

THE VESSEL

SUMMER 2020



A Letter from the President

Dear BDA Community,

We miss you all and our great community. This pandemic has been tough on all of us and has affected almost every part of our lives. Although some things may be reopening, and some sense of normalcy, we are still in a very tough position. Our goal is to get back to our fun, in person events, but we also want to be safe in all that we do.

We trust that day will come, but for now we will continue to find ways to connect virtually and safely...



Message continued on page 2

Michael Deeb, President

ENTER TO WIN A GIFTCARD!

Visit us on our website to take a survey www.bdaneny.org



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LETTER FROM THE PRESIDENT

We know this has been and continues to be a particularly challenging time for all. If there is any way the BDANENY can help, please do not hesitate to reach out.

Remember we will always stand by our motto, 'We Are Here For You.' With the future unknown, we want to make sure we can serve you all in the best way possible. If you have any ideas for our organization moving forward or would like to help in any capacity, please let us know. We will get through this together and continue to bring any support needed to our community. Please stay connected and remain strong.

Sincerely
Michael Deeb
President

Meet our Operations Manager

Patricia Bengraff has taken an expanded role in our organization as Operations Manager. Initially hired for bookkeeping services in November 2017 with her extensive experience and knowledge of QuickBooks software, she also has applied her office and project management skills to pitch in when needed!



Patricia Bengraff,
Operations Manager

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Jivi[®] Extension Study

Explore the study design and see the safety and efficacy data from patients who were part of the study.

► Dive in at [JiviExtensionStudy.com](https://www.JiviExtensionStudy.com)



GETTING IN THE GAME



A message from our sponsor-

We are excited to launch our Junior National Championship (JNC) summer video series! Today, we provide you with the first in a series of three instructional videos featuring Gettin' in the Game

Athlete Perry Parker, Professional Golfer living with Hemophilia A.

Every summer for the past 20 years, we at CSL Behring work hard to prepare for our annual Gettin' in the Game JNC, an annual event sponsored by CSL Behring to promote the health and well-being of patients who have a bleeding disorder. This year, faced with the challenges of a global pandemic due to COVID-19 and the need to social distance to slow down the spread of the virus, we have made the difficult decision to postpone the 2020 JNC. So, this summer, we decided to use this opportunity to

provide a different kind resource to families within the bleeding disorders community. We designed this series of instructional videos with everyone in mind, all ages and skill levels.

We hope that you share these videos with the members of your chapter so that everyone can learn some new skills from Perry Parker, and be inspired to stay active this summer.

To learn more please visit: csljnc.com

Sincerely,

Jessica Graham, Community Support Liaison
on behalf of CSL Behring



Golf Instruction - Stretching is Key

<https://www.youtube.com/watch?v=B5h0-OZVZ0c>

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

17% Factor IX (FIX) levels sustained after 7 days with a single 40 IU/kg dose in adults with $\leq 2\%$ factor levels^a



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

^aIn two phase 3 studies, factor levels were evaluated for 1 week after the first dose of Rebinyn® 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.

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

INDICATIONS AND USAGE

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

Rebinyn® is an injectable medicine used to replace clotting Factor IX that is missing in patients with hemophilia B. 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.

IMPORTANT SAFETY INFORMATION

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. Carefully follow your healthcare provider's instructions regarding the dose and schedule for infusing Rebinyn®.

Who should not use Rebinyn®?

Do not use Rebinyn® if you:

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

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

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 Rebinyn®?

- Rebinyn® is given as an infusion into the vein.

- Call your healthcare provider right away if your bleeding does not stop after taking Rebinyn®.

- Do not stop using Rebinyn® without consulting your healthcare provider.

What are the possible side effects of Rebinyn®?

- 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 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.

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

Rebinyn® is a prescription medication.

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.

Learn more at
rebinyn.com



Novo Nordisk Inc., 800 Scudders Mill Road, Plainsboro, New Jersey 08536 U.S.A.
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rebinyn®
Coagulation Factor IX
(Recombinant), GlycoPEGylated

MEET OUR OPERATIONS MANAGER (Continued)



Patricia Bengraff,
Operations Manager

Patricia Bengraff has taken an expanded role in our organization as Operations Manager. Initially hired for bookkeeping services in November 2017 with her extensive experience and knowledge of QuickBooks software, she also has applied her office and project management skills to pitch in when needed.

