

Fall 2021

HANJournal

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HANJ's Medical Advisor
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Want to be Happier?
Try Volunteering!
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Hemophilia Association of New Jersey Upcoming 2021 Events

HANJ has taken great care to follow the CDC guidelines to keep our bleeding disorders community safe during the Coronavirus Pandemic. Please make note of the dates below.

Casino Night Postponed

**Annual Kelly Brothers Scholarship Benefit
In Memory of Bob & Dennis**
Friendly Sons of the Shillelagh
Sunday, October 3, 2021

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

Educational Programs Scheduled

Reframe Your Mindset
Sponsored by Genentech
Thursday, October 14, 2021
7PM

Tell Your Story
Sponsored by Sanofi Genzyme
Thursday, November 11, 2021
7PM



President's Message By Steve Moersdorf



As we celebrate the fiftieth anniversary of the founding of the Hemophilia Association of New Jersey, it is my honor to begin my term as President of the Board of Trustees. It has been my pleasure to serve as a Trustee, a member of the Executive Board and on various committees over the last twenty-four years. Thank you to the membership for entrusting me with the Presidency of this organization as we move forward through our fiftieth year and into the future.

We have recently been successfully navigating our way through the Covid 19 pandemic. Thank you to our volunteers, donors, and staff who have all helped us not only survive but to flourish during this difficult time. Unfortunately, it does not seem like the pandemic is done with us yet. Please join me in hoping and praying that it will soon be over.

This fall, we are trying to get back on track with our fundraising events, many of which had to be postponed or cancelled last year. So, please watch out for information about our upcoming fundraising events:

- Run to the Hemophilia Walk
- Kelly Brothers Scholarship Picnic

Please support these events in any way that you can.

We will also be continuing with our many existing programs such as Blood Brotherhood, and our newer Head Health program which is our mental health initiative. The Publicity and Education Committee has been working diligently on new programs for next year and beyond. Thanks to them for the hard work. Stay tuned for more information.

Lastly, I have an appeal for you. While we have a very dedicated group of volunteers, we can always use more. Volunteer opportunities exist on various levels including serving on one of our planning committees, participating in educational programming and assisting at one of our events. If you have the time, talent, energy and passion, to get more involved with HANJ, please reach out to Stephanie Lapidow to discuss your areas of interest and our areas of need.





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 197 Route 18 South
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Phone: 732-249-6000
 Fax: 732-249-7999
 Editor: Genevieve Christo
 E-mail: info@hanj.org
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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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**Social Worker Update
 By Neidy Olarte, MSW
 Social Service Coordinator**

It's Fall and the new school year is upon us. The beginning of the school year naturally brings new friends and classmates into your child's circle. Very often kids are anxious or timid about talking about hemophilia with new friends, so I've put together this simple guide for broaching the topic with your child - it can be **EASY** if you follow these steps:

Educate: Remind your child that most kids his or her age won't know what hemophilia is and to be patient when answering the questions they might have.

Action plan: Children with hemophilia should make it clear to their peers that they can still play most games or non-contact activities but that they, and the adults in their lives, have an action plan if something should happen.

Set the record straight: Being up-front with friends and classmates about what activities he or she can and cannot participate in will cut down on constant questions or awkward situations throughout the year.

You - be yourself! Make sure that your child highlights the fact that even though they may have a disease that makes them bleed more than others, they are still just a kid like everyone else!

Hopefully, this will help you with the questions - spoken or unspoken - your child will likely have about talking to his or her peers about hemophilia. If you have not yet discussed an action plan with your child's school staff, coaches, and extracurricular activity leaders, please contact the social worker at your HTC to coordinate a service session with your school. I also encourage you to reach out to us at HANJ for additional resources on how to prepare your child for the school year. We can work together to make sure a plan is in place and give you and your child peace of mind. Wishing all students a successful school year!





My Vaccination Records

Secure, accessible digital record of your vaccines



We are here to help.

HANJ provides MedicAlert memberships for our community.
 For more information and an order form, please contact:

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

WHAT'S HAPPENING

New Jersey Hemophilia Treatment Centers

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

By Emily Fusco, LSW

Happy Fall! The staff from the Comprehensive Hemophilia Treatment Center at Newark Beth Israel Medical Center and Children's Hospital of New Jersey would like to share some updates, current programs, and plans with you. We hope you are all doing well!

NEWS: **Hemophilia Camp:**

We missed hearing about summer camp experiences this year but are looking forward to next year! Hole in the Wall Gang Camp is offering Fall Family Weekends this September and October. Camp can be an integral part of a patients' journey towards independence. **For more information about camp family weekends, or if your child or family is interested in attending camp in the future, please contact Emily, our Social Worker, at the HTC.**

ONGOING PROGRAMS

Insurance Changes:

Please be sure to update the HTC on **any and all** changes to your insurance coverage. **If you have any questions about insurance coverage, your deductibles, co-pay issues, or plan changes please contact our Financial Coordinator, Cassandra.**

Treatment Logs:

ATHN has created a new application called Robust Health. The new application will allow users to track bleeds, infusions and/or treatments in a log and share the information with us at the HTC. 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. **Robust Health 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 Emily.**

School Visits:

As students are transitioning back to school, we know that you might need forms completed, letters for school, or virtual school visits scheduled. While school visits will be virtual, they 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 Emily, our Social Worker.** Emily 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 HTCs sustain themselves, and provide better care for their eligible

patients, Congress created the 340B Program as part of the Veteran's Health Care Act of 1992. Across the United States almost all of the HTCs participate in 340B Programs. Depending on their healthcare coverage, patients may have a variety of pharmacy options to choose from. Our HTC is contracted with 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.

