

# HANJournal

*The quarterly news journal of the Hemophilia Association of New Jersey*



**In 2016, March was officially designated as Bleeding Disorders Awareness Month. Join HANJ in celebrating and honoring the bleeding disorders community.**

**Annual HANJ  
Community  
Resource  
Guide**

**HANJournal**  
*the quarterly  
publication of the  
Hemophilia  
Association of  
New Jersey*

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*#communityisinourblood*

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The Hemophilia Association of New Jersey is dedicated to improving the lives of people with bleeding disorders and their families by providing access to resources, education, and advocacy.

## HANJ – Your Ultimate Resource

*Stephanie Lapidow*  
*Executive Director*



In our current age of technology, all you need to do is turn to Google and presto – you have abundant facts and figures at your fingertips! This is both amazing and frustrating when you are trying to gather information about a particular topic. Where do you begin, and which source do you believe? HANJ recognizes that the search for good information can be frustrating. That is why we are dedicated to our mission of improving the lives of people with bleeding disorders and their families by providing access to resources, education, and advocacy. We continually strive to gather and update information that is important to our community in an effort to serve as a valuable resource that is meaningful to our members. For example, in this issue of the HANJournal, we have compiled a comprehensive guide to pharmaceutical and non-pharmaceutical assistance programs that I am sure you will find useful. We are constantly updating this list and you can always find the latest updates on our website.

HANJ provides many educational resources for our members. We host educational programs throughout the year. In fact, our Community Connections event is just around the corner and will provide educational sessions of interest to our members. If you have not yet registered for this program, simply go to our website, and register today!

If you are looking to keep updated about the latest news stories pertinent to the community, our social media accounts repost news articles regularly. These articles are also reposted to our website. HANJ is fortunate to have volunteer committees whose members work to inform and empower our members throughout their journeys. Our Mental Health Committee was integral in compiling the survey included in this mailing of HANJournal. If you have not yet completed this survey, please do so as the results can be used to provide the community with programming to meet their needs.

These are just a few of the many resources HANJ makes available to our community. Remember, we are always here for you. If you are having difficulty finding information or resources you might need, please do not hesitate to call the office, or drop us an email – it's our mission to serve you!



# Dedication and Personal Support

**Your Pfizer Patient Affairs Liaison** is a professional dedicated to serving you and the hemophilia community by connecting patients and caregivers with Pfizer Hemophilia tools and resources. These Pfizer colleagues are committed to continuing Pfizer's more-than-20-year history of listening to the hemophilia community and working to meet its needs.



## Annie Sukhnandan

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*"I've been a passionate and dedicated advocate for the rare disease community for over 16 years."*

### My work is guided by:

#### Compassion

Listening to your needs and addressing questions and concerns that you may have

#### Commitment

Educating you about Pfizer's tools and resources, including the Pfizer Community Connections Program, the HemMobile® app for logging bleeds and infusions, B2B materials, and more

#### Connection

Connecting you with hemophilia advocacy groups and programs like Leading Edge, the National Hemophilia Foundation, The Coalition for Hemophilia B, and others

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## Become Your Own Advocate

*Jeff Lynch, MD*

*HANJ Medical Advisor*

March is Bleeding Disorders Awareness Month and you can expect a significant effort by our own HANJ as well as the national organizations to educate the parts of society and government that affect our wellbeing. Over time we have done a good job of bringing insurers and government to understand the needs of our community although it takes constant attention to maintain that progress. Unfortunately, the wider medical community is not deep with understanding of bleeding disorders. Hemophilia Treatment Centers have been a huge benefit ensuring our proper care. However, outside of the HTC we are often confronted by little knowledge of how Hemophilia impacts other medical care that we may require. Perhaps all of us have experienced the emergency room staff mystified at what we are telling them. I had the experience with my daughter and myself at a major medical center. Managing an injury in a patient with a bleeding disorder is often almost the opposite of routine care. This brings me to the point that the most important bleeding disorder awareness is our own and that of relatives and friends who may need to help in an emergency. In the summer issue of this newsletter, we will be providing a saveable copy of "Guidelines for Emergency Department Care of Individuals with Hemophilia and other Bleeding Disorders" from the National Hemophilia Foundation. This document is suitable to be carried to emergency rooms or doctor visits and outlines the proper sequence of management injuries and other emergency situations. For our community, learning the contents of this document can make us "the smartest person in the room" in emergency situations. I firmly believe that even with our extensive medical system we need to be our own experts to protect our well-being. So do learn about your own condition. Be able to give a complete health history as well as a current treatment summary and have a friend or relative who can do the same. Be able to instruct someone else to infuse your factor and have a backup person able to locate it. Meanwhile participate in all the awareness events this month as these are also crucially important in continuing and extending the progress we have made. But also take time to become your own personal source of awareness. Have a great and healthy spring!

# Ready to be Kinder to Yourself?

Ten Steps Toward Self-Compassion

Gary McClain, MS, PhD, LMCH, CEAP

“You knew that would happen!”

“Can’t you do anything right?”

Or how about:

“Idiot!”

Who’s saying all those mean things to you? Most likely, your own harshest critic. YOU!

We human beings sure can be tough on ourselves. Pointing out our mistakes. Our misjudgments. Anything we do that falls short of a demand we didn’t meet. All too often demands we created for ourselves that weren’t realistic in the first place.

And just where does that critical voice come from? I suspect it’s a voice we hear as children, maybe from parents who criticized and scolded, when we were judged as not having met the demands that were placed on us. Or teachers. Maybe other kids. Somewhere along the way, we learn that when we make a mistake, or can’t quite perform as well as someone else thinks we should, we are going to hear about it. Often with some pretty harsh words.



*Dr. Gary McClain is a psychotherapist, patient advocate, blogger, and author, specializing in helping clients deal with the emotional impact of chronic and life-threatening illnesses. His website is [JustGotDiagnosed.com](http://JustGotDiagnosed.com). His email is [gary@JustGotDiagnosed.com](mailto:gary@JustGotDiagnosed.com). He welcomes your questions and comments.*

Sure, criticism can make you better. That’s probably what was behind all that criticism that came your way as a child. Or at least that’s what you were told.

