

Spring 2021



HANJournal

Hello
Spring



**March is Bleeding Disorders Month.
See the Resolution on page 17.**

**COVID—19
Jeff Lynch, MD,
HANJ's Medical Advisor
page 15**



WE'RE IN THIS TOGETHER.

Thursday 3:24 pm
Practicing yoga with her mom
Mariana, living with von Willebrand disease

Not an actual patient

Let's make today brilliant.

Takeda is here to support you throughout your journey and help you embrace life's possibilities. Our focus on factor treatments and educational programs, and our dedication to the bleeding disorders community, remain unchanged. And our commitment to adult patients with von Willebrand disease is stronger than ever.

Not all activities are appropriate for all individuals. Consult your doctor prior to engaging in any activity.



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Executive Director's Message By Stephanie Lapidow

The warm sun on your cheeks, buds forming on the trees, and the growth of flowers peeking out of the ground, Spring is near, and we are ready for it!

We have had a very productive winter. The HANJ Board of Trustees and staff have been hard at work transforming our events, means of communication, and our entire operation to meet this new digital age. From committee meetings to board meetings, educational programs and more, you can attend all the HANJ has to offer from the comfort of your home and personal device. Make no mistake, this was not an easy feat. It was important to us we spend the final days of 2020 reflecting on the unprecedented year, yet also look to the future and remind ourselves our services and resources to the New Jersey bleeding disorders community are still intact. For that, we are grateful.

First on the list this year has been transforming our largest member event to all virtual. For those who have attended our Winter Membership Gathering in years past, you know it is filled with fun, games, family friendly atmosphere, and tons of excellent educational opportunities. Transforming this event to a virtual platform took much effort and coordination, but we did it!! Over 44 families registered and our two-day virtual Winter Membership Gathering went off without a hitch in February. Thank you again to our entire team for pulling this off, but especially to our Events Coordinator, Mary Lou Billings. Mary Lou is celebrating 40 years with the HANJ this month. We thank her greatly for her tireless work for the New Jersey bleeding disorders community.

With our feet wet and our dedication stronger than ever, I am happy to say we will be bringing you many more virtual programs and events in the months to come. COVID-19 may have changed our world but has not dulled our spirit. Your participation and contributions make us who we are and allow us the opportunity to continue to provide such valuable, vital resources. Lastly, be sure to stay safe. The COVID-19 virus is still with us, so please be sure to mask up and continue to socially distance yourselves.

Be well,
Stephanie





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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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Stephanie Lapidow

What's in this Issue:





Executive Director's Message	page 3
HANJ Social Worker Update	page 7
HTC's Updates	page 9
HANJ's Medical Advisor Jeff Lynch, MD Message	page 15
Resolution for March being Bleeding Disorders Month	page 17
Mental Health Awareness Committee	page 19
Resources	page 22
Common Factor Support Group	page 29
Looking Outside the Insurance Box	page 32



EXPERIENCE MATTERS

BeneFix is FDA approved for once-weekly prophylaxis and on-demand use to fit your dosing needs— from the only recombinant factor IX supporting individuals with hemophilia B for more than 20 years.*

Not actual patients.

-  **More than 20 years* of experience**—the first recombinant treatment for individuals with hemophilia B
-  **Dosing options to meet your needs**—for once-weekly prophylaxis and on-demand use
-  Designed with viral safety in mind. More than 150 quality control tests are done on each batch of BeneFix
-  The convenience of the BeneFix Rapid Reconstitution (R2) Kit with a range of vial sizes



What Is BeneFix?

BeneFix, Coagulation Factor IX (Recombinant), is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia B. Your doctor might also give you BeneFix before surgical procedures.

BeneFix is **NOT** used to treat hemophilia A.

Important Safety Information

- BeneFix is contraindicated in patients who have manifested life-threatening, immediate hypersensitivity reactions, including anaphylaxis, to the product or its components, including hamster protein.
- Call your health care provider right away if your bleeding is not controlled after using BeneFix.
- Allergic reactions may occur with BeneFix. Call your health care provider or get emergency treatment right away if you have any of the following symptoms: wheezing, difficulty breathing, chest tightness, your lips and gums turning blue, fast heartbeat, facial swelling, faintness, rash, or hives.
- Your body can make antibodies, called "inhibitors," which may stop BeneFix from working properly.
- If you have risk factors for developing blood clots, such as a venous catheter through which BeneFix is given by continuous infusion, BeneFix may increase the risk of abnormal blood clots. The safety and efficacy of BeneFix administration by continuous infusion have not been established.
- Some common side effects of BeneFix are fever, cough, nausea, injection site reaction, injection site pain, headache, dizziness, and rash.

Please see the Brief Summary for BeneFix on the next page.

ASK YOUR DOCTOR WHICH BENEFIX DOSING OPTIONS MAY BE RIGHT FOR YOU





Rx only

Brief Summary

See package insert for full Prescribing Information. This product's label may have been updated. For further product information and current package insert, please visit www.Pfizer.com or call our medical communications department toll-free at 1-800-438-1985.

Please read this Patient Information carefully before using BeneFix and each time you get a refill. There may be new information. This brief summary does not take the place of talking with your doctor about your medical problems or your treatment.

What is BeneFix?

BeneFix is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia B. Hemophilia B is also called congenital factor IX deficiency or Christmas disease. Your doctor might also give you BeneFix before surgical procedures.

BeneFix is **NOT** used to treat hemophilia A.

What should I tell my doctor before using BeneFix?

Tell your doctor and pharmacist about all of the medicines you take, including all prescription and non-prescription medicines, such as over-the-counter medicines, supplements, or herbal medicines.

Tell your doctor about all of your medical conditions, including if you:

- have any allergies, including allergies to hamsters.
- are pregnant or planning to become pregnant. It is not known if BeneFix may harm your unborn baby.
- are breastfeeding. It is not known if BeneFix passes into the milk and if it can harm your baby.

How should I infuse BeneFix?

The initial administrations of BeneFix should be administered under proper medical supervision, where proper medical care for severe allergic reactions could be provided.

See the step-by-step instructions for infusing in the complete patient labeling.

You should always follow the specific instructions given by your doctor. If you are unsure of the procedures, please call your doctor or pharmacist before using.

Call your doctor right away if bleeding is not controlled after using BeneFix.

Your doctor will prescribe the dose that you should take. Your doctor may need to test your blood from time to time. BeneFix should not be administered by continuous infusion.

What if I take too much BeneFix?

Call your doctor if you take too much BeneFix.

What are the possible side effects of BeneFix?

Allergic reactions may occur with BeneFix. Call your doctor or get emergency treatment right away if you have any of the following symptoms:

wheezing	fast heartbeat
difficulty breathing	swelling of the face
chest tightness	faintness
turning blue	rash
(look at lips and gums)	hives

Your body can also make antibodies, called "inhibitors," against BeneFix, which may stop BeneFix from working properly.

Some common side effects of BeneFix are fever, cough, nausea, injection site reaction, injection site pain, headache, dizziness and rash.

BeneFix may increase the risk of thromboembolism (abnormal blood clots) in your body if you have risk factors for developing blood clots, including an indwelling venous catheter through which BeneFix is given by continuous infusion. There have been reports of severe blood clotting events, including life-threatening blood clots in critically ill neonates, while receiving continuous-infusion BeneFix through a central venous catheter. The safety and efficacy of BeneFix administration by continuous infusion have not been established.

These are not all the possible side effects of BeneFix.

Tell your doctor about any side effect that bothers you or that does not go away.

How should I store BeneFix?

DO NOT FREEZE the BeneFix kit. The BeneFix kit can be stored at room temperature (below 86°F) or under refrigeration. Throw away any unused BeneFix and diluent after the expiration date indicated on the label.

Freezing should be avoided to prevent damage to the pre-filled diluent syringe.

BeneFix does not contain a preservative. After reconstituting BeneFix, you can store it at room temperature for up to 3 hours. If you have not used it in 3 hours, throw it away.

Do not use BeneFix if the reconstituted solution is not clear and colorless.

What else should I know about BeneFix?

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

If you would like more information, talk with your doctor. You can ask your doctor or pharmacist for information about BeneFix that was written for healthcare professionals.

This brief summary is based on BeneFix® [Coagulation Factor IX (Recombinant)] Prescribing Information LAB-0464-12.0, revised June 2020.



Social Worker Update By Neidy Olarte, MSW Social Service Coordinator

Extended Open Enrollment for NJ Marketplace Coverage

Did you know that the deadline to apply for insurance through Get Covered NJ, the state's official Health Insurance Marketplace, has been extended? If you lost coverage or have not had a chance to select an insurance plan, NJ residents are able to obtain insurance on the NJ Marketplace through the COVID-19 Special Enrollment Period until May 15, 2021. You can log onto the Get Covered NJ website for information on how you can get insurance as well as see if you qualify for any subsidies to help pay for your insurance premium. Please visit their website at:

www.getcovered.nj.gov or contact them by phone at 1-833-677-1010. As always you can reach out to me directly to help assist with any insurance questions.

Coverage will take effect on the first day of the month following a plan selection through the COVID-19 SEP.

The coverage effective dates are as follows:

Enroll by **February 28th**, coverage effective **March 1st**;

Enroll by **March 31st**, coverage effective **April 1st**;

Enroll by **April 30th**, coverage effective **May 1st**;

Enroll by **May 15th**, coverage effective **June 1st**.

Insurance Grant Renewals

Please note that the deadline to submit the renewal applications is May 31, 2021.