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:
Emily Fusco, LSW
(973) 926-4197
Emily.Fusco@RWJbh.org
Fax: (973) 391-0048

Rutgers Robert Wood Johnson Medical School Hemophilia Treatment Center

By Lisa Cohen, MSW, LSW

The Rutgers RWJ Hemophilia Treatment Center (HTC) recognizes the changing landscape of the global COVID health crisis and continues to focus on the provision of comprehensive care for our bleeding disorder patients. The HTC is fully operational with a hybrid operation of tele-health and in person clinical care. The clinic continues to take measures to minimize the risk to patients and staff. Please do not hesitate to contact the clinic if you have any questions.

Contact can be made with the Rutgers RWJMS HTC at the telephone numbers listed to the right.

PROGRAMS & SCHOOL VISITS: Due to COVID, educational programs are virtual at this time. Stay tuned for updates



regarding upcoming programs for families in October. As the school year begins, the HTC is scheduling in service presentations which are being conducted via Zoom. If you anticipate the need for a school or daycare in service program, please contact Lisa Cohen, MSW at: cohenlr@rwjms.rutgers.edu or by phone at (732) 235- 6533.

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

St. Michael's Medical Center

By Joanne Rodriguez

Fall and COVID-19:

Fall is here!!! We know that the weather is getting colder and after more than a year of quarantine, we all want to continue to enjoy the outdoors. So, we need to be mindful and remember that we are still dealing with a Pandemic. Wearing masks, keeping our distance and hand washing are some of the best ways to keep safe. Even if you have been vaccinated, you still have to follow the CDC guidelines. If you are not vaccinated but are interested, please follow the link below:
[covid19.nj.gov/pages/vaccine](https://www.nj.gov/pages/vaccine).

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.



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

St. Michael's Medical Center prays 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 Fax (973) 877-5466
JRodriguez27@primehealthcare.com

GO SEEK. GO EXPLORE.
GO AHEAD.

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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
- shortness of breath	- headache
- chest pain or tightness	- numbness in your face
- fast heart rate	- eye pain or swelling
	- trouble seeing

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

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

What is HEMLIBRA?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children, 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,
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 U.S. License No. 1048
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 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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It's that time again.... Back to School!

By Emily Fusco, LSW



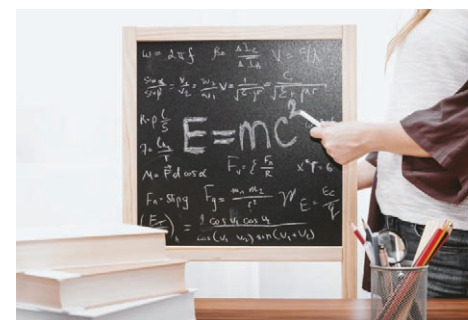
It's back to school time! The perfect time to educate your child's school about their bleeding disorder. This year is especially important as children are going back into school and want to make the best out of the year. In addition, many children may be in a new school where the staff is unfamiliar with your child's condition. There are a few ways to prepare such as letters to give to the school, forms that need to be completed or a virtual school visit.

Virtual visits are a great way for the HTC nurses and social workers to connect with school or daycare teachers and staff. The presentations cover the basic information about hemophilia and other bleeding disorders, answer any questions school staff have, teach them what to look for, when to call parents and how to respond to medical emergencies. In addition, we discuss some important topics such as possible psychosocial concerns, safe sports in gym and recess, and the importance of exercise. We can also work with the families and staff to ensure your child is receiving the proper academic and social services for their IEP or 504 plan. A school visit is a great way to open the lines of communication between the child's school or daycare center and the HTC. Parents are welcome to attend as well.

School letters are also important for families and schools to have. These letters give written information on your child and their bleeding disorder for the school to have on file. Schools may also need this information for 504's and IEP's. The HTC can also give the school an emergency room letter to have on hand in case of an emergency.

If you would like to schedule a school visit, you need letters or forms completed, please contact your HTC. They will ask you to fill out a form giving them permission to contact the school and may ask you to give the school notice the HTC will be contacting them.

We want to help you make sure your child has a safe, enjoyable, and successful school year!