## Turn Off the Self-Criticism and Replace It with Kindness

But what happens is that, as we become adults, that baton magically gets passed to us. And unfortunately, we latch onto it. By doing so, we invite those critical voices into our minds and give them free reign to sound off at will. And they truly take advantage of every opportunity! While compassion for ourselves gets pushed off into the corner.

If you’re living with a chronic condition like a bleeding disorder, you know about demands. Your condition places all kinds of demands on you, every day. With each demand, it is another reason to be hard on yourself when your performance doesn’t quite measure up.

Let me ask you something: Have you ever thought about the toll it takes on you when the person in the mirror always has a good scolding ready, just waiting to unleash it? That’s a lot of pressure to live with. And another question: Is it possible that you might be demanding a little too much of yourself in some areas of your life? And how about this: Is all the scolding the only way you have to keep yourself motivated?

You’ve heard that expression, with friends like you, who needs enemies? So I have to ask: Are you being a friend to yourself?

And I have to add something here. When you’re that hard on yourself, that becomes your view of the world. And that can translate into being hard on other people, too.

## Ten Steps Toward Self-Compassion continued

Compassion starts with being kind to yourself  
Here’s how to get started:

**Set priorities.** Sit down with yourself and think about what you really need to do to take the best possible care of yourself. Focus on the basics, what you need to do to maintain your optimal health, physically, emotionally, and in your relationships. Make a list. And a schedule. These are your priorities.

**Remind yourself that not everything is a crisis.** One of the best ways to give yourself a rough time is to look at anything less than perfection as an absolute catastrophe and then make yourself at fault. Take a step back and consider the situation. Let’s say you slipped up or made a mistake in judgment. Is this something that can be fixed? Do you know how to get things back on track? And if not, is there someone who can help? All that energy spent on self-criticism can be channeled toward finding a solution.

**Focus on the big picture.** Who knows, you may even decide that what felt like a crisis at the moment was only a bump in a much longer road. What a relief, right?

**Look for the lesson.** Here’s where you have a choice. You can look at a mistake or a setback as a reason for punishment, and call yourself lazy, stupid, etc. Or you can turn this into an opportunity for learning. Try this: “Oh, so that’s what happens if I... At least I know how to avoid this problem in the future.” And then move forward, that much more educated.

**Watch your self-talk.** We spend our waking hours talking to ourselves. Evaluating, predicting, explaining... judging. And it’s that judgment talk that can make us very unhappy. So be more aware of your self-talk. When you feel the critical voice gearing up to let loose with a good old scolding, tell him/her to be quiet. And then engage that kindly, compassionate voice that’s been cowering in the corner for too long.

**Give yourself a break.** Ask that voice of kindness for a little pep talk. Remind yourself: “I’m human. I’m trying hard. This is not an easy road. And I am doing the best I can, even if not everything I do is perfect.” Having trouble conjuring up that voice? It might help to sit down with a sheet of paper and do some journaling. Give yourself a positive self-talk script you can read when you need a lift. Try some affirmations. Start out with: “I am a work in progress. I get better every day.”

If you would like to read more blog entries by Dr. Gary, scan the QR Code:



**And let yourself feel.** One of the ways we punish ourselves is by telling ourselves that we shouldn’t be feeling the way we feel. But there is no right or wrong way to feel. So as emotions come up, don’t swallow them. Let yourself feel, whether that judging voice approves or not. Sad, mad, afraid. It’s all part of being human. That’s being kind to yourself.

**Replace punishment with rewards.** Chances are, if you are letting loose on yourself with that critical voice, you may also be punishing yourself in some way. Avoiding people. Not doing things you know you would enjoy. Pushing yourself to overwork. What if you gave yourself some rewards when you meet an expectation you have for yourself? This is a way to shift your focus to what’s going well and to give yourself some encouragement to keep up whatever you’re doing that got you there. Indulge in something you enjoy that promotes your wellness, a little break, a favorite activity, some fun with a friend or family member. You deserve it!

**Let somebody help.** Limit your time with critical people. Instead, try to surround yourself with people who bring out the best in you. Be kind back. Kindness leads to more kindness. And it sure feels a whole lot better than criticism!

**Smile at your imperfections.** Nobody’s perfect. Now, how do such imperfect people manage to dress themselves in the morning? It’s a mystery. We’re all so imperfect that we just have to shake our heads and laugh at ourselves sometimes. How’s that for lightening up?

You’re dealing with a lot. So how about giving yourself credit for doing the best you can? Show yourself some compassion and some love while you’re at it. Be kind to yourself.



## St. Michael's Medical Center

Joanne Rodriguez

### Spring

The weather is starting to get better as spring is approaching but please be mindful and remember that we are still dealing with a Pandemic. Wearing masks, keeping our distance and handwashing still stands. 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://covid19.nj.gov/pages/vaccine).

### Walk-in COVID-19 Clinic at St. Michael's Medical Center

You may walk in on Thursdays between the hours of 7:30a.m.-11:30a.m. to get your COVID-19 vaccine or Booster. We are offering all three vaccines, Moderna, Johnson & Johnson, and Pfizer. If you have any further questions, please feel to call The Blood Research Institute at (973)877-5342.

### Travel Letters

Spring holiday travel is approaching and people are starting to make travel plans. We recommend that you call our office at least a couple of weeks before the travel date to request travel letters. Please call our center at (973)877-5342 and ask for Social Worker, Joanne Rodriguez at 973-877-2967.

### Insurance

If you need to call our office to make an appointment but are not sure if your insurance is accepted in the hospital or clinic, please let us help you with any questions or concerns you may have. We can help with questions pertaining to co-payments, deductible and coverage issues as well. Also, if any changes need to be made to your insurance, we are here to help.

### Re-Evaluation

We are open and servicing our community. Give us a call and schedule your re-evaluation for the year. Annual evaluations are an important aspect of the patient's treatment care. Evaluations are important as we can assess the medical, social, emotional, and psychological components of each individual. You can contact us at (973)877-5342 Monday through Friday to schedule yours.