HANJ provides financial assistance specifically for individuals with hemophilia A or B, von Willebrand disease (vWD), qualitative platelet disorders, and/or acquired hemophilia who demonstrate a financial need and are not eligible for other assistance programs. The HANJ Insurance Grant Program also covers co-pays and deductibles that are affiliated with a bleeding disorder. If you would

Scholarship Deadline

April 30th, 2021

like more information on our grant program or other programs, please feel free to contact me at the office or directly at nolarte@hanj.org.

Scholarships

There is still time to apply for scholarships. Deadline to submit a scholarship application is April 30th, 2021.

If you are interested in applying for a HANJ scholarship for the 2021-2022 school year, please contact HANJ for the requirements of scholarship eligibility and an application form or you may print one from our website at www.hanj.org.

HANJ awards four undergraduate scholarships for full-time students in the amount of \$1,500 per year (renewable for up to 3 additional years) and one Graduate level scholarship for full-time students in the amount of \$2,000 (renewable for up to one additional year). Part-Time graduate students can apply for \$1,000 (renewable for up to 3 additional years). Your complete application must be submitted to us by April 30th, 2021.

We also have compiled a list of Scholarships available from other sources for individuals and families with a bleeding disorders. Please contact us for a copy or visit our website to print that list at www.hanj.org.

Upcoming Programs & Events:

**Spring Educational Symposium
Saturday, March 20th, 2021**

**"Jeopardy Night"
Sponsored by BioMarin
Wednesday, April 7th, 2021**

**"Plant a Seed Night"
Thursday, April 22nd, 2021**

**"Mexican Loteria Bingo Night"
Wednesday, May 5th, 2021**



Explore HEAD-TO-HEAD Pharmacokinetic (PK) Study Data

See half-life, clearance and other PK data from the crossover study comparing **Jivi®** and **Eloctate®**

Visit PKStudies.com to find out more.

► **Pharmacokinetics** is the study of the activity of drugs in the body over a period of time.

Jivi
antihemophilic factor
(recombinant) PEGylated-acl
LET'S GO

WHAT'S HAPPENING

New Jersey Hemophilia Treatment Centers

Rutgers Robert Wood Johnson Medical School Hemophilia Treatment Center

By Lisa Cohen, MSW, LSW

Operations During COVID19:

The Rutgers RWJ Hemophilia Treatment Center (HTC) recognizes that the global health crisis we are facing today with COVID-19 is of particular concern for patients and their families who rely on clinical coordination of care, factor and home care nursing. We would like to assure you that the HTC remains operational and is able to provide care for our patients with bleeding disorders. The clinic continues to take measures to minimize the risk to patients and staff. The majority of clinic visits are currently being conducted via telemedicine. Physical therapy is now being scheduled in person in the clinic. HTC nurses are present in the clinic and triage calls and coordinate lab work as is the case during normal operations. Please do not hesitate to contact the clinic with any concerns or issues that you may have.

Contact can be made with Rutgers RWJMS HTC at the usual telephone numbers:

For Nurses:
(732) 235-6542 or
(732) 235-6531

For Social Worker:
(732) 235-6533

Programs & School Visits:

Currently educational programs and school visits are being conducted via Zoom. A meet and greet zoom program was held for new families in February and a second program is being scheduled for later this spring. If you anticipate the need for a school, camp or daycare visit, please contact Lisa Cohen, MSW at cohenlr@rwjms.rutgers.edu or by phone at (732) 235-6533.



We urge all of our patients to abide by New Jersey & CDC guidelines, which include:

- Wear a mask.
- Maintain social distancing.
- Limiting indoor contact.

These measures are increasingly important during the winter and given the increasing cases throughout New Jersey and the country.

Stay Safe!



**Rutgers RWJ Medical School
Hemophilia Treatment Center
125 Paterson Street, 5th Flr, Ste5200
New Brunswick, NJ 08901
For appointments: (732) 235-7226
Nurse Direct Line for
Medical Issues: (732) 235-6531
Social Worker: Lisa Cohen, MSW, LSW
(732) 235-6533
cohenlr@rwjms.rutgers.edu**

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

By Erica Stuppler, LCSW



Happy Spring from the staff at the Comprehensive Hemophilia Treatment Center at Newark Beth Israel Medical Center and Children's Hospital of New Jersey! We are happy to share with you the latest news from our treatment center.

UPCOMING Hemophilia Camp:

Stay tuned for updates regarding the 2021 Camp season. **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.**

Scholarships:

Scholarships are now available. Please be mindful of the deadlines to submit the applications and the eligibility criteria for each scholarship. Also, please remember to complete your FAFSA forms as early as possible to secure available funds. **If you have any questions about scholarships, internships, or coordinating your care away from home please contact our Social Worker Erica.**

NEWS

COVID-19:

As the pandemic continues, the HTC staff wanted to remind you that we are here for you for your medical needs, questions, and concerns about COVID-19 as well as to connect you to resources as we recognize that the pandemic may have impacted your life. Please reach out to the HTC staff as needed.

ONGOING PROGRAMS

Insurance Changes:

As the New Year continues, we know that your insurance coverage might change and insurance issues may arise. Please be sure to update the HTC on **any and all** changes to your insurance coverage for 2021. **If you have any questions about insurance coverage, your deductibles, co-pay issues, or plan changes please contact our Financial Coordinator, Cassandra, at the HTC.**

Treatment Logs:

The HTC is aiming to get all patients (who treat their bleeding disorder with medication) to track their infusions and/or treatment in a treatment log. In an effort to provide the best possible care for our patients, it is extremely important that our physicians and nurses can see a patient's treatment logs, in real time, for the management of their bleeding disorder. **ATHNadvoy is a web-based application that allows patients, or their caregivers, to track treatment related to their bleeding disorder in a user friendly way directly through their smart phone, tablet, laptop, or computer.** When a user creates an account, they choose their treatment center; linking the patient and the HTC, and allowing the HTC to have access to view a patient's treatment log. **For more information, or to sign up, please contact our Social Worker, Erica.**

School Visits:

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.

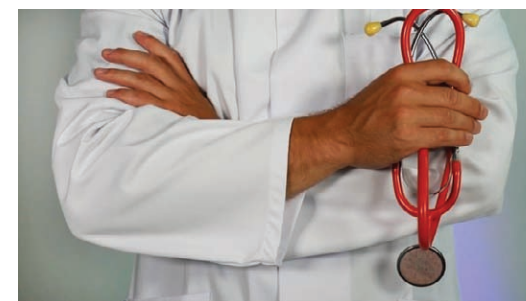
If you are going to want a school visit scheduled for your child's school or daycare center, or need a letter for school/forms completed, please contact Erica, our Social Worker. Erica will make sure that we have a release on file, and will coordinate your needs with the school and schedule a visit. **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.

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 HTC's 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 HTC's 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 three different home care companies; Accredo, BDRN, and Option Care Health/Bioscrip. Patients who are not currently using one of these three 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.**

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, musculoskeletal, 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.**



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.

Manufacturer Factor 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 your home care company or our Financial Coordinator, Cassandra.**

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

Newark Beth Israel Medical Center & Children's Hospital of New Jersey Hemophilia Treatment Center
201 Lyons Ave. (E2),
Newark, NJ 07112
Main Number: (973) 926-6511
Social Worker:
Erica Stuppler, LCSW
(973) 926-4197
Erica.Stuppler@RWJBH.org
Fax: (973) 391-0048



St. Michael's Medical Center

By Joanne Rodriguez

Spring and COVID-19:

Spring is here!!!! We know that the weather is getting better and after a year in quarantine, we all want to go out and enjoy the beautiful weather. Please be mindful and remember that we are still dealing with a Pandemic. Wearing masks, keeping our distance and hand washing still stands even if we are starting to see good weather. Even if you were vaccinated, you still have to follow the CDC Guidelines. If you are not vaccinated but are interested, please follow the link below to register.

COVID-19 Vaccine:

If anyone is interested in getting the COVID-19 Vaccine, you may register at covid19.nj.gov/pages/vaccine.

Mental Health:

As we all know mental health issues are on the rise and COVID-19 hasn't made things easier. If you or anyone you know is in need of help please know that you are not alone. There's help for you and others:

National Suicide Prevention Lifeline
(800)273-8255
Online Chat:
suicidepreventionlifeline.org
Depression Test:
screening.mhanational.org
Emergency: 911

Re-Evaluations:

We are open and servicing our community. Give us a call and schedule your re-evaluations for the year. You can contact us at (973)877-5342, Monday through Friday.