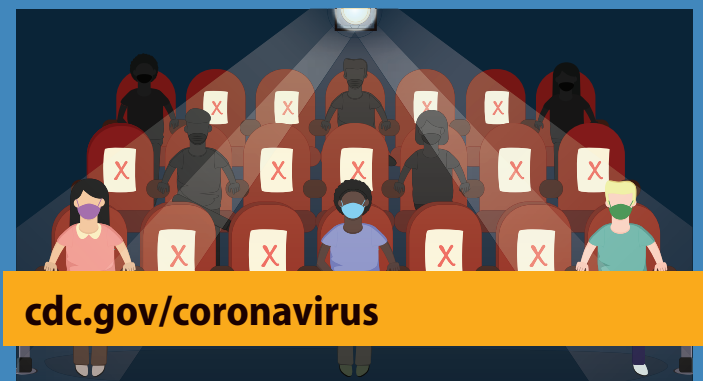
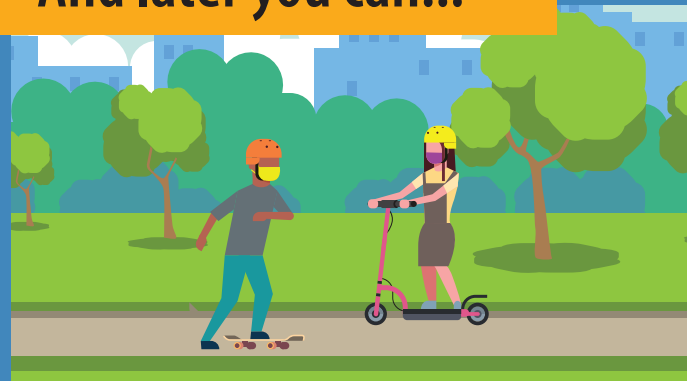
Do it for Yourself and Your Friends

If you have or think you have COVID-19

Stay home, get rest, and hydrate



And later you can...



cdc.gov/coronavirus



CS 318104-A 07/09/2020

COVID-19 Update... Jeff Lynch, MD HANJ Medical Advisor

I sincerely hope that our community experienced a safe and healthy summer season. While not back to previously normal levels recreational activities became available enough to relieve some of the stress of the pandemic.

As Covid-19 rolls on into yet another season it has been increasingly difficult to write something that is not outdated by the time of publication. It does seem safe to say that the pandemic will be with us for some time and that adapting to live with it will become more of a focus. This will come partly by mandate and partly by personal choice with a lot of back and forth between the two.

Masking is an odds on favorite to be a measure with plenty of back and forth as schools reopen and more public venues resume operations. Unfortunately the argument over mandate versus personal choice has overwhelmed the evaluation of whether they work and under what circumstances. A brief review of known qualities of masks may help decision making.

Under test conditions multi-layered cloth masks and over the counter medical masks prevent the wearer from spreading small respiratory droplets which may carry the virus. They block a high percentage but not all droplets and are affected by intensity of breathing, speech and coughing. To a lesser extent they protect the wearer from exposure to respiratory droplets produced by a nearby individual. Also under controlled conditions masks have not reduced oxygen levels or raised carbon dioxide levels.

In small studies of individuals in close proximity masks seem to have reduced virus transmission. Lacking is a large scale study such as one town masked and one town unmasked to better judge their value. This would be the normal standard on which to base a medical recommendation. In the middle of a pandemic we may have to go with the best available information and be aware it may change.

Going forward I urge everyone to remain informed beyond the usual news. Check the CDC website and read the background information not just the recommendations. We have a wide range of lifestyles and our comfort zones differ. Learning where we are comfortable and where we sense danger will become important to still do as much in life as we can.

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



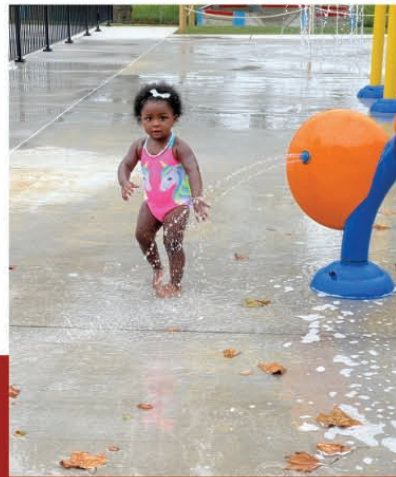
We are here to help you ...

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.

Summer Camp Wellness Gathering Eagle's Landing Day Camp

August 28 , 2021



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Medical Center | HEALTH



For more event
photos, scan
QR code:



Reframe Your Mindset



Explore how to change negative patterns during times of change.

Thursday, October 14, 2021 at 7 PM

This program was created by the University of Pennsylvania Positive Psychology Center



Tell Your Story

Discover how to define and deliver a compelling personal message or story.

Thursday, November 11, 2021 at 7 PM

Designed for teens and adults in the hemophilia community.

These events will be presented virtually. A link will be sent to you after registration.

To register for these events, contact Cindy Hansen:

732-249-6000

chansen@hanj.org





To learn more about our educational programs, visit our website by scanning this QR code:



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



*BeneFix was approved February 11, 1997.



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 (look at lips and gums)	rash
	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.