### Scholarships

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

### Patient Education

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

### Educational Program:

Due to COVID-19, we haven't been able to have our monthly educational meetings but, we can have individualized sessions which will provide guidance for any questions or concerns that you may have. Do not hesitate to give us a call should you have questions about new therapies or new programs, insurance, or any other topics that may be of interest to you. Give us a call and schedule your session by calling us at (973)877-5342.

### Factor Programs:

Manufacturers have programs for individuals that are having issues with insurance. Patients can be enrolled in these programs but of course, these programs have requirements that must be met.

Yearly re-enrollment may be necessary but is beneficial as this will help in continuing with the program. If you need assistance with factor due to insurance problems, please call Joanne Rodriguez, Social Worker at (973)877-2967 for further information and assistance.

### 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](https://suicidepreventionlifeline.org)

Depression Test: [screening.mhanational.org](https://screening.mhanational.org)

Emergency: 911

For any additional help, call your insurance company and find out providers in your area (Social Workers, Psychologist, Psychiatrist, Counselors) that may assist with your mental health issues long term.

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



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Social Worker:

Joanne Rodriguez, CSW

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973-877-2967

973-877-5466 (fax)

**Newark Beth Israel  
Medical Center and  
Children's Hospital of New Jersey**  
*Emily Fusco, LSW*

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.

**News:**

**Hemophilia Camp:** Camp season is quickly approaching. Children can attend a hemophilia camp at either Double H Ranch or The Hole in the Wall Gang Camp. Both camps also offer family programming. Camp can be an integral part of a patient's journey towards independence. For more information about camp, or if your child is interested in attending, please contact our Social Worker, Emily.

**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 Emily.

**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:** 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. 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. This app will take the place of Advoy sometime in 2022. 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 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 or 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 before 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.



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**973-926-4197**  
**973-391-0048 (fax)**



**Rutgers Robert Wood Johnson  
Medical School  
Hemophilia Treatment Center**  
*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 with an increase in availability of in-person appointments with all HTC physicians beginning in March. 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 by calling the general clinic line to reach the nurses at 732-235-6542 and by calling 732-235-6533 to reach the social worker.

**STUDIES:** Two studies are currently ongoing at the HTC: 1) Prospective, Randomized, Crossover Trial Comparing Recombinant von Willebrand Factor (rVWF) vs. Tranexamic Acid (TA) to Minimize Menorrhagia in Women with von Willebrand Disease: The VWD Minimize Study. 2) Genetic Analyses of Patients with Incomplete Plasminogen Activator Inhibitor (PAI) - 1 Deficiencies and Bleeding Diatheses. The purpose of this research is to identify differences in the genes associated with plasminogen activator inhibitor 1 (PAI-1) in patients with low PAI-1 activity. This study is currently enrolling.

**PROGRAMS & SCHOOL VISITS:** Educational programs and school visits continue virtually at this time. Stay tuned for updates regarding upcoming programs for new families in the spring. If you anticipate the need for a school or daycare in-service program, please contact Lisa Cohen, MSW at [cohenlr@rwjms.rutgers.edu](mailto:cohenlr@rwjms.rutgers.edu) or by phone at 732-235-6533.

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**Nurse direct line for medical issues:**  
**732-235-6531**  
**Social Worker:**  
**Lisa Cohen, MSW, LSW**  
**[cohenlr@rwjms.rutgers.edu](mailto:cohenlr@rwjms.rutgers.edu)**  
**732-235-6533**



## COVID-19 and Hemophilia Preparedness and Self-Care in a Pandemic

*This information is provided for educational purposes only and is not intended to replace discussions with a health care provider. Speak to your treatment team if you have any questions about your/your child's care.*

This content is brought to you by Pfizer.

**The COVID-19 pandemic brought with it many lessons that can be carried into the future, including ones on preparedness, health care provider (HCP) communication, and self-care.**

### HCP Communication

Good communication with your hemophilia treatment center or care team can be an important part of living with hemophilia. During a pandemic, your team can help you understand possible risks based on your condition, as well as advise on treatment and vaccination.

### Being prepared and proactive in hemophilia care<sup>1</sup>

One of the lessons of the COVID-19 pandemic is that it is important to be prepared, and that also applies to the hemophilia community. National Hemophilia Foundation's (NHF's) Medical and Scientific Advisory Council recommends:

- Having a 14-day supply of factor products available during crisis for those who treat at home
- If an ER visit is required, call in advance so staff knows you are coming and why; this will help them prepare
- Staying in contact with your doctor's office or hemophilia treatment center (HTC). They can explain what to do if you need to visit in person or can help get you connected with telehealth appointments, if available

### Caring for yourself<sup>2</sup>

Events such as the COVID-19 pandemic can create uncertainty for many, which can stir up emotions such as anxiety, fear, anger, sadness, discouragement, or a sense of being out of control. Self-care is important to help you

address these feelings. Here are a few tips you can use to take care of your mental health:

- Set and maintain a routine
- Focus on things you can control
- Use technology to maintain social connections with your loved ones
- Focus on reasons to be grateful
- Read books or listen to music
- Take a break from news and social media if it makes you anxious
- Look for ways to help your community
- Acknowledge and appreciate what others are doing to help

### Further information

Many of the larger advocacy groups have sites to keep you in the know, see below:

- **The Coalition for Hemophilia B**  
[hemob.org](http://hemob.org)
- **Hemophilia Federation of America**  
[hemophiliafed.org](http://hemophiliafed.org)
- **Hope for Hemophilia**  
[hopeforhemophilia.org](http://hopeforhemophilia.org)
- **National Hemophilia Foundation**  
[hemophilia.org](http://hemophilia.org)
- **World Federation of Hemophilia**  
[wfh.org](http://wfh.org)

These websites are neither owned nor controlled by Pfizer. Pfizer does not endorse and is not responsible for the content or services of these sites.

Be sure to also inquire of your local chapter/advocacy organization and speak to your HTC's social worker for more information about available assistance programs.