Patient Education:

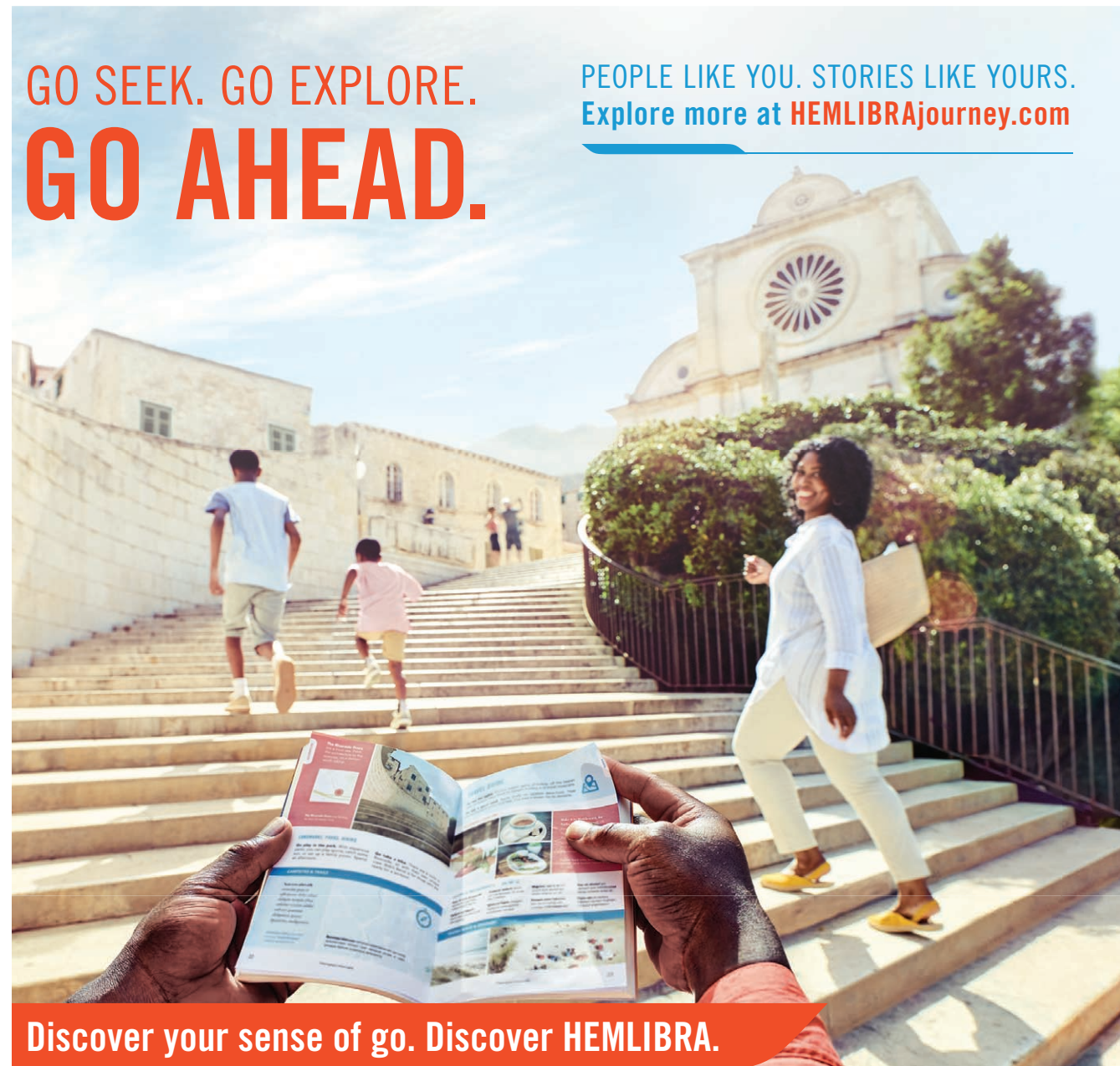
Our patients are always welcome to ask questions about New Therapies and Insurance updates. If any of you have any questions or concerns, please give us a call and we will provide you with the most up to date medical and insurance information. You may call Dominique Joseph, Nurse at (973) 877-5340 or Joanne Rodriguez, Social Worker at (973) 877-2967.

Here at St. Michael's Medical Center we are committed to keeping our patients safe. We pray for all of our families as well as the rest of the world during this difficult time.

St. Michael's Medical Center Hemophilia Treatment Center
111 Central Ave., Bldg. M2
Newark, NJ 07102
Patient's call: (973) 877-5340 or (973) 877-5341 or (973) 877-5342
Social Worker: Joanne Rodriguez, CSW (973) 877-2967
JRodriguez27@primehealthcare.com
Fax (973) 877-5466



The Hemophilia Association of New Jersey provides MedicAlert Memberships and IDs for patients with hemophilia and vWD. Medical ID jewelry is essential for people with bleeding disorders. Wearing a Medical ID ensures emergency responders and hospital staff have the most up-to-date medical information the moment they need it, to make informed decisions about treatment and care. For more information and an order form, please contact: Cindy Hansen at HANJ at (732) 249-6000 or chansen@hanj.org.




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, ages newborn and older, with hemophilia A with or without factor VIII inhibitors.

What is the most important information I should know about HEMLIBRA?
HEMLIBRA increases the potential for your blood to clot. People who use activated prothrombin complex concentrate (aPCC; Feiba®) to treat breakthrough bleeds while taking HEMLIBRA may be at risk of serious side effects related to blood clots.

These serious side effects include:

- **Thrombotic microangiopathy (TMA)**, a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs
- **Blood clots (thrombotic events)**, which may form in blood vessels in your arm, leg, lung, or head

Please see Brief Summary of Medication Guide on following page for Important Safety Information, including **Serious Side Effects**.



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

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

HEMLIBRA increases the potential for your blood to clot. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent or factor VIII (FVIII) and the recommended dose and schedule to use for breakthrough bleed treatment.

HEMLIBRA may cause the following serious side effects when used with activated prothrombin complex concentrate (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 following signs or symptoms during or after treatment with HEMLIBRA:

- confusion	- stomach (abdomen) or back pain
- weakness	- or back pain
- swelling of arms and legs	- nausea or vomiting
- yellowing of skin and eyes	- 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	- cough up blood
- pain or redness in your arms or legs	- feel faint
	- headache
- shortness of breath	- numbness in your face
- chest pain or tightness	- eye pain or swelling
- fast heart rate	- 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, ages newborn and older, with hemophilia A with or without 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.
- **Stop (discontinue) prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis.**
- **You may continue prophylactic use of FVIII for the first week of HEMLIBRA prophylaxis.**
- 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.
- You will receive HEMLIBRA 1 time a week for the first four weeks. Then you will receive a maintenance dose as prescribed by 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 as soon as possible before the next scheduled dose, and then continue with your normal dosing schedule. **Do not** give two doses on the same day 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 a total of 7 days or at a temperature greater than 86°F (30°C).
- 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-kxwh

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
 U.S. License No. 1048

HEMLIBRA® is a registered trademark of Chugai Pharmaceutical Co., Ltd., Tokyo, Japan
 ©2018 Genentech, Inc. All rights reserved.
 For more information, go to www.HEMLIBRA.com or call 1-866-HEMLIBRA.
 This Medication Guide has been approved by the U.S. Food and Drug Administration
 Revised: 10/2018



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 The Genentech logo is a registered trademark of Genentech, Inc.
 All other trademarks are the property of their respective owners.
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Genentech
 A Member of the Roche Group

COVID-19 Update...

Jeff Lynch, MD
HANJ Medical Advisor

I hope that this newsletter finds our membership having survived the winter in good health. As of early March the number of daily COVID cases in New Jersey has been in steady decline since the January peak. The rate of transmission stands at 0.87 which means that on average each person infected passes the disease to less than one other person. The long term effect of this is for the presence of the disease to decline. Vaccines are now available to speed this decline even further as well as to prevent a resurgence.

Presently there are three approved vaccines. The Pfizer and Moderna vaccines are two shot vaccinations while the J&J vaccine will be one shot. Results from the Pfizer vaccine are strong enough that it may give sufficient immunity in one dose. All three vaccines have similar protective effects so it is not necessary to try to choose one. To find your eligibility and a location to receive a vaccine it remains necessary to diligently research information sites. Unfortunately a bleeding disorder itself so far does not count as a qualifying condition. The New Jersey COVID Hub covid19.nj.gov is still the best information site. Be aware that none of the vaccine registration sites are linked. The best way to access a vaccination is to place your information on as many locations as possible.

A recent national survey of the bleeding disorders community revealed the magnitude of the COVID 19 pandemic. Significant percentages of the community had lost work and were unable to pay basic food and health bills. The largest effect was on mental health with 74% reporting a decline in their psychological well being. The most successful coping measures were reaching out and staying connected with family and friends. In February, HANJ hosted a virtual Winter Membership Gathering that was aimed at connecting with our community. Perry Parker a professional golfer with hemophilia gave an inspirational talk on living a positive life with a bleeding disorder. Dr. Claudio Sandoval of Octapharma gave a truly passionate presentation on the past and future of hemophilia treatment. We hope to have more such events that will help keep us all together and looking forward to the future.

New Jersey regularly updates local and State information at:
www.covid19.nj.gov

HFA (Hemophilia Federation of America) maintains information specific to the bleeding community at:
www.hemophiliafed.org

NHF (National Hemophilia Foundation) is the leading/largest/only national non-profit organization dedicated to finding better treatments and cures for inheritable bleeding disorders and to preventing the complications of these disorders through education, advocacy, and research. Check their website at:
www.hemophilia.org



We are here to help you ...

Do you need assistance with your health insurance premium, co-pays and deductibles? HANJ offers assistance to eligible individuals, through our Medical Insurance Grant.

Please contact Neidy Olarte, **HANJ Social Worker**, via email at nolarte@hanj.org or call **(732) 249-6000** for information about the requirements and how to apply for assistance.

SAY HELLO TO JAMES

He has hemophilia A and has gone through two major surgeries while keeping to his factor regimen with the support of his hemophilia care team

"RECOVERY WAS TOUGH, BUT I LEARNED I HAD MORE SUPPORT THAN I THOUGHT POSSIBLE."



Read stories like James' in Hello Factor magazine: BleedingDisorders.com



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In March of 2018 The Hemophilia Association of New Jersey pursued and obtained legislation to make March "Bleeding Disorder Awareness Month".

JOINT RESOLUTION NO. 2

A JOINT RESOLUTION designating March of each year as "Bleeding Disorders Awareness Month" in New Jersey.