**Want to be Happier?
Try Volunteering!**


By Stephanie Lapidow
Executive Director

Most of us are still social distancing, making us feel isolated and stressed. During these stressful times, it is increasingly important to take care of our mental health. Interestingly, research suggests that volunteering can actually be beneficial to our mental health. Studies have shown that the benefits of volunteering can be enormous. Volunteering your time to help others can help you to find friends, connect with the community, learn new skills, and even advance your career. Additionally, turning our attention on someone or something else can take our minds off our worries. We feel satisfied with giving of our time and talents, and that results in improved mood and less stress.

Research suggests that people who volunteer actually experience a boost in their mental health — good news at a time when more than a third¹ of Americans report feeling symptoms of anxiety or depression. In a study published last year in the *Journal of Happiness Studies*, researchers found that compared to people who didn't volunteer, people who had volunteered in the past year were more satisfied with their lives and rated their overall health as better. Additionally, the researchers found that people who volunteered more frequently experienced greater benefits. Those who volunteered at least once a month reported better mental health than participants who volunteered infrequently or not at all.


HANJ understands the importance of volunteering on this level as well as on the organizational level. We could not exist without the dedicated volunteers who give of their time and talent, day after day, year after year. If you are looking for a way to channel your energy into a cause you believe in, please reach out so we might determine how to find the best volunteer fit for you. I look forward to hearing from you!

1.) Mental Health - Household Pulse Survey - COVID-19 (cdc.gov)



I have not let hemophilia hold me back in my life. It has been amazing to grow up in a time when we get to see the advancements being made in treatment.
Trevor Graham

It is important to me that I try to be available to anyone in the community who might be struggling in ways I have struggled.
Max Feinstein



Benefits of Volunteering:

1. Reduces Stress
2. Combats Depression
3. Prevents Feelings of Isolation
4. Increases Confidence
5. Gives a Sense of Purpose
6. Ignites Passion
7. Makes You Happy

Meet Max Feinstein and Trevor Graham, two of our newest volunteers. HANJ is so fortunate that these two have decided to take time out of their busy lives to lend their time and talent. Scan the QR code below and read more about Max and Trevor and learn more about volunteer opportunities at HANJ.





JIVI[®] ADYNOVATE[®]

PK (Pharmacokinetics) Study Data



Talk to your doctor
about the study.



Scan the QR code to learn more
about PK at [UnderstandingPK.com](https://www.understandingpk.com)

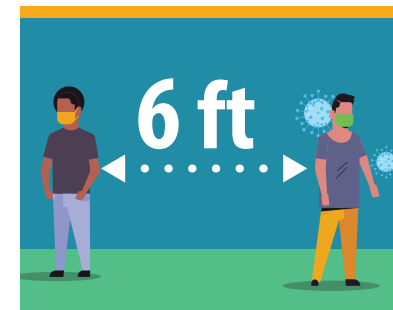
STOP THE SPREAD OF GERMS | COVID-19 |



Get a COVID-19 vaccine.



Cover your cough or sneeze with a tissue, then throw the tissue in the trash and wash your hands.



Stay at least 6 feet
(about 2 arm lengths)
from other people.



When in public,
wear a mask over your
nose and mouth.



Do not touch your
eyes, nose, and mouth.



Clean and disinfect
frequently touched
objects and surfaces.



Stay home when you
are sick, except to get
medical care.

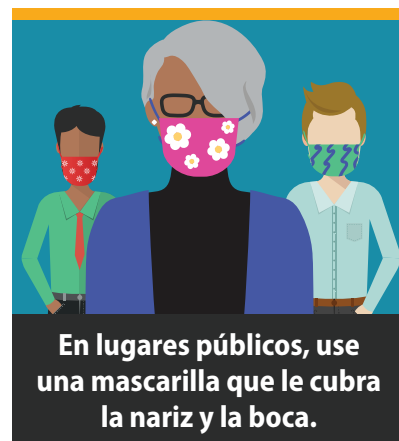


Wash your hands often
with soap and water for
at least 20 seconds.



[cdc.gov/coronavirus](https://www.cdc.gov/coronavirus)

DETENGA LA PROPAGACIÓN DE GÉRMENES | COVID-19 |



<https://espanol.cdc.gov/coronavirus/2019-ncov/index.html>



Seasonal Affective Disorder

Also called: SAD, Seasonal depression, Seasonal mood disorder
Summary From National Institute of Mental Health

Seasonal affective disorder (SAD) is a type of depression that comes and goes with the seasons. It usually starts in the late fall and early winter and goes away during the spring and summer. Some people do have episodes of depression that start in the spring or summer, but that is a lot less common. Symptoms of SAD may include:

- Sadness
- Gloomy outlook
- Feeling hopeless, worthless, and irritable
- Loss of interest or pleasure in activities you used to enjoy
- Low energy
- Difficulty sleeping or oversleeping
- Carbohydrate cravings and weight gain
- Thoughts of death or suicide

SAD is more common in women, young people, and those who live far from the equator. You are also more likely to have SAD if you or your family members have depression.

The exact causes of SAD are unknown. Researchers have found that people with SAD may have an imbalance of serotonin, a brain chemical that affects your mood. Their bodies also make too much melatonin, a hormone that regulates sleep, and not enough vitamin D.