**References:** 1. Supplemental MASAC statement regarding home delivery and refill under state of emergency declaration. National Hemophilia Foundation website. Published March 30, 2020. Accessed July 27, 2021. <https://www.hemophilia.org/news/supplemental-masac-statement-regarding-home-delivery-and-refill-under-state-of-emergency-declaration> 2. Reichert S. Self-care tips during the COVID-19 pandemic. Mayo Clinic Health System website. Published April 7, 2020. Accessed March 30, 2021. <https://www.mayoclinichealthsystem.org/hometown-health/speaking-of-health/self-care-tips-during-the-covid-19-pandemic>



Patient Affairs Liaisons are a team of non-sales, non-promotional field-based professionals. Pfizer's Patient Affairs Liaisons are dedicated to serving the rare disease community by connecting patients and caregivers with Pfizer Rare Disease tools, including educational resources, access support, and community events in your area.

Visit [www.pfizerpal.com](http://www.pfizerpal.com) to connect with your Patient Affairs Liaison.



# Navigating the Costs of a Bleeding Disorder

*Cassandra Amos  
Financial Coordinator  
Newark Beth Israel Medical Center*

Health insurance has become more costly than ever, and even more difficult to navigate. It is especially difficult for anyone living with a chronic illness. When selecting insurance coverage, patients and families tend to choose plans with lower monthly premiums. However, when making that choice you may not realize that although the monthly premiums are lower, copays, deductibles, and co-insurances are typically much higher, making your overall payment higher. Unfortunately, once a plan selection is made during the open enrollment period, you must wait until the next enrollment period to make changes regarding coverage. Therefore, it is important to make sure you are looking at all parts of the plan before making a selection.

Another large part of living with a chronic illness is the cost of medication. Prescription drug costs have made life-saving medications out of reach for many. For example, medications used to treat bleeding and clotting disorders are the most expensive drugs on the market. A 30 day supply of Factor products cost tens of thousands of dollars. Bleeding disorder patients don't have the luxury of "doing without" their medications. As many of you know, it is a life-and-death situation. To help offset some of the cost, many manufacturers offer copay cards for those who qualify. Copay cards, in most cases, are only beneficial to patients with commercial insurance.



Those who have Medicare, Medicaid, or any government sponsored insurance, are excluded from using copay cards, making it more difficult for patients to get assistance with their medication. Fortunately, there are grants to assist patients. If you are looking for some support, Healthwell Foundation offers assistance with medication copays, insurance premiums, and in some cases transportation costs. PAN Foundation, The Patient Assistance Fund (PAF), are additional insurance and financial resources for patients in the bleeding disorder community.

Although health insurance and medication can be complicated and costly, there are resources that are available for patients and families. It is recommended that patients contact their HTC if they are having difficulty paying for their medications or trouble navigating health insurance.

# Social Worker Update

*Neidy Olarte, MSW  
Social Service Coordinator*

Have you filled out or updated your Member Registration Form? As we continue to provide additional services and assistance to our members, it is important that we have your most up-to-date information to better assist you and your needs. Filling out the membership registration form also helps us provide services that are of interest to the bleeding disorder community. If you have not filled out a member registration form in a while or if you have moved recently or changed your contact information and would like to reconnect with us, please take a minute and fill out the member registration form. You can fill out a form by logging on to our website at [www.hanj.org](http://www.hanj.org) or reaching out to us via email at [chansen@hanj.org](mailto:chansen@hanj.org) or by calling us at the office.

## *HANJ Insurance Grant Program*

The Hemophilia Association of New Jersey continues to provide financial assistance to those in the bleeding disorder community. HANJ provides health insurance premium assistance 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. To learn more about our eligibility requirements, or if you would like to apply to the HANJ Insurance Grant Program, please feel free to contact me at the office or directly at [nolarte@hanj.org](mailto:nolarte@hanj.org). Please note that those individuals currently on our Insurance Grant Program will be receiving their renewal applications in February. The deadline to submit the renewal applications is May 31, 2022.

## *Emergency Assistance Program*

The Emergency Assistance Program provides financial assistance to members who are experiencing a financial hardship. This program should be utilized as a last resort. Applicants must show other efforts were made to resolve current financial hardship; i.e, contact with Hemophilia Treatment Center Social Worker, contact to the electric company, and/or contact to social services. Assistance under the Direct Financial Assistance Program includes:

- Transportation to and from the treatment center (gas money, parking fees)
- Utilities: gas, water, electricity
- Co-pays deductibles or otherwise uncovered pharmaceutical or medical services
- Emergency Dental Assistance

Utility and Emergency Dental assistance is limited to \$500, regardless of the billing cycle. Rent and/or mortgage payments are not eligible expenses. Only one request can be made per calendar year. For more information about the Emergency Assistance Program or to request an application, please contact HANJ directly at (732) 249-6000.

## *Scholarships*

The Publicity and Education Committee of the Hemophilia Association of New Jersey is proud to offer scholarships once again 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 2022-2023 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](http://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, 2020.

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](http://www.hanj.org). Please note the deadline to submit a scholarship application is April 30, 2022.



# Member Spotlight

*Matt Porges*

Matt Porges is excited to be back home in New Jersey and involved with HANJ again. He (or his parents) were involved with HANJ when he was very young before his family moved to Connecticut when he was seven years old. Since then, he has lived in Boston and New York City for most of his adult life; Matt recently moved to Jersey City.

When Matt was a child, his parents and grandparents ran blood drives to benefit him and other kids and adults with hemophilia. People used to show up regularly to donate blood and, even when the blood drives ended, people would ask his grandparents, who lived in Belmar, about how he was doing. Today, Matt has been a practicing lawyer for seventeen years. He enjoys fundraising and is on the Fundraising Committee at HANJ. He hopes we will be back to having Casino Night in 2022!

Within the last couple of months, Matt became the co-coordinator of the Blood Brotherhood with Max Feinstein, who was also involved as a kid. Max is younger but they are looking forward to seeing all of the pictures of them that Mary Lou has found in the HANJ office!

Matt also has been actively involved with other hemophilia organizations on the national level: the National Hemophilia Foundation and the Hemophilia Foundation, the latter of which he previously served as a board member.