WHEREAS, A bleeding disorder is a condition that develops when the blood cannot clot properly. The clotting process, also known as coagulation, changes blood from a liquid to a solid. This process occurs when platelets clump together to form a plug at the site of a damaged or injured blood vessel, which prevents blood from flowing out of the blood vessel; and

WHEREAS, When a bleeding disorder is present, blood does not coagulate properly. As a result, excessive or prolonged bleeding can occur after an injury, surgery, trauma, or during menstruation and can lead to spontaneous or sudden bleeding in the muscles, joints, or other parts of the body; and

WHEREAS, Blood disorders can lead to significant morbidity and can be fatal if not treated effectively; and

WHEREAS, The majority of bleeding disorders are inherited but some develop because of a medical condition, low red blood cell count, vitamin K deficiency, or as a side effect of anti-coagulant medications; and

WHEREAS, The two most common inherited bleeding disorders are hemophilia and von Willebrand Disease (vWD); and

WHEREAS, Hemophilia is a rare condition carried on the X-chromosome that affects mostly males. It occurs when there are low levels of clotting factors in the blood, and causes heavy or unusual bleeding into the joints; and

WHEREAS, Many individuals with hemophilia became infected with HIV and Hepatitis C during the 1980s due to the contamination of the blood supply and blood products; and

WHEREAS, vWD is the most common inherited bleeding disorder. It develops when the blood lacks von Willebrand factor, which helps the blood to clot. More than three million individuals, an estimated one percent of the U.S. population, are impacted by vWD; and

WHEREAS, In 2016, the United States Department of Health and Human Services (HHS) approved for inclusion on its National Health Observances calendar the annual designation of March as "Bleeding Disorders Awareness Month"; and

WHEREAS, The inclusion of "Bleeding Disorders Awareness Month" as a National Health Observance formalizes and expands upon the designation by President Ronald Reagan of March 1986 as "Hemophilia Awareness Month"; and

WHEREAS, Increased public awareness of bleeding disorders will generate a greater understanding of not only hemophilia and von Willebrand Disease but all inheritable bleeding disorders and foster a greater sense of community and shared purpose among individuals with inheritable bleeding disorders and the general public; now, therefore,

BE IT RESOLVED by the Senate and General Assembly of the State of New Jersey:

C.36:2-325 "Bleeding Disorders Awareness Month," March; designated.

1. March of each year is designated as "Bleeding Disorders Awareness Month" in New Jersey in order to increase public awareness about bleeding disorders, generate a greater understanding of all inheritable bleeding disorders, and foster a greater sense of community and shared purpose among individuals with inheritable bleeding disorders and the general public.

C.36:2-326 Annual observance.

2. The Governor is respectfully requested to annually issue a proclamation designating March as "Bleeding Disorders Awareness Month" in New Jersey, and calling upon public officials and the citizens of the State to observe the month with appropriate activities and programs.

3. Copies of this resolution, as filed with the Secretary of the State, shall be transmitted by the Clerk of the General Assembly or the Secretary of the Senate to the Hemophilia Association of New Jersey.

4. This joint resolution shall take effect immediately.

Approved March 20, 2018.

STATEMENT

This resolution designates March of each year as "Bleeding Disorders Awareness Month" in New Jersey in order to increase public awareness about bleeding disorders, generate a greater understanding of all inheritable bleeding disorders, and foster a greater sense of community and shared purpose among individuals with inheritable bleeding disorders and the general public.

Designates March of each year as "Bleeding Disorders Awareness Month."



Specialty Pharmacy. Experienced Care.

At Accredo, we understand it can be difficult to live with a chronic or complex illness and subsequent care.

As one of the nation's leading and largest providers of specialty pharmaceuticals, our dedicated therapy teams work diligently to coordinate solutions for the challenges of those living with a bleeding disorder.

With accurate and timely delivery of medication, as well as expert guidance through ongoing therapy directives, you can trust Accredo to provide experienced care.

Contact us for more information.
 Patients call: 866.712.5200
 Physician offices call: 866.712.5007
hemophilia.com

accredo[®]

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 HEM-00282-071719 amc8026 CRP17_A0043

Mental Health Awareness Committee

Dear HANJ Members,

I am happy to announce that I have become Chair of HANJ's newly formed Mental Health Awareness Committee. Over the past few years and more importantly since the Covid-19 pandemic, HANJ has recognized the need for assisting our members that are experiencing mental health issues and combat them before it elevates to the point of self-infliction due to mental health circumstances.

In February, myself and other members of our Board of Directors came together to outline what we thought was best to combat issues surrounding mental health. We have chosen to invite members of the community who have directly or indirectly been involved with someone that has needed mental health guidance. We encourage members who have experienced these bouts to join us as we navigate ways to identify and alleviate these issues before it is too late.

We have decided to have one meeting per month for the first six months and will explore, after that, a frequency which we feel would work and that will remain effective. If you feel that you can be a benefit to our Mental Health Awareness Committee, please do not hesitate to reach out to Stephanie Lapidow or myself to volunteer with this initiative.

More importantly, if you or someone you know is suffering with Mental Health issues, please do not hesitate to reach out to us so that we can provide you with the right resources. All inquiries will remain anonymous.

Thank-You!

Sincerely,
 Peter Marcano
PeterMarcano@gmail.com

The Crisis Text Line

Text "**Home**" to **741741** when you are feeling depressed or suicidal. A crisis worker will text you back immediately and continue to text with you. Many people don't like talking on the phone and would be more comfortable texting.

It's a **FREE** and confidential service to ANY-ONE—teens, adults, etc...who live in the U.S. and it is available 24/7

2-1-1

2-1-1 is a **special abbreviated telephone number** reserved in Canada and the United States as an easy-to-remember three-digit telephone number meant to provide information and referrals to health, human, and social service organizations.

Please take the time for yourself to use one of these resources if you feel depressed or need someone to talk to.

You are not alone... Mental Health Services

Suicide Prevention Line
1 (800) 273-8255
www.suicidepreventionlifeline.org

National Alliance on Mental Illness (NAMI) **1 (800) 950-6264**
www.nami.org or info@nami.org

Division of Mental Health & Addiction Services (Adults)
1 (800) 382-6717

Behavioral Health & Developmental Disability Services for Children and Youth Under Age 21
1 (877) 652-7624

NJ Connect for Recovery
1 (855) 652-3737
www.njconnectforrecovery.org

NJMentalHealthCares
1(866) 202-Help (4357)
7 days a week, 8am to 8pm

Marc Pangilinan

Patient advocate

About Marc

Marc is a Novo Nordisk Hemophilia Community Liaison who lives with hemophilia. He has a passion to become more ingrained within the bleeding disorders community and share what he learns with others.

Hobbies

- Traveling
- Hiking
- Swimming
- Reading
- Biking

“I enjoy experiencing the trust and shared experiences within the community, whether you have hemophilia or care for someone who does.”