“I sincerely appreciate the many accolades I have received and grateful for the confidence the Board has placed in my

abilities. I look forward to participating in the continued effort to not only maintain but grow this essential organization. It will be an honor for me to lend my time and abilities to help BDA continue to make a difference in the community and the lives of the families that rely on us as a resource. I can't wait to start participating in upcoming

events, assist our Executive Director and begin meeting the wonderful families we serve.”

On a personal note, when I'm not in the office I am managing my husband and son's lives by using my never-ending attention to every little detail. Just ask them ;) I always want to make a difference in the world and love being outdoors, searching for wild herbs and quiet walks in the woods with my dog.

- Trish
Operations Manager at BDANENY

CHECK IT OUT

Here at BDANENY we are excited to share some of our favorite links for you and your family with things to do:



Free stories from Amazon to share with your kids

<https://stories.audible.com/start-listen>



Check out this link to “Take the work out of working out”

<https://hemaware.org/mind-body/take-work-out-working-out-0>

To me, it's personal.

As a Community Relations and Education Manager for Sanofi Genzyme, I'm here to help provide support and resources for you and the New York hemophilia community.

Aliana Soto
CoRe Manager for New York

Let's connect.

Call, text, video chat: 917-301-0756

Email: alliana.soto@sanofi.com

Facebook: [@HemophiliaCoRes](https://www.facebook.com/HemophiliaCoRes)

SANOFI GENZYME 



HAPPENINGS IN TROY

“Parents Night Out”

August 28, 2020 | 5pm to 9pm

Through the good or bad times, ups & downs,
mini victories learned or losses gained;

This Troy Night Out, before the start of the School Year,

we celebrate the Parent figures in our lives:
who have juggled homeschooling during the pandemic, been the rock, the light,
and the unwavering person(s) that brings life.



[Click to go to: https://www.downtowntroy.org/troy-night-out](https://www.downtowntroy.org/troy-night-out)

Support downtown small businesses!

September 4th - 13th



Keep The Summer Alive!

September 4 through 13

RESTAURANT WEEK

PIG OUT ON DAILY SPECIALS FROM YOUR FAVORITE RESTAURANTS

Enjoy Outdoor Dining . Eat In . Take Out with Curbside Pickup!

LEARN MORE AT [DOWNTOWNTROY.ORG](https://www.downtowntroy.org)

TROY'S
SUMMER
SQUARE



[Click to go to: https://www.downtowntroy.org/troy-night-out](https://www.downtowntroy.org/troy-night-out)

SAVE THE DATE!

Black & Blue Bash In Saratoga, NY-

“This is our 4th year hosting the Black & Blue Bash with the goal of helping the Bleeding Disorders Association of Northeastern NY, and their dedication towards finding better treatments and a CURE for inheritable bleeding disorders...”



BRINGED TO YOU BY YOUR FRIENDS AT
COTTRILL'S
PHARMACY, INC



Join us
for a Women's
Virtual Wreath
Making & Sip Party

SEPTEMBER 29TH, 2020

Limited space is available, so RSVP quickly!

**EACH PARTICIPANT WILL RECEIVE A FREE
WREATH MAKING KIT VIA
MAIL PRIOR TO THE VIRTUAL SESSION**

First come, first serve. To RSVP, please email your full name and address to Melissa.d@bdaneny.org.
RSVP deadline is September 18th, 2020 or until spaces are filled. (Whichever comes first)



[Check their website for
upcoming details and
updates-](http://www.blackandbluebash.com)
www.blackandbluebash.com

NATIONAL NEWS / EVENTS

Hemophilia Federation of America's Symposium 2020 has an amazing virtual conference scheduled. It includes an online agenda & programs. Also, check out their mobile app.

[Click below to go to their site!](https://www.hemophiliafed.org/our-role-and-programs/national-community-events/annual-symposium/)



SYMPOSIUM IS VIRTUAL!