Other regional organizations with which Matt has been involved include the Hemophilia Association of New York and the New York City Hemophilia Chapter (previously a board member). He tries to attend the national conventions whenever possible and hopes to attend the World Federation of Hemophilia convention in May 2022.

# Community Connections

**Sunday, March 27th**

**9 AM - 4 PM**

**iPlay America, Freehold**



Celebrate Bleeding Awareness Month with HANJ and your fellow community members at this fun and informative event.

## Tell us what's on your mind

As you probably noticed, we have included a survey within this mailing of the HANJournal. You are invited to take part in this survey to help the HANJ learn about the relationship between disorders and mental health. Your opinion matters to us and helps us determine what programs and services will best serve our community.

Please complete the survey and mail it back to us in the included self-addressed envelope. Or, if you prefer, you can take the survey online by scanning the QR Code:



To learn more about and register for this event, scan the QR Code:



# Annual HANJ Community Resource Guide

## Pharmaceutical Resources for Bleeding Disorders

### Bayer

[www.jivi-us.com](http://www.jivi-us.com) [www.kovaltry.com](http://www.kovaltry.com) [www.livingwithhemophilia.com](http://www.livingwithhemophilia.com)

Access Services by Bayer 1-800-288-8374

·\$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.llibrerogers@bayer.com](mailto:margarita.llibrerogers@bayer.com)

### CSL Behring

CSL Behring Assurance Program: Contact a CSL Behring Assurance Program Care Coordinator at 1-866-415-2164 [www.cslbehringassurance.com](http://www.cslbehringassurance.com)

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, IDELVION or AFSTYLA. Please call 1-(800)-676-4266.

### Genentech

1-866-422-2377

[www.genentech-access.com/hemlibra](http://www.genentech-access.com/hemlibra): Information related to HEMLIBRA Access and patients inquiring about HEMLIBRA (877) 436-3683. [www.HEMLIBRA.COM](http://www.HEMLIBRA.COM)

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://www.hemlibra.com/patient/patient-resources/financial-support.html> for more information.

## Pharmaceutical Resources for Bleeding Disorders continued

### Grifols

FACTORS FOR HEALTH

[www.grifolspatientcare.com](http://www.grifolspatientcare.com)

1-844-MY-FACTOR (693-2286)

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.

### Hema Biologics

[www.sevenfact.com](http://www.sevenfact.com)

For more information about what HEMA Biologics Cares can do for you, go to or call 855-718-HEMA (4362) and select Option 3.

HEMA Biologics Cares™ assists patients throughout their SEVENFACT experience. They offer information, resources, and financial assistance programs to support and assist patients.

SEVENFACT Co-pay Savings Program – If patients qualify for this program, HEMA Biologics Cares can help them receive up to \$12,000 in savings per calendar year

Patient Assistance Program (PAP) – HEMA Biologics recognizes that not everyone has health insurance. The PAP provides SEVENFACT at no cost to patients who meet certain income requirements

Quick Start Program – for patients new to therapy who are experiencing an insurance coverage related delay in getting their prescription, HEMA Biologics may be able to provide SEVENFACT to assist in the interim

Bridge Program – for existing SEVENFACT patients who are experiencing a delay in getting their prescription due to a change in insurance coverage, HEMA Biologics may be able to provide SEVENFACT to assist in the interim

Benefit investigation/coverage determination – HEMA Biologics can help determine patients' insurance coverage and what benefits they qualify for

Prior Authorization (PA) support – if insurance requires a PA for SEVENFACT, HEMA Biologics can assist in the process

### Kedrion

[www.mykoate.com](http://www.mykoate.com)

1-855-353-7466

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:

·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.



## Pharmaceutical Resources for Bleeding Disorders continued

### Novo Nordisk

www.MyNovoSecure.com  
Novo Nordisk NovoSecure Hotline 1-844-NOVOSEC (1-844-668-6732)  
Novo Nordisk Co-pay Assistance Program – Save up to \$12,000 annually on co-pay, deductible, and coinsurance costs, regardless of income.  
Product Assistance Program – [http://www.mynovosecure.com/support/continue\\_your\\_treatment.html](http://www.mynovosecure.com/support/continue_your_treatment.html)  
Product Assistance Program (PAP)/Trial Program – Download the application at [www.mynovosecure.com/support/continue\\_your\\_treatment.html](http://www.mynovosecure.com/support/continue_your_treatment.html)  
[www.novonordisk-us.com](http://www.novonordisk-us.com)  
<https://www.novoeight.com>  
<https://www.novosevenrt.com>  
<https://www.rebinyn.com>  
<https://www.tretten.com>  
<https://www.esperoct.com>

### Octapharma

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.  
·Questions? Call the Factor My Way Support Center (855)-498-4260 or email at [usreimbursement@octapharma.com](mailto:usreimbursement@octapharma.com)



HANJ offers financial assistance for medical alert ID's and MedicAlert membership.

To learn more about the MedicAlert ID assistance program please contact Cindy Hansen at [chansen@hanj.org](mailto:chansen@hanj.org)

## Pharmaceutical Resources for Bleeding Disorders continued

### Novo Nordisk

www.MyNovoSecure.com  
Novo Nordisk NovoSecure Hotline 1-844-NOVOSEC (1-844-668-6732)  
Novo Nordisk Co-pay Assistance Program – Save up to \$12,000 annually on co-pay, deductible, and coinsurance costs, regardless of income.  
Product Assistance Program – [http://www.mynovosecure.com/support/continue\\_your\\_treatment.html](http://www.mynovosecure.com/support/continue_your_treatment.html)  
Product Assistance Program (PAP)/Trial Program – Download the application at [www.mynovosecure.com/support/continue\\_your\\_treatment.html](http://www.mynovosecure.com/support/continue_your_treatment.html)  
[www.novonordisk-us.com](http://www.novonordisk-us.com)  
<https://www.novoeight.com> <https://www.novosevenrt.com> <https://www.rebinyn.com>  
<https://www.tretten.com> <https://www.esperoct.com>

### Octapharma

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.  
·Questions? Call the Factor My Way Support Center (855)-498-4260 or email at [usreimbursement@octapharma.com](mailto:usreimbursement@octapharma.com)

### Pfizer

[www.hemophiliavillage.com](http://www.hemophiliavillage.com)  
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](http://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](http://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 the website [www.PfizerRxPathways.com](http://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.