Connect with Marc

MPGL@novonordisk.com
(332) 215-2772

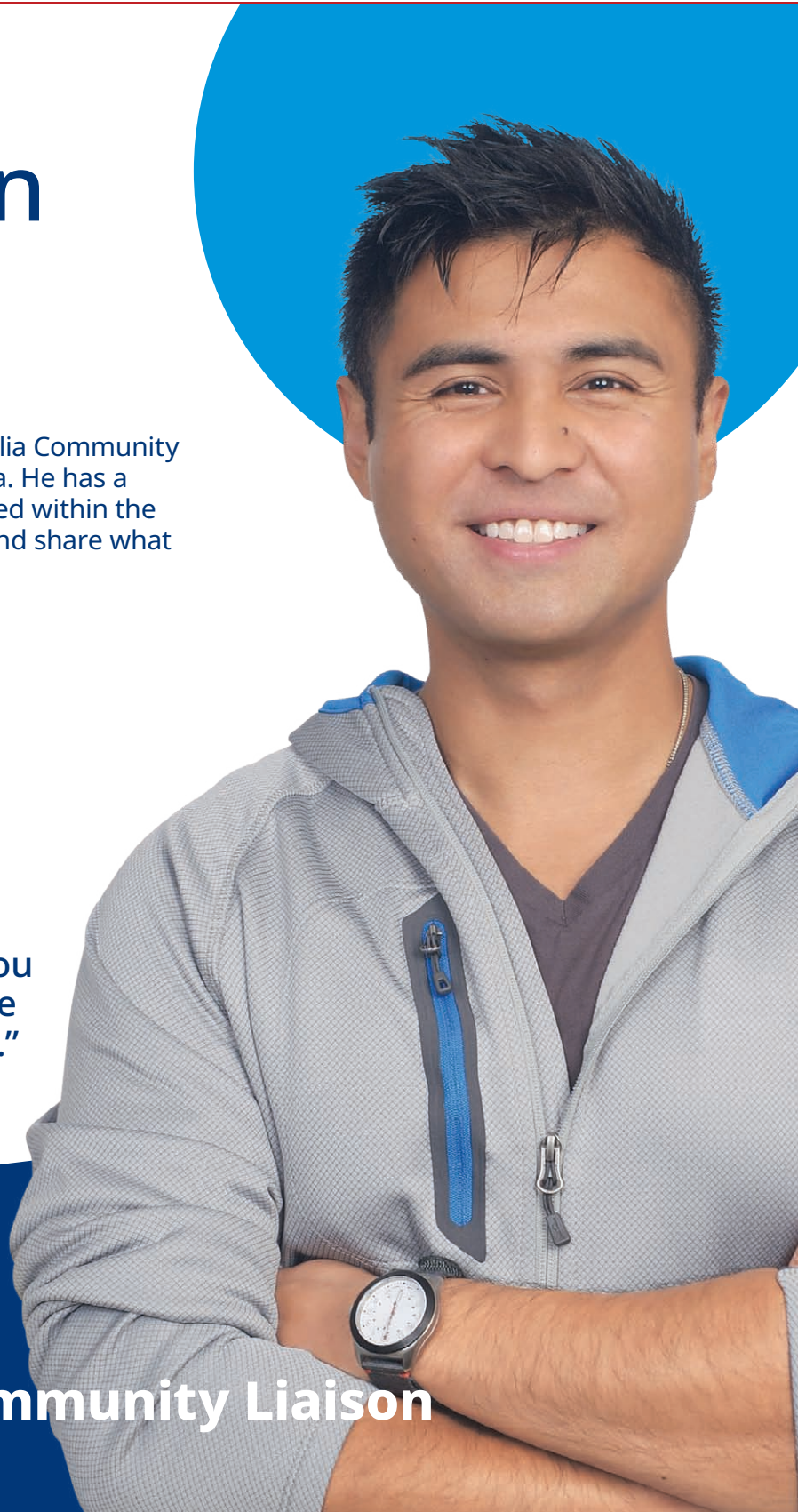
Hemophilia Community Liaison

NYC, NJ, Eastern PA

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

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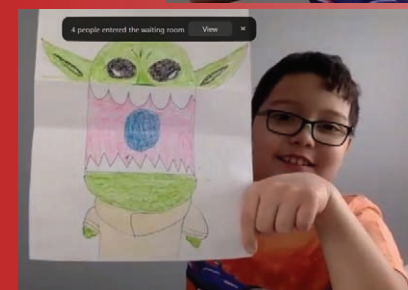
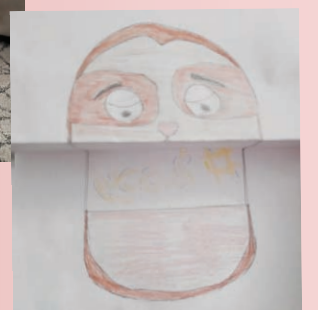


NHF's Washington Days March 1st to 5th 2021



NHF's Washington Days is an opportunity for people affected by bleeding disorders to advocate for issues that are important to them. Due to the Pandemic, Washington Days was held virtually this year. HANJ continued to attend along with some of our members to share their stories and advocate on behalf of the New Jersey Bleeding Disorder community. If you would like to attend next year, please contact the HANJ office for more details. We would love your support to help advocate for the bleeding disorders community. Your story could really make a difference.

Virtual Winter Membership Gathering February 19th and 20th, 2021



HANJ continued, without skipping a beat, with our Virtual Winter Membership Gathering. See our members, Nicholas on the left and Andrea to the right of Nicholas, participating in one of the children's programs.

Everyone enjoyed themselves!

Pharmaceutical Resources for Bleeding Disorders Free Factor & Co-Pay/Deductible Assistance Programs

Manufacturer	Program Name & Contact Information	Details
Bayer	<p>www.jivi.us.com www.kovaltry.com www.livingwithhemophilia.com</p> <p>To access services by Bayer: 1 (800) 288-8374</p>	<ul style="list-style-type: none"> • \$0 Product Co-pay Program: You may receive up to \$12,000 in assistance per year, regardless of income. • Free Trial Program: Enroll today for up to 6 free doses of Jivi, Kovaltry, or Kogenate FS • Loyalty Program: Each month you use Jivi, Kovaltry, or Kogenate FS you will earn 1 Loyalty Program point. Points can be used during a gap in insurance coverage, if you experience challenges getting insurance coverage for your Bayer products, or if you are uninsured or underinsured. • Questions: Margarita Llibre Rogers, Hemophilia Community Relations (412) 522-9018, Margarita.librerogers@bayer.com
CSL Behring	<p>www.cslbehringassurance.com</p> <p>www.cslbehring.com/patients/support/support-and-assistance</p>	<ul style="list-style-type: none"> • CSL Behring Assurance Program: Contact a <i>CSL Behring Assurance Program</i> Care Coordinator at 1 (866) 415-2164 • CSL Behring Patient Assistance Program: 1(844)727-2752 • My Access — This program may provide assistance up to \$12,000 for out-of-pocket expenses to Qualified CSL Behring patients on Humate-P, IDEL VION or AFSTYLA. Please call: 1 (800) 676-4266.
Genentech	<p>1 (866) 422-2377 www.genentech-access.com/ hemlibra: Information related to HEMLIBRA Access and patients inquiring about HEMLIBRA 1 (877) 436-3683</p> <p>www.HEMLIBRA.COM</p>	<ul style="list-style-type: none"> • The Hemlibra Co-pay Program helps people with commercial health insurance. This might be a plan you get through your employer or one you purchased through a Health Insurance Marketplace like HealthCare.gov. To qualify, you must also meet other criteria. • Independent Co-pay Assistance Foundations: If you need help with the co-pay for your Genentech medicine, HEMLIBRA Access Solutions can refer you to an independent co-pay assistance foundation. Independent co-pay assistance foundations help patients with public or commercial health insurance. Call HEMLIBRA Access Solutions at (877) 233-3981 for a referral. • Genentech Patient Foundation gives free Genentech medicine to people who don't have insurance coverage or who have financial concerns. Visit https://hemlibra.com/patient/patientresources/financial-support.html for more information.
Grifols	<p>FACTORS FOR HEALTH 1 (844) MY-FACTOR (693-2286)</p> <p>www.grifolspatientcare.com</p>	<ul style="list-style-type: none"> • The \$0 Copay Program, wherein eligible patients or caregivers may pay as little as \$0 for prescriptions. • The Free Trial Program for eligible patients who are new to treatments from Grifols. • Benefits investigation and support services to help you coordinate with your insurer. • The Patient Assistance Program (PAP) for patients with no coverage or lapsed coverage. • Care Coordination to help you access and stay on treatment.

Manufacturer	Program Name & Contact Information	Details
Kedrion	<p>1 (855) 353-7466</p> <p>www.mykoate.com</p>	<p>Kedrion Connect: Created to help provide eligible KOATE® [Anti-hemophilic Factor (Human)] patients with financial support. There are two programs under Kedrion Connect to assist eligible patients:</p> <ul style="list-style-type: none"> • Co-pay Assistance – Helps eligible patients with their co-pay costs. The Co-pay card covers up to \$16,000 per calendar year. • Insurance Premium Support Program – Helps with private insurance premiums and assistance for those who qualify.
Medexus Therapeutics	<p>IXINITY Savings Program</p> <p>http://ixinity.com/support-savings/ixinity-savings-program/</p> <p>1 (855) 494-6489</p> <p>Free Trial—Starter Kit— Your</p> <p>IXINITY Patient Assistance Programs:</p>	<ul style="list-style-type: none"> • Must have valid prescription for IXINITY • Must have commercial insurance • No monthly limits unless limit total is reached. • No income requirements • Co-pay program can be used retroactively for up to 12 months • Limit Total \$12,000 <p>IXperience; on the go, no matter where your next adventure takes you. With your FREE trial of IXINITY, you'll receive 1 month of free treatment up to 20,000 IU.</p> <p>After that, if you're covered by commercial insurance, you may continue to pay nothing out-of-pocket for IXINITY regardless of income.</p> <p>Download and complete the IXINITY FREE Trial Form and bring to your doctor to get started. Questions? Connect with a Hemophilia Territory Manager.</p> <p>This program helps deliver treatment to those in need, even if they don't have insurance. If you are uninsured or experience a lapse in coverage, this program may cover you. Learn more about the IXINTY Patient Assistance Program. Call your IXperience Concierge at 1-855-IXINITY (1-855-494-6489).</p>
Novo Nordisk	<p>www.MyNovoSecure.com Novo Nordisk NovoSecure Hotline 1 (844) NOVASEC Or 1 (844) 668-6732</p> <p>www.novonordisk-us.com</p> <p>https://www.novoeight.com https://www.novosevenrt.com https://www.rebinyn.com https://www.tretten.com https://www.esperoct.com</p>	<p>Novo Nordisk Co-pay Assistance Program – Save up to \$12,000 annually on co-pay, deductible, and co-insurance costs, regardless of income.</p> <p>Product Assistance Program – http://www.mynovosecure.com/support/continue_your_treatment.html</p> <p>Product Assistance Program (PAP)/Trial Program – Download the application at www.mynovosecure.com/support.continue_your_treatment.html</p>
Octapharma	<p>Questions? Call the Factor My Way Support Center (855) 498-4260 or email at usreimbursement@octapharma.com</p>	<p>Factor My Way Co-Pay Assistance Program Factor My Way™ The Factor My Way Assistance Program offers a Co-pay Assistance Program with savings of up to \$12,000, a Free-Trial Program for patients with hemophilia A or VWD, Reimbursement for Octapharma Factor Therapy Treatment and a Compassionate Access Program for no cost therapy for eligible patients.</p>

Manufacturer
Pfizer
**Program Name
& Contact
Information**
www.hemophiliavillage.com
Details

- **Trial Prescription Program for Eligible Patients**- Allows patients to get a one-time, one-month supply up to 20,000 IU of Pfizer factor product delivered at no cost to him or her. Call Pfizer Hemophilia Connect at 1-844-989-HEMO (4366) for more information or visit the website www.HemophiliaVillage.com
- **Pfizer Factor Savings Card** – Up to \$12,000 annual support for co-pay, deductible and coinsurance costs. If you have questions, please call 888-240-9040 or send questions to Pfizer Factor Savings Program, 2250 Perimeter Park Drive, Suite 300, Morrisville, NC 27560, or visit www.HemophiliaVillage.com
- **Pfizer RxPathways** – A comprehensive assistance program that provides eligible patients (insured, uninsured, and underinsured) with a range of support services (<https://pparx.org>). Call Pfizer Hemophilia Connect at 1-866-706-2400 for more information or visit website www.PfizerRxPathways.com
- **Reimbursement Support Services for Eligible Patients** – Benefit Verifications, Prior Authorization Assistance and Appeals Assistance. Call Pfizer Hemophilia Connect at 1-844-989-HEMO (4366) for more information.
- If you're having trouble finding the Pfizer program that's right for you, call 1-844-989-PATH (7284) and speak with a Medicine Access Counselor who can work with you to map out your path to prescription assistance.