August 24-29, 2020



<https://www.hemophiliafed.org/our-role-and-programs/national-community-events/annual-symposium/>

Stalled by COVID-19, teens from BioMarin-backed hemophilia musical reunite remotely

by Beth Snyder Bulik | Apr 17, 2020

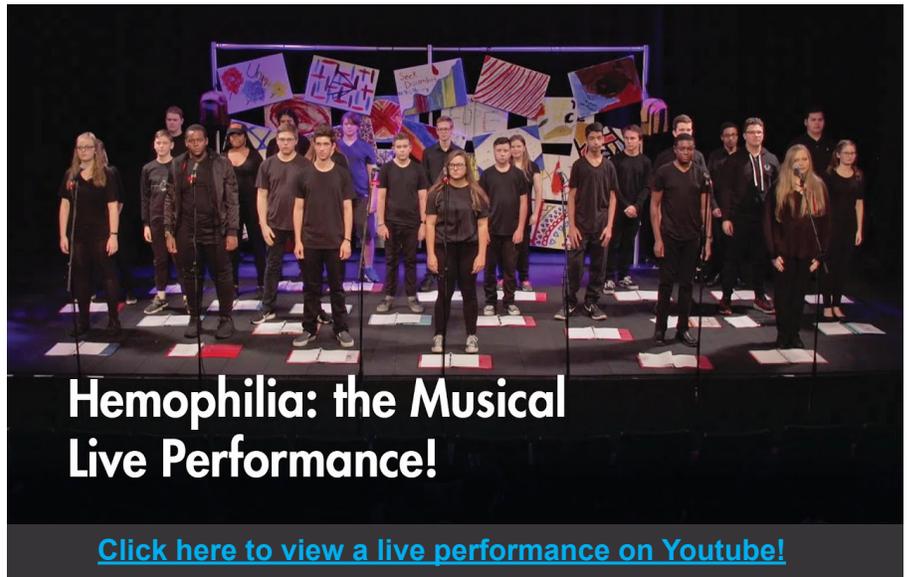
For the teens involved in the BioMarin-sponsored "Hemophilia the Musical" arts program, the show must go on in spite of COVID-19. That's the message they're sending on World Hemophilia Day Friday as they reunite remotely while sheltering in place.



The pandemic shut down the national program and in-person creative collaborations, so some of the teens worked together from home to create a socially distanced music video to celebrate the day and spread hope.

Article continued on next page

In personal videos and Zoom-room divided screens, the original cast of the first off-Broadway show share messages and sing “Today” from the “Breaking Through” musical in 2018. The song about the struggles of hemophilia can also apply to the isolation—and personal strength—that many people are feeling under COVID-19, said Patrick James Lynch, co-founder and CEO of Believe Limited, which runs the arts program and put the online performance together.



[Read the full article here!](#)

COVID INFO



NATIONAL HEMOPHILIA FOUNDATION

for all bleeding disorders



**COVID-19
INFORMATION**

Click the image to go to their page

<https://www.hemophilia.org/Newsroom/COVID->

Visit the National Hemophilia Foundation for COVID related information and news

LIFE HAPPENS

AND ADVATE WILL BE THERE WHEN IT DOES

ADVATE has over 15 years of treatment experience in the real world and provides clinically proven bleed protection* for patients with hemophilia A.¹



[Antihemophilic Factor (Recombinant)]

REAL LIFE. REAL BLEED PROTECTION.*

AdvateRealLife.com

*In clinical trials, ADVATE demonstrated the ability to help prevent bleeding episodes using a prophylaxis regimen.

Not an actual patient.

Prophylaxis with ADVATE prevented bleeds¹

The ability of ADVATE to treat or prevent bleeds was evaluated in a clinical study using a standard prophylaxis, pharmacokinetic driven prophylaxis, and on-demand treatment. 53 previously treated patients (PTPs) with severe to moderately severe hemophilia A were analyzed. For the first 6 months of the study, patients received on-demand treatment. For the following 12 months of the study, patients received either standard prophylaxis every 48 hours or a pharmacokinetic-driven prophylaxis every 72 hours. The primary goal of the study was to compare annual bleeding rates between those receiving prophylaxis treatment and those receiving treatment on-demand. The number of bleeds per year for the 2 prophylaxis regimens were comparable.