## Pharmaceutical Resources for Bleeding Disorders continued

### Sanofi Genzyme (formerly Bioverativ):

Learn about all the resources, support, and financial assistance options available to you at the following links. 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](mailto:MyEloctateCoordinator@sanofi.com) or [MyAlprolixCoordinator@sanofi.com](mailto: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): Patient Support & Affordability Resources:

<https://www.hematologysupport.com/copay-assistance/>

Phone (888) 229-8379 -- Mon-Fri 8:30am-8:00pm -- Fax: 1-866-467-7740

Hematology Support Center: One-Stop Resource for Hematology Resources (Medical Professionals):

<https://www.hematologysupportpro.com/> 1-888-229-8379 (Prompt 1)

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

## Non-Pharmaceutical Assistance

### • Patient Access Network Foundation (PAN)

Email: [info@panfoundation.org](mailto:info@panfoundation.org)

PO Box 30500

Bethesda, MD 20824

1-866-316-7263

Fax 1-866-316-7261

[www.panfoundation.org](http://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.

### • Patient Services Inc.

[www.patientservicesinc.org](http://www.patientservicesinc.org)

P.O. Box 5930

Midlothian, VA 23112

Email: [uneeedpsi@uneeedpsi.org](mailto:uneeedpsi@uneeedpsi.org)

1-(800) 366-7741

Fax 1-(804) 744-9388

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. Call 1-877-851-9065 [www.patientservicesinc.org](http://www.patientservicesinc.org)

### • National Organization of Rare Diseases (NORD)

NORD Patient Assistance Programs help patients obtain life-saving or life-sustaining medication.

<https://rarediseases.org/about/>



Need help? Check out the NJHelps website.

This site will help to see if you are eligible for food assistance (SNAP), cash assistance (WFNJ/TANF or WFNJ/GA), and health Insurance (NJ FamilyCare/Medicaid). From there you can apply for services or learn about additional resources. Scan the QR Code to go to the website:





## Non-Pharmaceutical Assistance

- **Hope for Hemophilia:** Patient Resource Program and Direct Financial Assistance Program.

PO Box 77728  
Baton Rouge, LA 70879  
(888) 529-8023  
Fax (888) 835-1449  
info@hope-charities.org  
www.hopeforhemophilia.org

- **Colburn Keenan Foundation:** Provides financial assistance programs to individuals and families living with chronic conditions, with priority placed on those living with bleeding disorders.

The Colburn-Keenan Foundation, Inc.  
PO Box 811  
Enfield, CT 06083  
Toll free Phone: 800-966-2431  
Fax: 888-345-0259  
Email: admin@colkeen.org  
www.colkeen.org

- **Hemophilia Federation of America:** 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](http://www.hemophilia.org/our-role-and-programs/assisting-and-advocating/financial-assistance).

Hemophilia Federation of America (HFA)  
999 N. Capitol Street NE, Suite 201  
Washington, DC 20002  
Phone: (202) 675-6984  
Toll Free: (800) 230-9797  
Fax: (202) 675-6983  
Email: info@hemophiliafed.org

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

## Additional Resources

- **211 United Way:** Provides free and confidential information and referrals to local services including housing, food, employment, healthcare, counseling, and more. Check the website or call your local United Way. Links to additional resources in your local area for specific needs:

United Way Worldwide  
701 N. Fairfax Street  
Alexandria, VA 22314  
(703) 836-7112  
www.unitedway.org  
Dial 2-1-1 or call 1-(877)-652-1148  
email: info@NJ211.org  
www.nj211.org  
1-(877)622-7258

- **The Assistance Fund:** 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-payment, co-insurance, deductibles and other health-related expenses. Go to their website to confirm eligibility and other resources.

<https://tafcares.org>  
1-855-845-3663

- **Health Well Foundation:** Slogan: When Health Insurance is not enough. Mission Statement: To reduce financial barriers to care for underinsured patients with chronic or life-altering diseases. 1-(800) 675-8416 Health Well Foundation, PO Box 489, Buckeystown, MD 21717 <https://www.healthwellfoundation.org/patients/>

- **MAT**

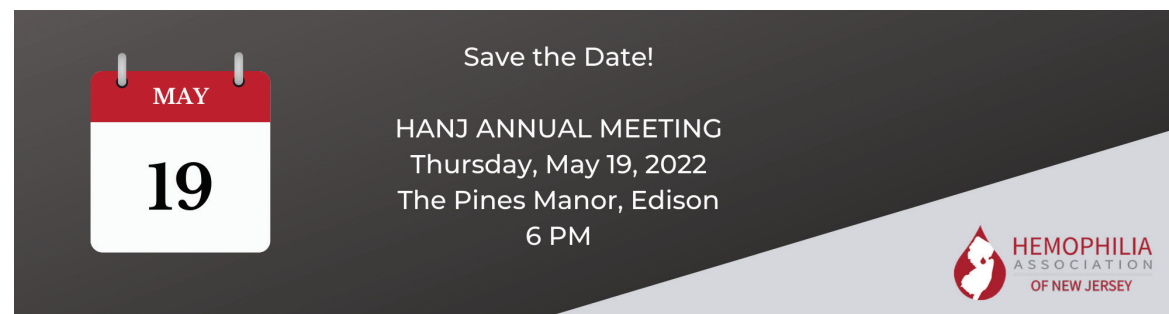
<https://mat.org/>  
Cost-Saving Programs -- Medicine Assistance Tool (MAT)  
Worried about affording your medicine? MAT is here to help.  
(571) 350-8643

- **Needy Meds:** A national non-profit organization that maintains a website of free information on programs that help people who cannot afford medications and other healthcare costs.

NeedyMeds, Inc.  
PO Box 219  
Gloucester, MA 01931  
Helpline: 1-800-503-6897  
www.needymeds.org  
info@needymeds.org

- **New Jersey Children's System of Care**

The State of New Jersey offers behavioral health Resources for Parents and Caregivers through PerformCare.  
<https://www.performcarenj.org/families/emergency-services.aspx>  
1-(877)-652-7624



## Additional Resources continued

· Patient Advocate Foundation (PAF): Provides case management and assistance in accessing health insurance. Co-pay assistance programs are available.