**Sanofi Genzyme
(formerly
Bioverativ)**

Learn about all the resources, support and financial assistance options available to you at the links below. Eligible patients need to be a resident of the United States, you do not have to be a citizen of the United States to receive assistance.
<https://www.eloctate.com/resources/financial-assistance.aspx> or call: (855) 693-5628 (Hem A)
<https://www.alprolix.com/resources/financial-assistance.aspx> or call: (855) 692-5776 (Hem B)
Email: MyEloctateCoordinator@sanofi.com or MyAlprolixCoordinator@sanofi.com

Eloctate and Alprolix both offer the following assistance programs:

- **Free Trial Plus Program** –Eligible patients may apply for a free 30-day trial of medicine. Patients could also receive free factor for up to 1 year, if needed.
- **Factor Access Program** – Helps patients with factor access even if your insurance coverage is interrupted.
- **Co-Pay Assistance Program** – Provides up to \$20,000 co-pay/co-insurance assistance for eligible patients who use Eloctate or Alprolix. No income requirements!

**Takeda(formerly
Shire)**

Resources:
<https://www.hematologysupport.com/copay-assistance/>
 (888) 229-8379 Mon to Fri 8:30am to 8:00 pm
 Fax: 1-(866) 467-7740

www.hematologysupportpro.com
 (888) 229-8379 (Prompt 1)

Hematology Support Center: One stop resource for Hematology resources (Medical Professionals):

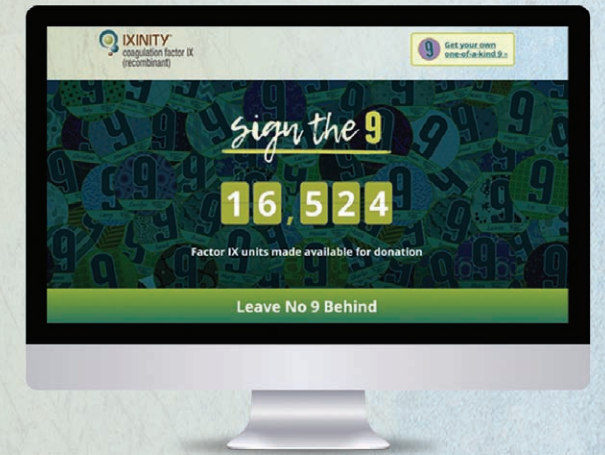
- **Assistance Programs** - Available to eligible patients who have a US mailing address with no insurance or a gap in coverage (eligibility and application requirements)
- **Freedom of Choice** – Eligible patients can receive free sample dose of eligible Takeda's hemophilia products along with educational resources.
- **Co-Pay Assistance Program** –Non-Financial Needs Based Program (Commercial insurance only)
- Reimbursement Resources
- Product Information

Sign the 9 is now online!

Now it's easier than ever to make a difference.

Help make IXINITY® available to individuals in the United States who can't afford to be without it. It's easy. Just **visit signthe9.com** and fill out a brief form. When you do, **9 IU of IXINITY will be donated in your name**. While you're there, build your own one-of-a-kind 9. Add your name, share your 9 on social media...and watch the support grow!

► Visit signthe9.com today!



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Aptevo BioTherapeutics LLC, Chicago, IL 60606

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IXINITY
coagulation factor IX
(recombinant)

Let's get together to talk about IXINITY®

“After many years, I continue to be inspired by the strength and sense of family in the bleeding disorders community. It brings me great joy to be a part of it!

—Ellen Rowe, your resource for all things IXINITY



► Contact Ellen at 215-908-4276 or ellen.rowe@medexus.com

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Aptevo BioTherapeutics LLC, Chicago, IL 60606

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IXINITY
coagulation factor IX
(recombinant)

Non-Pharmaceutical Assistance Programs

Organization

The Colburn-Keenan Foundation, Inc.
PO Box 811
Enfield, CT 06083
Email: admin@colkeen.org

Contact Information

www.colkeen.org
Toll free Phone: (800) 966-2431
Fax: (888) 345-0259

Details

Provides financial assistance programs to individuals and families living with chronic conditions, with priority placed on those living with bleeding disorders.

HFA Helping Hands

Hemophilia Federation of America (HFA)
999 N. Capitol Street NE,
Suite 201
Washington, DC 20002
Email: info@hemophiliafed.org

www.hemophiliafed.org/
programs/helping-hands

Phone: (202) 675-6984
Toll Free: (800) 230-9797
Fax: (202) 675-6983

<http://www.hemophiliafed.org/our-role-and-programs/assisting-and-advocating/financial-assistance/helping-hands-emergency-assistance/>

Hemophilia Federation of America is a national non-profit organization that assists, educates and advocates for the bleeding disorders community. HFA's Helping Hands Emergency Assistance is designed to establish a rapid, non-invasive source of relief for emergency situations or urgent needs to persons who are affected by diagnosed bleeding disorders. Each year, Helping Hands aids hundreds of families with emergency/urgent funding to assist in crisis situations such as housing, transportation, and utility bills. Helping Hands cannot cover any medical expenses including medical bills, dental bills, insurance premiums, co-payments, deductibles, medications, factor, etc. Please visit : www.hemophilia.org/our-role-and-programs/assisting-and-advocating/financial-assistance.

Hope for Hemophilia

PO Box 77728
Baton Rouge, LA 70879

(888) 529-8023

Fax (888) 835-1449

info@hope-charities.org
www.hopeforhemophilia.org

Patient Resource Program and Direct Financial Assistance Program.

Patient Services Inc.

P.O. Box 5930
Midlothian, VA 23112
Email:
uneedpsi@uneedpsi.org

www.patientservicesinc.org
1-(800) 366-7741
Fax 1-(804) 744-9388

1 (877) 851-9065
www.patientservicesinc.org

- Premium Assistance (PSI—Patient Services, Inc.)
- **PSI.-A.C.C.E.S.S. Legal Hotline (PSI – Patient Services, Inc.)** Supports patients with Social Security Disability and Supplemental Security Income benefits via legal counseling.

Patient Access Network Foundation (PAN)

P.O. Box 30500
Bethesda, MD 20824
Email:
info@panfoundation.org

(866) 316-7263
Fax (866) 316-7261

www.panfoundation.org

Assistance Programs: PAN Foundation offers nearly 70 disease-specific assistance programs to help patients pay for their out-of-pocket costs, such as deductibles, co-pays and coinsurance, travel expenses and health insurance premiums. Contact PAN by phone or email for more information.

Please note that all co-pay/deductible assistance programs are for patients with private insurance. Patients with Medicaid or Medicare are not eligible.

Additional Resources

Organization

211 United Way
United Way Worldwide
701 N. Fairfax Street
Alexandria, VA 22314

Email: info@NJ211.org

Contact Information

1(703) 836-7112

www.unitedway.org
www.nj211.org
1(877)622-7258

Dial 211 or 1(877) 652-1148

Details

Provides free and confidential information and referrals to local services including housing, food, employment, healthcare, counseling, and more. Check the website of call your local United Way.

Links to additional resources in your local area for specific needs.

The Assistance Fund

1(855) 845-3663

<https://tafcares.org>

The Assistance Fund (TAF) is an independent charitable assistance foundation that helps patients and families facing high medical out-of-pocket costs by providing financial assistance for their co-payments, co-insurance, deductibles and other health-related expenses. Go to their website to confirm eligibility and other resources.

Slogan: When Health Insurance is not enough.
Mission Statement: To reduce financial barriers to care for underinsured patients with chronic or life altering diseases.

Health Well Foundation

PO Box 489
Buckeystown, MD 21717

1(800)675-8416

<https://www.healthwellfoundation.org/patients/>

Needy Meds

NeedyMeds, Inc.
PO Box 219
Gloucester, MA 01931
info@needymeds.org

Helpline: 1(800) 503-6897
www.needymeds.org

A national non-profit organization that maintains a website of free information on programs that help people who can't afford medications and healthcare costs.

New Jersey Children's System of Care

1(877) 652-7624

<https://www.performcarenj.org/families/emergency-services.aspx>

The State of New Jersey offers behavioral health resources for parents and caregivers through Perform Care.

Patient Advocate Foundation (PAF)

PAF
421 Butler Farm Road
Hampton, VA 23666

1(800) 532-5274

www.patientadvocate.org

help@patientadvocate.org

Provides case management and assistance in accessing health insurance. Co-pay assistance programs are available.

RxHope

<https://www.rxhope.com/about.aspx>

A web-based information resource to help low-income US residents access patient assistance programs.

RxOutreach

1(888) 796-1234

www.rxoutreach.org

A patient assistance program that provides discounts on prescription drugs. A fully licensed non-profit mail order pharmacy.

United Healthcare Children's Foundation

MN017-W400
9700 Healthcare Lane
Minneapolis, MN 55343
email:

customerservice@uhccf.org

1(855) 698-4223

www.uhccf.org

Provides medical grants to help children gain access to health-related services not covered, or not fully covered, by a commercial health insurance plan. You do not need to have United Healthcare to be eligible.