The main treatment for SAD is light therapy. The idea behind light therapy is to replace the sunshine that you miss during the fall and winter months. You sit in front of a light therapy box every morning to get daily exposure to bright, artificial light. But some people with SAD do not respond to light therapy alone. Antidepressant medicines and talk therapy can reduce SAD symptoms, either alone or combined with light therapy.

NIH: National Institute of Mental Health

Courtesy of MedlinePlus from the National Library of Medicine



It's
apple picking
season!

Join the Blood Brotherhood
for their upcoming apple
picking event.

The NJ Blood Brotherhood
program holds free events for
men with bleeding disorders.

If you would like to learn more about the
Blood Brotherhood group and attend one of
their events, please go to the HANJ website
by scanning this QR code:



Blood Brotherhood Program



The purpose of the Blood Brotherhood program is to
provide an opportunity for adult hemophiliacs to connect
with their peers in a fun, relaxed setting.

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

If you would like to join the Blood Brotherhood group and attend one
of our events, **please reach out to:**

Max Feinstein, Co-Chair feinmusic@gmail.com (201) 723-6324

Matt Porges, Co-Chair msporges@gmail.com (347) 693-8875

Or call HANJ directly at (732) 249-6000.

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



HANJ has launched an
instagram account.
Scan the QR code to
like and follow us!



A LETTER TO MY 13-YEAR-OLD SELF

*Reprinted with permission from BioMatrix News:
www.biomatrixsprx.com
BY RICHARD VOGEL

Life is an unknown. And that's what makes living it so special. Having a bleeding disorder makes it twice as difficult. What if we had some insight into our future? Not that we could change our life but to encourage us when moments look dark. As a 65-year-old man with severe hemophilia, I look back and remember the uncertainty, the worries and fears, and the deep desire to actually live my life no matter what obstacles it had in store for me. If I could write a letter to my 13-year-old self it would go something like this...

Dear 13-year-old Me,

Things look sort of dismal right now lying on the couch with yet another bleed – a knee the size of a basketball, even after having it aspirated. As always, you'll get through. It was pretty disappointing you couldn't go to Woodstock with your older brother that weekend, but you couldn't put pressure on your knee, so walking was out. But you don't tend to blame disappointments in life on your hemophilia. Your motto will be, "Tomorrow is another day." Always know you are a fighter.

There will be some milestones in your life that will make you become the man you are today. For one, you will have outlived your life expectancy by 45 years so far! When you were born in 1956, you were not expected to make it to your 20th birthday. And you almost didn't. Remember when you had that brain bleed at 3? For someone with hemophilia to survive a brain bleed being treated with whole blood was nothing short of a miracle. Or luck. Look at the bright side – just by surviving you earned a place in medical history.

You don't realize this yet, but Mom and Dad don't treat you any differently than your siblings. They want you to live a normal life even though, aside from whole blood and plasma, there is no



8th Grade President

other therapy for hemophilia. When you were 9, Dr. Judith Graham Pool discovered cryoprecipitate "cryo," which helped with your bleeding episodes. Three years later, you learned how to self-infuse this new lyophilized product called clotting factor.

In time, you will see major advances in hemophilia therapies... and these advances will also cause you to suffer some heartache. Because of the vast amounts of donated blood needed to make this new clotting factor, you will contract blood-borne hepatitis B and non-A non-B, which years later will be called hepatitis C. Christmas 1973, at 17, you will have jaundice, but it won't get you down.

In the early 1970s, you'll be busy living your life. It's a time of change, politically, musically and creatively, and you are determined to be a part of it, despite hemophilia. You'll participate in sit-ins protesting the Vietnam War, have fun at Grateful Dead concerts, and discover photography, first as an art form and later, a career. Mom and Dad know it will be difficult for you to hold a steady job because of the spontaneous bleeds, so they will support you in whatever you want to do. They'll even be okay with you growing your hair long when you tell them it will help you fit in and maybe no one will notice how you limp.

Over the next few years, you will have some great experiences and will learn to live life on your own. Traveling cross country in your van and spend months in New Mexico doing photo-documentary work for the New Mexico Solar Energy Commission and photographing the construction of solar greenhouses on various American Indian reservations are in your future.

That will be the start of wanting to help others, but you won't realize it for a while. Your photography career will continue in New York City, first apprenticing for a well-known fashion photographer and then opening your own studio. You will take your first trip by plane and sit staring out the window like you're 13 again - the start of your desire to travel and see the world. Living in Greenwich Village, you will develop a wide range of musical tastes hanging out at clubs like Max's Kansas City, the Bitter End, and the Village Vanguard. Enjoy those times. You won't have regrets.

I am sorry to tell you though, in 1982, in addition to hepatitis, you will contract HIV from the clotting factor you're using to control your bleeding. You will be at the Perry Street Theater seeing *A Christmas Carol* with Orson Wells as Scrooge. Halfway through you will have a spontaneous elbow bleed and rather than ruin the evening by leaving, you will sit in pain until you can get home to infuse. You're used to the cloudy factor you'll infuse that night, but the next day you will be sick with flu-like symptoms.