PAF  
421 Butler Farm Road  
Hampton, VA 23666  
1-(800)-532-5274  
www.patientadvocate.org  
help@patientadvocate.org

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

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

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

www.rxoutreach.org  
1-888-796-1234

· United Healthcare Children's Foundation: 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.

UnitedHealthcare Children's Foundation  
MN017-W400  
9700 Healthcare Lane  
Minnetonka, MN 55343  
www.uhccf.org  
1-855-698-4223  
email: customerservice@uhccf.org

The Hemophilia Association of New Jersey is pleased to provide the community with these resources. We are dedicated to improving the lives of people with bleeding disorders and their families by providing access to resources, education, and advocacy.

*HANJ is constantly updating the resource page on our website. You can find the resource page on our website by clicking this QR Code:*



## Val Bias

**March 20, 1958 - Dec. 30, 2021**

***The Hemophilia Association of New Jersey is saddened by the death of former NHF CEO and community member, Val Bias, who passed away suddenly this winter.***

Diagnosed with severe hemophilia B at birth, Val successfully crusaded for better health care for those with hemophilia and HIV/AIDS. Having contracted hepatitis from blood transfusions and HIV from a clotting factor infusion, he became co-chairman of the National Hemophilia Foundation's Blood Safety Working Group and encouraged the Federal Drug Administration to mandate testing on all blood donations.

A member of the National Hemophilia Foundation board of trustees, he was sent to Washington, D.C., in 1994 to represent the foundation as a lobbyist. He pressed Congress for a compassionate relief fund for those living with bleeding disorders and HIV/AIDS, which led to the passage of the Ricky Ray Hemophilia Relief Fund Act of 1998.

When two Bay Area hospitals and the Hemophilia Foundation of North California established the region's first hemophilia summer camp, he became a counselor and went on to be the camp's program director. He established a leadership program that trained counselors and continued serving as director until he moved to New York City in 2008. A member of the National Hemophilia Foundation board of trustees, he was sent to Washington, D.C., in 1994 to represent the foundation as a lobbyist. He pressed Congress for a compassionate relief fund for those living with bleeding disorders and HIV/AIDS, which led to the passage of the Ricky Ray Hemophilia Relief Fund Act of 1998. From 1999 to 2003, he was an advocate and consultant on bleeding disorders with the Centers for Disease Control and Prevention in Atlanta and the University of California, San Francisco.

In 2003, Mr. Bias began serving as the executive director of the Hemophilia Council of California, where he created its Future Leaders Program to train youth as advocates for those with bleeding disorders.

He had served as board chairman of the National Hemophilia Foundation in the early 1990s. As the foundation's CEO from 2008 to 2019, he was in the thick of the debate over health care reform. He pushed strongly to provide insurance for those with pre-existing conditions in the Affordable Care Act and to eliminate caps on lifetime coverage. It is often said that his biggest achievement came in 2009 with the creation of ACT (Access to Care Today, Achieving Cures Tomorrow), which strengthened the organization down to the local chapter level and encouraged research. His goal with the ACT initiative was to standardize access to resources and education for every person with a bleeding disorder, whether they lived in a big city with great resources or a small rural community where the nearest chapter was miles away.

His contributions to the community were many; he was an accomplished leader and will never be forgotten.

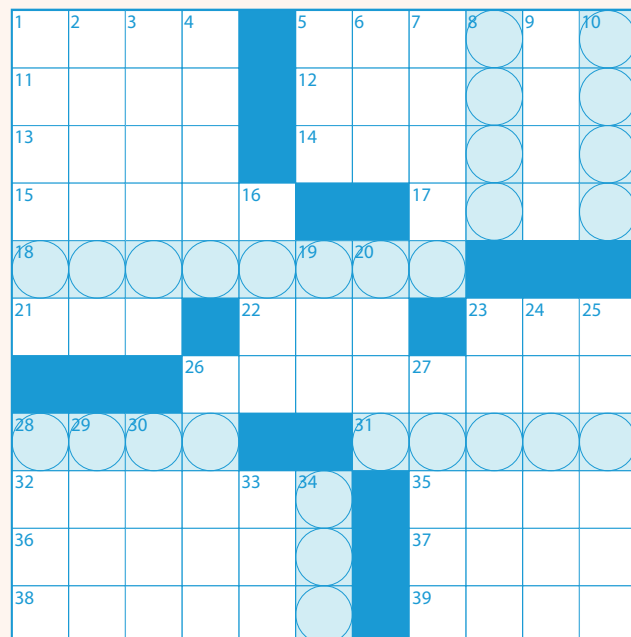


CAN YOU SOLVE

# FOR A DIFFERENT HEMOPHILIA A

TREATMENT?

Test your HEMLIBRA knowledge



## ACROSS

1. Wine barrel
5. Deep fissures
11. Mideast gulf port
12. District
13. Ripped
14. Familiar with
15. Mean
17. Roost
18. The #1 prescribed prophylaxis for hemophilia A\*

\*According to IQVIA claims data from various insurance plan types from October 2019 to November 2020 and accounts for usage in prophylaxis settings in the US.

21. Calendar divs.
22. Regret
23. Banquet hosts (abbr.)
26. International travel necessity
28. Check out the \_\_\_\_\_ treated bleeds data with HEMLIBRA
31. Number of dosing options HEMLIBRA offers

†Number of people with hemophilia A treated as of February 2021.