FREE educational webinar! Participate from the comfort of your HOME.

Anyone under 18 years of age must be accompanied by a parent or caregiver.

Common Connections 2-Part Webinar
Part 1: Learn About IDELVION for the Treatment of Hemophilia B
Part 2: Explore Music Therapy

Thursday, March 18, 2021

8:00 PM – 9:00 PM ET

Featured Speakers:

Dezarae Tate, RN

Tim Ringgold, MT-BC

REGISTER NOW



REGISTER ONLINE or **BY PHONE**

Online: www.CommonConnectionsCSL.com

Phone: 1-866-992-9940

Important Safety Information

IDELVION®, Coagulation Factor IX (Recombinant), Albumin Fusion Protein (rFIX-FP), is used to control and prevent bleeding episodes in people with hemophilia B. Your doctor might also give you IDELVION before surgical procedures. Used regularly as prophylaxis, IDELVION can reduce number of bleeding episodes.

IDELVION is administered by intravenous injection into the bloodstream, and can be self-administered or administered by a caregiver. Do not inject IDELVION without training and approval from your healthcare provider or hemophilia treatment center.

Tell your healthcare provider of any medical condition you might have, including allergies and pregnancy, as well as all medications you are taking. Do not use IDELVION if you know you are allergic to any of its ingredients, including hamster proteins. Tell your doctor if you previously had an allergic reaction to any FIX product.

Stop treatment and immediately contact your healthcare provider if you see signs of an allergic reaction, including a rash or hives, itching, tightness of chest or throat, difficulty breathing, lightheadedness, dizziness, nausea, or a decrease in blood pressure.

Your body can make antibodies, called inhibitors, against Factor IX, which could stop IDELVION from working properly. You might need to be tested for inhibitors from time to time. IDELVION might also increase the risk of abnormal blood clots in your body, especially if you have risk factors. Call your healthcare provider if you have chest pain, difficulty breathing, or leg tenderness or swelling.

In clinical trials for IDELVION, headache was the only side effect occurring in more than 1% of patients (1.8%), but is not the only side effect possible. Tell your healthcare provider about any side effect that bothers you or does not go away, or if bleeding is not controlled with IDELVION.

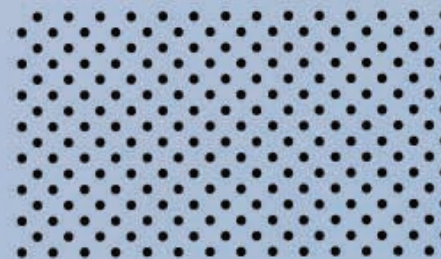
Please see accompanying full prescribing information for IDELVION, including the patient product information.

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

You can also report side effects to CSL Behring's Pharmacovigilance Department at 1-866-915-6958.

IDELVION is manufactured by CSL Behring GmbH and distributed by CSL Behring LLC. IDELVION® is a registered trademark of CSL Behring Lenggau AG. Biotherapies for Life® is a registered trademark of CSL Behring LLC.

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The Common Factor

Last year HANJ had the pleasure of creating a virtual support group for our members. We wanted to create the group as a way of helping the bleeding disorder community stay connected virtually during these unprecedented times.

This year we would like to continue to offer this opportunity by reintroducing our virtual community group, now called **The Common Factor**. The goal of The Common Factor is to connect the bleeding disorder community, allowing for a safe space, to be a support system for all. The meetings are open to all individuals in the bleeding disorder community, including family and friends that would like to support the mission of the group.

Throughout the upcoming months, we will be introducing topics that are of interest to the group as well as partake in many fun, member chosen activities. This will be a place where there is no judgement, a great place to get to meet, connect, network and just have fun.

As a group we are hoping to not only be there as a support system for those in need, we also would like to encourage anyone who has a talent or hobby, to feel open to share with the group. HANJ has a community of talented individuals, and we, as a group, would love for you to showcase your talents and passions with us.

At this time, meetings will be held virtually once every other month. The goal is to have monthly meetings as our group evolves, and eventually gather for in person sessions. We are looking for information, suggestions, and recommendations for topics, activities etc...from the HANJ member population. As a way to collect that information we are attaching a link to a brief survey. If you are interested in participating, or simply want to help us improve our group, please take a minute to complete the survey.

For more information about The Common Factor group, and if you would like to participate in our future meetings, please visit our website at <https://hanj.org/virtual-support-group>, or reach out to me directly at nolarte@hanj.org. I look forward to seeing you at our future meetings.

Improve How Your Mask Protects You

Accessible version: <https://www.cdc.gov/coronavirus/2019-ncov/your-health/effective-masks.html>



When choosing a mask, look at how well it fits, how well it filters the air, and how many layers it has:

- 1 Make sure your mask fits snugly against your face.
- 2 Pick a mask with layers to keep your respiratory droplets in and others' out.

Do

Improve fit



Choose a mask with a **nose wire**

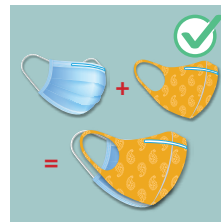


Use a **mask fitter** or **brace**



Check that it **fits snugly** over your nose, mouth, and chin

Add layers of material

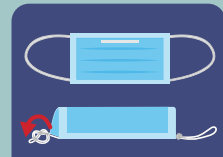


2 ways to layer

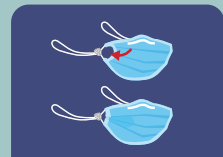
- Use a cloth mask that has multiple layers of fabric
- Wear a disposable mask underneath a cloth mask. The cloth mask should push the edges of the disposable mask against your face.

Make sure you can see and breathe easily

Knot and tuck ear loops of a 3-ply mask



Knot the ear loops



Fold and tuck in unneeded material



Check for close fit

Do NOT



Combine two disposable masks



Combine a KN95 mask with any other mask.



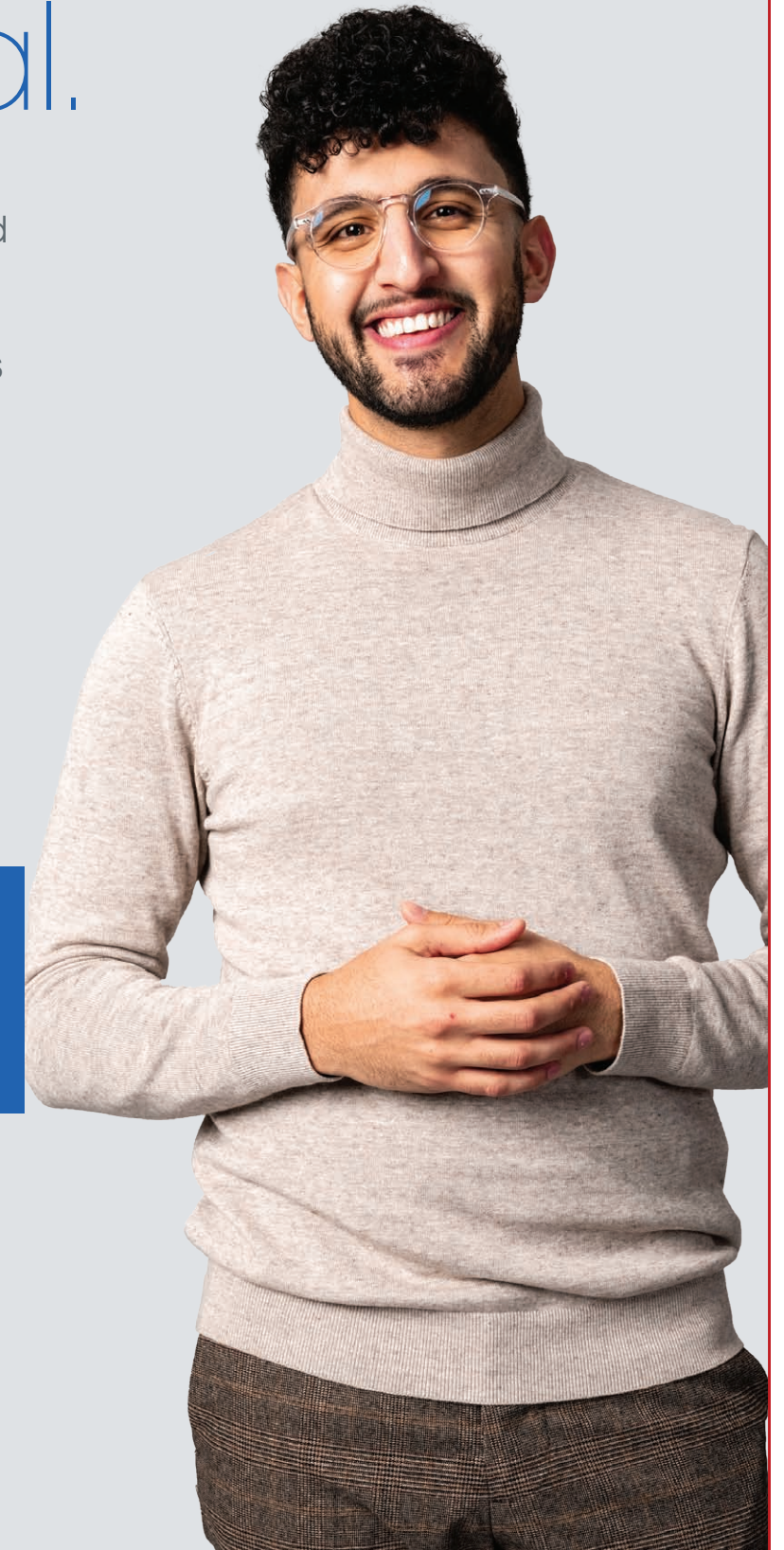
CS 323019-A 03/11/2021

cdc.gov/coronavirus

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 Jersey hemophilia community.