Richard Johnson, former HANJ Outreach Coordinator, laughing it up with my father.



8th Grade Graduation

That's the HIV. Once the news channels report that HIV is found in the blood supply, you will figure it was inevitable. After all, by then you will have received many doses of clotting factor and blood transfusions.

When you do find out about HIV, the doctor will tell your wife (yes...you get married – twice!), "Why would you want to have kids with him, he will be dead in five years." You won't complain though. You won't ask, "Why me?" You'll just go on living your life.

At 27, you're still a little naive. You've grown up with these doctors, they've kept you alive. Why would doctors and national organizations tell us to keep infusing when HIV was in the blood products? You trust them, but no one trusts them more than Dad. When the first legal trials against the pharmaceutical companies start, many doctors begin testifying against their own patients.



The President, Anna DeSimone, Presented Dad with HANJ's Past Presidents Award.

Dad will walk up to my doctor after she testifies for the manufacturers, a woman he considers part of our family, and will tell her she has broken his heart. For a man who doesn't show his emotions, it is devastating. He won't ever speak to her again. This memory will stay with you forever. You will realize that day what a true advocate he has been.

But you're a fighter. A survivor. You won't let HIV bother you. Your attitude is, "I was exposed to this virus, but maybe I've built antibodies." Maybe you will or maybe you're just lucky, but you'll stay fine until 2010 when you develop thrombocytopenia. Possibly from the HIV, it seems your body will begin to turn on itself and start destroying platelets. This will lead to another brain bleed. Again, you will survive, even if the hospital misreads the CT scan and doesn't infuse you for three days. After that, you do start taking HIV anti-viral drugs. Maybe this will also help you survive the pandemic of 2020 - yes, we have one of those coming! Just maybe you'll be lucky again.

Even at a young age, you will never want to be a burden on society, so you will always work. Your first job will be in the shipping department of a men's store, and you will drive an ice cream truck after high school graduation. You will have a career as a professional freelance photographer, will start your own trial consulting business, and will advocate for people with bleeding disorders. You inherited the best of both worlds; Mom is a creative optimist while Dad is always pragmatic. It will take you years to see this, but the catalyst for your advocacy is another milestone in your life. Dad passes away when you're 39.

He will have taken better care of your hemophilia than you do. He made sure you had insurance. He will have held blood drives in your name so you could

use blood credits to get clotting factor, which insurance wouldn't cover at the time. He will have helped the Hemophilia Association of New Jersey (HANJ) pass legislation so insurance companies would be required to cover clotting factor.

With Dad gone, you will have to take control of your hemophilia. Following in his footsteps, you will jump in with both feet, serving as a HANJ board member and the New Jersey representative on the board of the recently formed Hemophilia Federation of America. In later years, you will serve as president of each of those organizations. It will be an honor when you received HANJ's Past Presidents Award, which includes Dad's name alongside other former presidents.

Side by side with advocates, you will be involved in getting the Ricky Ray Hemophilia Relief Fund Act of 1998 passed and funded. This will help patients and families get the compensation they rightly deserve. At 13, you haven't yet heard of Ricky Ray - he won't be born until 1977. Another young person with hemophilia - Ryan White will be born in 1971. Their lives will come to have much meaning for you.

Later in 2009, you will become a voting member of the Federal Advisory Committee on Blood Safety and Availability, which "...provides advice to the Secretary of Health and Human Services through the Assistant Secretary for Health on a range of policy issues related to blood, blood products, and tissues." You will continue to use your voice on behalf of and for the welfare of the bleeding disorders community. Dad would have been so proud of you.

You will reach another milestone in your life - 65 years old! I'll fill you in, not even talking hemophilia, as we get older, *everything* gets more difficult. Throw in some joint damage and diminished

range of motion and you're in for a bumpy ride. Things most people take for granted like buttoning the top button of a shirt are a challenge. By the way, what is the worst thing you can ask a man with hemophilia at the dinner table? Please pass the salt. Never lose the humor. It is what helps you get through the bad times.

I want you to know you WILL endure. Don't give up! You will find yourself in a very small group of surviving veterans - men over 60 with hemophilia, HIV, and other co-morbidities. You will be absolutely delighted to be in a group of old men with diabetes, high blood pressure, high cholesterol, and osteoporosis. Your kidneys will leak protein, but you know what? It's a small price to pay to still be here, working, helping people, traveling, whipping up a great meal, and enjoying life!

There will be many times in your life you will ask yourself if you made the right decision. Don't doubt yourself. You won't forget your failures so confront them head-on. They will give you the drive and determination to succeed. Despite the challenges, you will survive.

The future will have its ups and downs but by persistence, hardheadedness, and a little luck, I'm here to say you will make it! As your favorite group, the Grateful Dead will say next year, "Sometimes the light will be shining on you and sometimes you will barely be able to see but what a long, strange trip..." it will be.