- Those patients experienced a median of 1 overall bleed per year on either prophylaxis treatment vs 44 overall bleeds per year with on-demand treatment.[†] This represented a 98% reduction in overall bleeds per year.
- Zero bleeds were reported in 42% of patients (22 out of 53 patients) during 12 months on prophylaxis

[†]Median is the middle number in a group of numbers arranged from lowest to highest.

ADVATE Important Information

What is ADVATE?

- 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 (HCP) 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

Who should not use ADVATE?

Do not use ADVATE if you:

- Are allergic to mice or hamsters.
- Are allergic to any ingredients in ADVATE.

Tell your HCP if you are pregnant or breastfeeding because ADVATE may not be right for you.

What should I tell my HCP before using ADVATE?

Tell your HCP if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Are breastfeeding. It is not known if ADVATE passes into your milk and if it can harm your baby.

Reference: 1. ADVATE Prescribing Information.

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ADVATE is a registered trademark of Baxalta Incorporated, a Takeda company. US-ADV-0101v1.0 05/20

What should I tell my HCP before using ADVATE? (continued)

- Are or become pregnant. It is not known if ADVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADVATE may not work for you).

What important information do I need to know about ADVATE?

- You can have an allergic reaction to ADVATE. Call your HCP 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.
- Do not attempt to infuse yourself with ADVATE unless you have been taught by your HCP or hemophilia center.

What else should I know about ADVATE and Hemophilia A?

- Your body may form inhibitors to factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop ADVATE from working properly. Talk with your HCP to make sure you are carefully monitored with blood tests for the development of inhibitors to factor VIII.

What are possible side effects of ADVATE?

- 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 HCP 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 Important Facts about ADVATE on the following page and discuss with your HCP.

For Full Prescribing Information, visit www.ADVATE.com.





[Antihemophilic Factor (Recombinant)]

Important facts about

ADVATE [Antihemophilic Factor (Recombinant)]

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

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

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

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

What is ADVATE?

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). The product does not contain plasma or albumin. Hemophilia A is an inherited bleeding disorder that prevents blood from clotting normally.

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.

Who should not use ADVATE?

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.

How should I use ADVATE?

ADVATE is given directly into the bloodstream.

You may infuse ADVATE at a hemophilia treatment center, at your healthcare provider's office or in your home. You should be trained on how to do infusions by your healthcare provider or hemophilia treatment center. Many people with hemophilia A learn to infuse their ADVATE by themselves or with the help of a family member.

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

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

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

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

You should tell your healthcare provider if you:

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

What are the possible side effects of ADVATE?

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	rash

Tell your healthcare provider about any side effects that bother you or do not go away

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

What else should I know about ADVATE and Hemophilia A?

Your body may form inhibitors to factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop 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.

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

The risk information provided here is not comprehensive. To learn more, talk with your health care provider or pharmacist about ADVATE. The FDA-approved product labeling can be found at www.ADVATE.com or 1-877-825-3327.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

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Patented: see <https://www.takeda.com/en-us/patents/>

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ABOUT THE BDANENY

Who We Are

We are a chapter of the National Hemophilia Foundation and the Hemophilia Federation of America. We are a volunteer, not-for-profit organization that serves the congenital bleeding disorders community within Northeastern New York and adjacent areas.

Our Mission

We are a chapter of the National Hemophilia Foundation and the Hemophilia Federation of America. We are a volunteer, not-for-profit organization that serves the congenital bleeding disorders community within Northeastern New York and adjacent areas.

What We Do

We advocate for the bleeding disorders community by:

- Emergency Funding
- Educational Scholarships
- Community Education
- Fundraisers– 100% of all monies raised is returned to the community
- Camperships
- Monitoring of health issues with federal and state agencies and non-profit organizations
- Legislative lobbying at the national and state level

CONTACT US

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