Laith Elkurd
CoRe Manager for New Jersey



Let's connect.

Call, text, video chat: 857-270-1962
Email: laith.elkrud@sanofi.com
Facebook: @HemophiliaCoRes

SANOFI GENZYME

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HEM-US-7108 3/20

Looking Outside the Insurance Box

Matthew Barkdull

If asked what comes to mind when the term "hemophilia" or "bleeding disorder" is mentioned, most would say something about uncontrollable bleeding or bruising. When it comes to how I see a bleeding disorder, I think of it equally as a genetic medical condition and a *financial* condition. Bleeding disorders immediately force individuals and families into the cold and confusing world of insurance, with all the foreign babble that accompanies it.

Because it's human nature to heavily rely on professionals (or even armchair experts) when we're unsure how to navigate through the landmines of insurance, families are at the mercy of good, poor, or "meh" advice. Please indulge a few personal flashbacks:

In 2002, I got my first salary-based position that provided several benefits, including health and life insurance. When my wife and I pored through the life insurance policy, we found that it was just enough to bury me in a plywood coffin when I kicked the bucket. Not knowing much about "how the real world works" in terms of life insurance, we scheduled a visit with my company's financial advisor. I told him that I'd like to purchase more life insurance. After I had answered some questions about my severe hemophilia diagnosis and an earlier kidney transplant, the advisor quickly said that I could not qualify for more life insurance. "Your best bet is to save a ton of money throughout your career!" he said, nailing that discussion *closed*.

As a result, I became a disciple behind the "Got a medical problem? Don't bother applying for life insurance!" philosophy. But I terminated my discipleship 17 years later, when a good friend and brilliant financial adviser contested my views, saying that there were many possibilities to protect my loved ones if I kicked the bucket. The upshot? If I pass away at age 65, my plan now guarantees that my beneficiaries will be mostly financially independent as they go on through life. Not bad for a guy who not only has severe hemophilia, but is a former three-year dialysis patient, recipient of two kidney transplants, cancer survivor, and severe West Nile Virus survivor—and has been infected with hepatitis C. My

friend taught me the fine art of looking outside the box.

Another interesting experience involves medical insurance. I was born in the 1970s, when hemophilia treatment was still trying to get its footing, and when health insurance companies could cap coverage with lifetime maximums and limit or deny coverage because of the infamous pre-existing condition clause. Consequently, I was given the advice to always work for a company that was large enough to offer outstanding medical benefits and absorb the cost. It was unthinkable to venture off to be my own boss and start my own business, as my father had done throughout his life. I carried this belief until I lost my job at a company where I'd been employed for over 16 years. During my first year of unemployment, I tried without success to find another permanent job within a large company. For years, I had been contemplating a business idea, but never dared to pursue it because of my social and medical conditioning. As time went on without resources, I felt I was ready to go against the grain and open up my own organization, despite the hardship of not knowing how I'd ever cover my factor or my family's medical needs.

In the past, I had asked nonprofessionals and nonexperts about getting medical insurance as a small business owner. Their recommendations were all over the map. But when I started working with financial professionals, as well as experts within the hemophilia community, I became more and more comfortable, feeling there was more consistency in these recommendations. Being self-insured is a pricey ordeal with its own set of challenges, but after counseling with the executive director of my local hemophilia chapter, I was astounded at the resources she gave me. Pages and pages of resources, both in-house and outside of the chapter, showed me that I had little knowledge. The result? I was able to get my business underway, while national and local resources covered premium and deductible expenses to bless me and my family.

These are only two examples, out of dozens I could have used to illustrate important financial principles you need to understand when taking a step into unfamiliar territory—which is often saturated with misinformation, preconceived beliefs, and pop culture advice. The overarching financial

principle I wish to emphasize: *Always think outside the box.*

A few recommendations that will aid you and your family:

1. Never accept a single opinion or recommendation at full face value.

Years ago, I was employed as the health officer at a very large, international non-profit organization. One of my tasks was to work with worldwide medical institutions and other service providers to solve many kinds of problems patients were facing. During that time, I learned a valuable lesson: Never rely on one person's answer, opinion, or recommendation at full face value. This is different from assuming everyone is trying to snow or mislead us; they simply may not understand the full picture. This principle leads to the second principle.

2. Educate yourself.

And not just online, where everyone is taking a stab at a problem. Surround yourself with experts; get second opinions. It's okay to be persistent because often, even the most well-meaning professionals may not take as much interest in helping you as you do yourself. If you find a pattern of people answering similarly, you're probably receiving good advice.

3. Learn to ask questions.

I never pretend to know what I'm doing if I honestly don't know. So ask questions of those you're working with. If the financial or insurance expert is describing something with which you have little familiarity, feel free to ask questions as often as you need

to. Most people find it helpful to set expectations early: "Hey, just a quick warning. I'm really a novice when it comes to insurance. I'll probably be asking a ton of questions to make sure I'm understanding everything. I'd assume you're cool with this." And most of the time, they are!

Insurance of any kind has become a necessity in our lives, especially within the bleeding disorder population. It's critical that we not only understand insurance, but that we learn to build a team and to advocate for ourselves and our loved ones. My experience is that when I've been willing to take a risk and reach out for information and support, I've never regretted doing so.

Matthew Barkdull, MBA, MS, LMFT, MedFT, provides education, assessment, coaching, advocacy, and support through his organization *Wholeness Integrated Solutions, PLLC*. *WIS* works with individuals, couples, families, and institutions to assess and empower problem-solving within the *Eight Dimensions of Wholeness: biological, psychological, social, spiritual, nutritional, economical, educational, and environmental*. For a free consultation, please call Matt: 385-434-8136.

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Publication: Pulse 2020
Column: Transitions

Greek Yogurt Two Ways: Dip & Dessert By Monica Hansen, RD

Loaded Baked Potato Dip

Ingredients:

- 1 (16 ounce) container non-fat Greek yogurt
- 1 block Cabot 50% Reduced Fat Light Cheddar Cheese, shredded
- 4 slices turkey bacon, cooked and crumbled
- 1 teaspoon smoked paprika (could substitute liquid smoke)
- 1 bunch scallions, sliced
- 1 teaspoon garlic powder
- salt, pepper and cayenne to taste (optional)

Directions:

Cook bacon and chop finely. Mix everything together and enjoy with potato chips or veggies.



Vanilla Cinnamon Yogurt Dip

- 1 5.3 oz. container vanilla greek yogurt
- 1 Tablespoon honey (optional)
- ½ teaspoon cinnamon
- ¼ teaspoon vanilla
- Fruit, for serving

Directions:

Mix all ingredients together and adjust as desired.

NUWIQ[®]Antihemophilic Factor
(Recombinant)To learn more about our Free Trial and
Co-Pay Assistance Programs, call us at 800.554.4440**Contact your Octapharma Representative:****Kristin Marema**

Phone | 201.850.3686

E-mail | Kristin.Marema@octapharma.com**octapharma**
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Factor/Coagulation
Factor VIII Complex
(Human)To learn more about our Free Trial and
Co-Pay Assistance Programs, call us at 800.554.4440**Contact your Octapharma Representative:****KRISTIN MAREMA**PHONE:
201.850.3686EMAIL:
Kristin.Marema@octapharma.com**octapharma**
For the safe and optimal use of human proteins©2019. Octapharma USA Inc. All rights reserved.
Date of preparation: 4/2019. WIL-0206-CADwww.wilateusa.com**It's Scholarship time at HANJ!****February 2021**

The Publicity and Education Committee of the Hemophilia Association of New Jersey is proud to once again offer scholarship's to qualified individuals with Hemophilia, Von Willebrand disease, or a similar blood coagulation disorder.

If you are interested in applying for a HANJ scholarship for the 2021-2022 school year, please contact HANJ for the requirements of scholarship eligibility and an application form or you may print it from our website at www.hanj.org.

HANJ awards four undergraduate scholarships for full-time students in the amount of \$1,500 per year (renewable for up to 3 additional years) and one Graduate level scholarship for full-time students in the amount of \$2000 (renewable for up to one additional year). Part-Time graduate students can apply for \$1,000 (renewable for up to 3 additional years) **Your complete application must be submitted by April 30th, 2021.** Only one application needs to be completed to be considered for all four undergraduate scholarships.

We also have compiled a list of **Scholarships Available from Other Sources** for individuals and families with a bleeding disorder. Please contact us for a copy or visit our website to print that list at www.hanj.org.

Contact information:

Neidy Olarte, Social Service Coordinator
732-249-6000
neidyo@hanj.org

Cindy Hansen
732-249-6000
chansen@hanj.org

**Hemophilia Association
of New Jersey
Upcoming 2021 Events**

Due to the Coronavirus Pandemic, HANJ has taken great care to follow the CDC guidelines to keep our Community safe. Please make note of the dates below.

**Hemophilia Association of New Jersey
Annual Meeting**
Details to Follow.

42nd Dennis Keelty Memorial Golf Classic
Monday, June 21st, 2021

Summer Camp Wellness Gathering
Eagle's Landing Day Camp
Saturday, August 28th, 2021

HANJ Walk/Run
Sunday, September 26th, 2021

Casino Night
Saturday, October 23nd, 2021

39th Testimonial Humanitarian Award
Dinner Dance—Man of the Year:
Kevin Cummings
Chairman & Chief Executive Officer
of Investors Bank
Friday, November 19th, 2021