**Be happy,
65-year-old You**

***Reprinted with permission from "A Letter To My 13-Year-Old Self" by Richard Vogel. BioMatrix News, Volume 16, Issue 3, 2021.**



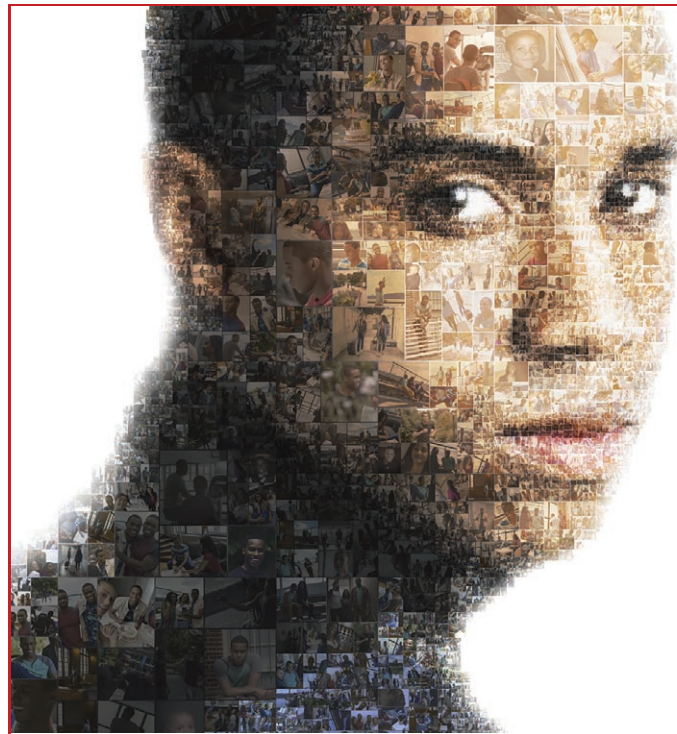
Confirmation



Smile Ready



Long hair and a big fish.



ADYNOVATE
[Antihemophilic Factor
(Recombinant), PEGylated]
REAL LIFE. REAL BLEED PROTECTION.*
AdynovateRealLife.com

HEMOPHILIA A IS A PIECE OF YOU. NOT ALL OF YOU.

ADYNOVATE® is a treatment that can be personalized to fit your lifestyle so you have more time to spend doing the other things that also make you, you. It has a simple, twice-weekly dosing schedule on the same 2 days every week.^{1,2}

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

No actual patients depicted.

ADYNOVATE twice-weekly prophylaxis prevented or reduced the number of bleeds²

ADYNOVATE was proven in 2 pivotal clinical trials to prevent or reduce the number of bleeding episodes in children and adults when used regularly (prophylaxis)²

- **Children Under 12 Years:** This study evaluated the efficacy of ADYNOVATE twice-weekly prophylaxis and determined the ability to treat bleeding episodes for 6 months in 66 children under 12 years old who received 40–60 IU/kg of ADYNOVATE prophylaxis treatment²
 - During the 6-month study in children under 12, those receiving twice-weekly prophylaxis treatment experienced a median¹ overall ABR* of 2.0
 - 0 bleeds in 38% (25 out of 66 patients) during 6 months on twice-weekly prophylaxis

- **Adolescents and Adults 12 Years and Older:** This study evaluated the efficacy of ADYNOVATE in a 6-month study that compared the efficacy of a twice-weekly prophylactic regimen with on-demand treatment and determined hemostatic efficacy in the treatment of bleeding episodes in 137 patients. These adolescents and adults were given either ADYNOVATE prophylaxis twice-weekly at a dose of 40–50 IU/kg (120 patients) or on-demand treatment with ADYNOVATE at a dose of 10–60 IU/kg (17 patients). The primary study goal was to compare ABR between the prophylaxis and on-demand treatment groups²
 - 95% reduction in median overall ABR (41.5 median ABR with on-demand [17 patients] vs 1.9 median ABR with prophylaxis [120 patients])
 - 0 bleeds in 40% (40 out of 101 per-protocol³ patients) during 6 months on twice-weekly prophylaxis

¹Median is defined as the middle number in a list of numbers arranged in numerical order.

²ABR=annualized bleed rate, the number of bleeds that occur over a year.

³Per-protocol patients were assigned to the prophylactic group and treated with their originally assigned dose for the entire duration of the study.

ADYNOVATE Important Information

What is ADYNOVATE?

- ADYNOVATE is an injectable medicine that is used to help treat and control bleeding in children and adults with hemophilia A (congenital factor VIII deficiency).
- Your healthcare provider (HCP) may give you ADYNOVATE when you have surgery.
- ADYNOVATE can reduce the number of bleeding episodes when used regularly (prophylaxis).

ADYNOVATE is not used to treat von Willebrand disease.

DETAILED IMPORTANT RISK INFORMATION

Who should not use ADYNOVATE?

Do not use ADYNOVATE if you:

- Are allergic to mouse or hamster protein.
- Are allergic to any ingredients in ADYNOVATE or ADVATE® [Antihemophilic Factor (Recombinant)].

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

What should I tell my HCP before using ADYNOVATE?

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 ADYNOVATE passes into your milk and if it can harm your baby.
- Are or become pregnant. It is not known if ADYNOVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADYNOVATE may not work for you).

