World Center Marriott, Orlando, FL

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

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

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

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(Recombinant), GlycoPEGylated

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Coagulation Factor IX (Recombinant), GlycoPEGylated

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

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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.

Who should not use REBINYN®?

You should not use REBINYN® if you

- 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 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.

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://novonordisk-us.com/patients/products/product-patents.html>

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THE HEMOPHILIA
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