32. Small hole in lace cloth
35. Central Plains tribe
36. Melodic
37. Towering
38. Reduce
39. Spanish cheers

## DOWN

1. Memorable, as an earworm
2. Devotee
3. Medical fluids
4. Prepare to propose, perhaps
5. PC's "brain"
6. Owns
7. Concert venue
8. See Medication Guide or talk to your doctor about potential \_\_\_\_\_ effects
9. Winter hrs. in Denver and El Paso
10. HEMLIBRA is the only prophylactic treatment offered this way under the skin

16. Pre-Euro currency in Italy
19. Subway alternative
20. Relax
23. Human
24. New Orleans cuisine
25. Mentally prepares
26. Collared shirts
27. Instagram post
28. Ardent enthusiasms
29. Brontë heroine Jane
30. Old Portuguese coins
33. Opposite of WNW
34. \_\_\_\_\_ thousand patients have been treated with HEMLIBRA worldwide†

## SOLUTIONS

Across: 1. cask, 5. chasms, 11. Aden, 12. parish, 13. tore, 14. used to, 15. creel, 17. nest, 18. HEMLIBRA, 21. yrs, 22. rue, 23. MCs, 26. passport, 28. zero, 31. three, 32. eyelid, 35. Ctoe, 36. anose, 37. tall, 38. lessen, 39. oles  
Down: 1. catchy, 2. adore, 3. serums, 4. kneel, 5. CPU, 6. has, 7. arena, 8. side, 9. MSTs, 10. shot, 16. lira, 19. bus, 20. rest, 23. mortal, 24. Creole, 25. steels, 26. polo, 27. photo, 28. zeal, 29. Eye, 30. Reis, 33. ESE, 34. ten

## 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
  - weakness
  - swelling of arms and legs
  - yellowing of skin and eyes
  - stomach (abdomen) or back pain
  - nausea or vomiting
  - feeling sick
  - decreased urination
- **Blood clots (thrombotic events).** Blood clots may form in blood vessels in your arm, leg, lung, or head. Get medical help right away if you have any of these signs or symptoms of blood clots during or after treatment with HEMLIBRA:
  - swelling in arms or legs
  - pain or redness in your arms or legs
  - shortness of breath
  - chest pain or tightness
  - fast heart rate
  - cough up blood
  - feel faint
  - headache
  - numbness in your face
  - eye pain or swelling
  - trouble seeing

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

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

### What is HEMLIBRA?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children, 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

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For more information, go to [www.HEMLIBRA.com](http://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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Please see Brief Summary of Medication Guide on following page for Important Safety Information, including **Serious Side Effects**.



April 17, 2022, is World Hemophilia Day. The theme of the event this year is “Access for All: Partnership. Policy. Progress. Engaging your government, integrating inherited bleeding disorders into national policy.” By raising awareness and bringing hemophilia and other inherited bleeding disorders to the attention of policymakers, we can increase sustainable and equitable access to care and treatment.

We invite you to share your story about how you or someone you know has been affected by inherited bleeding disorders. We want to hear your story, see photos, and share your artwork. Then, we will post these items on our social media networks to share with other community members. To submit your photos, artwork, and stories, just scan this QR Code:

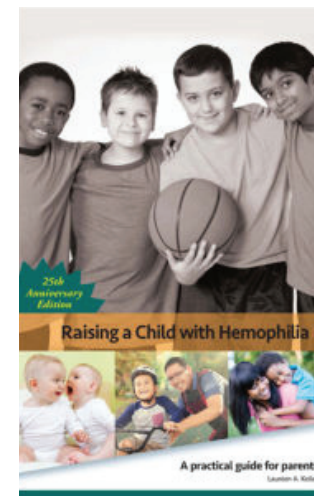


Please submit all entries by April 14th.

## Resources from LA Kelley Communications

This issue of the HANJournal is dedicated to highlighting the many resources available to our community. We are happy to include a piece from a recent issue of the Parent Empowerment Newsletter (PEN) produced by LA Kelley Communications, Inc. This issue of PEN serves as a resource to help in educating patients, finding support, and living with bleeding disorders. It contains a variety of resources including books, digital content, movies, apps, kits, booklets, podcasts, and gadgets available to the community.

Here are two great books highlighted in this issue of PEN:



### **Raising a Child with Hemophilia: A Practical Guide for Parents (5th ed.)**

*Laureen A. Kelley*

LA Kelley Communications, Inc. 2016

Free to hemophilia families

[kelleycom.com](http://kelleycom.com) • paperback or e-book

[amazon.com](http://amazon.com)

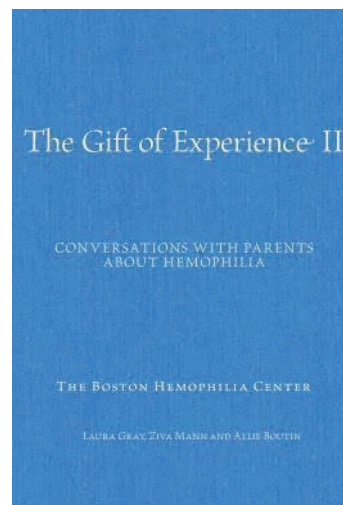
World's first parenting book on hemophilia written by a parent of a child with hemophilia. Practical, easy-to-understand info on medical treatment, genetic transmission, child development, consumer issues, school, sports. Includes advice from experienced parents, compiled from interviews with more than 180 families. Sponsored by CSL Behring.

### **The Gift of Experience II: Conversations with Parents About Hemophilia** *Laura Gray, LICSW, Ziva Mann, and Allie Boutin*

Boston Hemophilia Center 2014

[amazon.com](http://amazon.com)

Compilation of personal stories from parents and caregivers of hemophilia patients; offers insights into the daily life of raising a child with hemophilia.



To read the complete PEN Biennial Bleeding Disorder Resources Guide, scan this QR Code

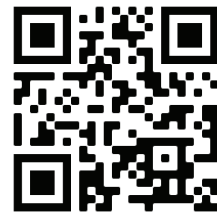






# Upcoming Events

HANJ is excited to announce the following upcoming events. Be sure to mark your calendars and join us! If you would like further information about these events, we are always updating our website with the latest information. You can access the HANJ website by scanning this QR Code:



**MARCH 27**  
***COMMUNITY CONNECTIONS***

**MAY 19**  
***ANNUAL MEETING***

**MAY 23**  
***GOLF CLASSIC***

**JULY 16**  
***SUMMER WELLNESS GATHERING***

**SEPTEMBER 24**  
***HANJ 5K RUN/ 1 MILE WALK***