What important information do I need to know about ADYNOVATE?

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

What else should I know about ADYNOVATE 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 ADYNOVATE 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 ADYNOVATE?

- The common side effects of ADYNOVATE are headache, diarrhea, rash, nausea, dizziness, and hives. These are not all the possible side effects with ADYNOVATE. Tell your HCP about any side effects that bother you or do not go away.

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 ADYNOVATE on the following page and discuss with your HCP.

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

References: 1. Valentino LA. Considerations in individualizing prophylaxis in patients with haemophilia A. *Haemophilia*. 2014;20(5):607-615. 2. ADYNOVATE Prescribing Information.

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ADYNOVATE [Antihemophilic Factor (Recombinant), PEGylated]

Patient Important Facts about

ADYNOVATE® [Antihemophilic Factor (Recombinant), PEGylated]

This leaflet summarizes important information about ADYNOVATE. 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 ADYNOVATE. If you have any questions after reading this, ask your healthcare provider.

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

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 ADYNOVATE so that your treatment will work best for you.

What is ADYNOVATE?

ADYNOVATE is an injectable medicine that is used to help treat and control bleeding in children and adults with hemophilia A (congenital Factor VIII deficiency). Your healthcare provider may give you ADYNOVATE when you have surgery. ADYNOVATE can reduce the number of bleeding episodes when used regularly (prophylaxis).

ADYNOVATE is not used to treat von Willebrand disease.

Who should not use ADYNOVATE?

You should not use ADYNOVATE if you:

- Are allergic to mice or hamster protein
- Are allergic to any ingredients in ADYNOVATE or ADVATE® [Antihemophilic Factor (Recombinant)]

Tell your healthcare provider if you are pregnant or breastfeeding because ADYNOVATE may not be right for you.

How should I use ADYNOVATE?

ADYNOVATE is given directly into the bloodstream.

You may infuse ADYNOVATE 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 ADYNOVATE by themselves or with the help of a family member.

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

Reconstituted product (after mixing dry product with wet diluent) must be used within 3 hours and cannot be stored or refrigerated. Discard any ADYNOVATE left in the vial at the end of your infusion as directed by your healthcare professional.

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

How should I use ADYNOVATE? (cont'd)

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

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

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 ADYNOVATE passes into your milk and if it can harm your baby.
- Are pregnant or planning to become pregnant. It is not known if ADYNOVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADYNOVATE may not work for you).

What are the possible side effects of ADYNOVATE?

You can have an allergic reaction to ADYNOVATE.

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.

The common side effects of ADYNOVATE are headache, diarrhea, rash, nausea, dizziness, and hives. 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 ADYNOVATE. You can ask your healthcare provider for information that is written for healthcare professionals.

What else should I know about ADYNOVATE 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 ADYNOVATE 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 ADYNOVATE for a condition for which it is not prescribed. Do not share ADYNOVATE 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 ADYNOVATE. The FDA-approved product labeling can be found at www.ADYNOVATE.com or 1-877-TAKEDA-7.

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.

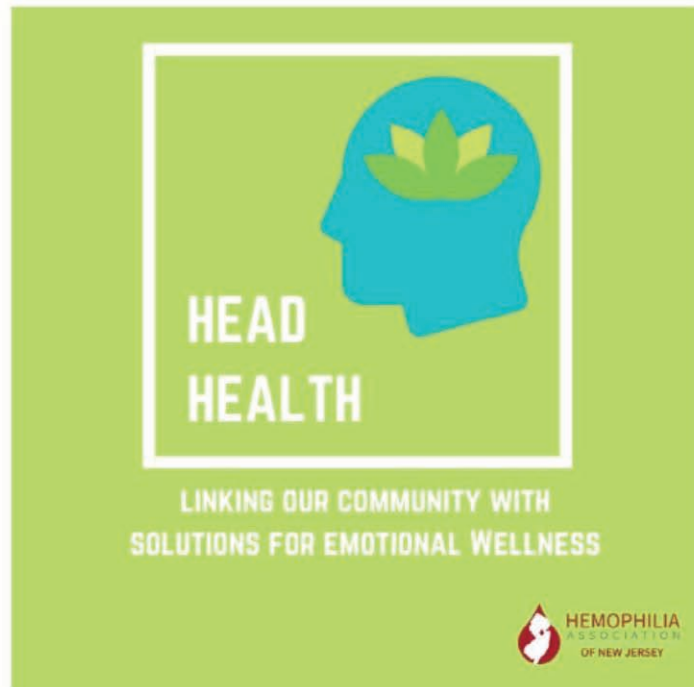
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HANJ is very proud of Head Health, a collaborative and thoughtful initiative created by our Mental Health Committee.

Some of the Head Health projects include:

- Bi-weekly emotional wellness blog
- Suicide Prevention workshop in support of Suicide Prevention Awareness Month
- Monthly website updates on mental health resources

We are excited about the upcoming projects in the works as we strive to assist the community in finding solutions for emotional wellness.

You can find more information about Head Health on the HANJ website. Scan this QR code to go there:

