

# HANJournal

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



**Join us for the annual  
Summer Wellness  
Gathering!**

**Saturday  
July 16, 2022  
Eagle's Landing  
Day Camp**

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

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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.



**HEMOPHILIA**  
ASSOCIATION  
OF NEW JERSEY

**HANJ New Slate**  
**July 1, 2022 to June 30, 2023**

|                            |                      |
|----------------------------|----------------------|
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| Richard Keelty | Rajh Odi                |
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Issaiah Williamson

## 2022 Scholarship Award Winners

HANJ was pleased to announce the new 2022 scholarship award winners at the 2022 Annual Meeting. We are very proud of all of our winners and we know we will be hearing great things from each of you.

*Madison McTigue has been awarded the Robert and Dennis Kelly Memorial Scholarship, renewable for 3 years. Madison will be attending the University of Maryland in the Fall of 2022 and is pursuing a degree in Biomedical Engineering.*

*Robert and Dennis Kelly  
Memorial Scholarship*



*Omar Cepeda has been awarded the Julie E. Frenkel Memorial Scholarship, renewable for 3 years. Omar will be attending Rutgers University-Newark in the Fall of 2022 and is pursuing a degree in Education with a concentration in Special Education.*

*Julie E. Frenkel  
Memorial Scholarship*



*Vinh Tran has been awarded the Hemophilia Association of New Jersey Scholarship, renewable for 3 years. Vinh will be attending Rutgers University-New Brunswick in the Fall of 2022 and is pursuing a degree in Pre-Med Biology.*

*Hemophilia Association  
of New Jersey Scholarship*



*Michael Caggiano has been awarded the Robert and Dennis Kelly Memorial Scholarship, renewable for 3 years. Michael will be attending the University of Miami in the Fall of 2022 and is pursuing a degree in Engineering.*

*Robert and Dennis Kelly  
Memorial Scholarship*



*Justin Najimian has been awarded the Paul D. Amitrani Graduate Scholarship. Justin will be attending Rutgers School of Public Health-New Brunswick and is pursuing a Specialized Graduate Degree in LGBTQ+ in Public Health.*

*Paul D. Amitrani  
Graduate Scholarship*



**THE HANJ ANNUAL MEETING WAS HELD ON MAY 19TH  
CONGRATULATIONS TO OUR AWARD WINNERS**



**SPECIAL AWARD**

This year's Special Award was presented to Nick Miller. Nick is a valued volunteer and contributor to HANJ. He is the Co-Chair of the Dennis Keely Memorial Golf Classic and, as such, he is responsible for making tournament-related decisions in collaboration with other Golf Tournament Committee members. Nick has also been instrumental in connecting HANJ to speakers and education opportunities to facilitate the community's unmet needs.

**UNsung HERO AWARD**

This year's Unsung Hero Award was presented to Jason Springer. Jason has been our webmaster, communications and email advisor, and trusted extension of our organization. Jason Springer came on board as a volunteer in 2016, where he was tasked with the undertaking of completely overhauling our website. Since launching the new website, Jason has not left our side, often communicating with the HANJ staff daily to ensure that our communication with the public and our community is effective and current.



**BENEFACTOR AWARD**

This year's Benefactor Award was presented to the Cepeda family. The Cepeda family has supported the HANJ for many years. If you have been to our fundraising events, you surely have seen this family rev up the crowd and get the energy going. Harry, Milibet, and Omar Cepeda have been the MC and DJ at our Walk/Run, Casino Night, Summer Camp Wellness, and countless other events. The Cepeda Family is always willing to support not only the HANJ but their fellow community members.



**HUMANITARIAN AWARD**

This year's Humanitarian Award was presented to one of our Mental Health Committee members. Dr. Gary McClain authors bi-weekly blogs for HANJ intended to address issues particular to the bleeding disorders community. He is a psychotherapist, patient advocate, blogger, professor, and author, specializing in helping clients deal with the emotional impact of chronic and life-threatening illnesses, as well as their families and professional caregivers. Gary has also volunteered as a speaker for several mental health and education programs and initiatives.

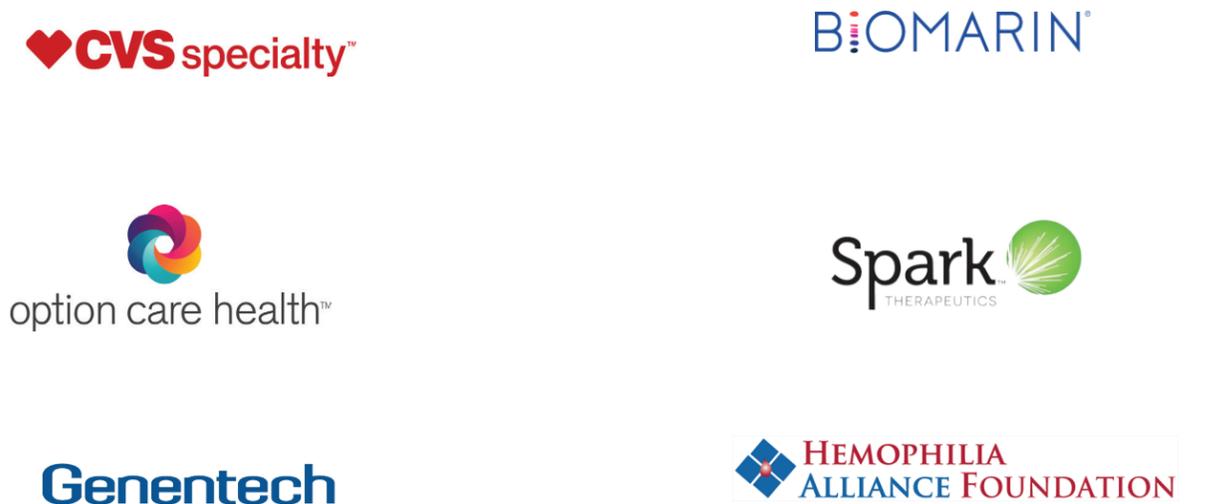


Thank you to our sponsors for their support of our Annual Meeting

**Silver Sponsors:**



**Bronze Sponsors:**



# 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, 21 years or older, with a bleeding disorder. Each of the events incorporates a bit of education, socializing, and physical activity. But, the time at the Blood Brotherhood events is typically spent getting to know one another. 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

If you would like to learn more about the Blood Brotherhood Program, head to our website by scanning the QR Code:



# 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

NY Metro, NJ, E. PA  
annie.sukhnandan@pfizer.com  
O: 347-757-0922

*"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

HemMobile is a registered trademark of Pfizer Inc. HemMobile is not intended for curing, treating, seeking treatment for, managing, or diagnosing a specific disease, disorder, or any specific health condition. Pfizer will not have access to any personal information you enter into HemMobile.



## St. Michael's Medical Center

Joanne Rodriguez

### Summer

The weather is starting to get better as summer 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

Summer 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 are able to 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 are in need of 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: [suicidpreventionlifeline.org](https://suicidpreventionlifeline.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



111 Central Avenue, Bldg. M2  
Newark, NJ 07102

973-877-5340

973-877-5341

973-877-5342

Social Worker:

Joanne Rodriguez, CSW

[JRodriguez@primehealthcare.com](mailto:JRodriguez@primehealthcare.com)

973-877-2967

973-877-5466 (fax)

**Rutgers Robert Wood Johnson  
Medical School  
Hemophilia Treatment Center**  
*Lisa Cohen, MSW, LSW*

The Rutgers RWJ Hemophilia Treatment Center (HTC) continues to focus on the provision of comprehensive care for our bleeding disorder patients amidst the changing landscape of the COVID pandemic. The HTC is fully functioning with the availability of both tele-health and in-person appointments. To meet growing patient needs, the HTC will be welcoming new staff in the coming months.

The clinic continues to take measures to minimize the risk of COVID exposure 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.

**Rutgers RWJ Medical School  
Hemophilia Treatment Center  
125 Paterson Street  
5th Floor, Suite 5200  
New Brunswick, NJ 08901**  
**For appointments:  
732-235-7226**  
**Nurse direct line for medical issues:  
732-235-6531**  
**Program Manager:  
Lisa Cohen, MSW, LSW  
cohenlr@rwjms.rutgers.edu  
732-235-6533**



**STUDIES:** Currently the following study is enrolling for patients who meet the criteria: 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.

**PROGRAMS & SCHOOL VISITS:** Educational programs and school visits continue virtually at this time. If you anticipate the need for a school, daycare or camp in service program, please contact the social worker at 732-235-6533.

## The Importance of a Care Plan

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

**This content is brought to you by Pfizer.**

**Living with hemophilia may leave a young person feeling as though they're different from their friends.<sup>1</sup> The time and effort needed to deal with the everyday management of hemophilia may disrupt school and activities. Even so, it's important to follow the care plan closely in order to prevent complications that could lead to more time away from friends and fun.<sup>2</sup>**

### Staying Ahead of Hemophilia

Young people are already coping with many life changes, and hemophilia treatment is another piece to fit into a busy life. Planning ahead to manage hemophilia is important in avoiding complications but it can also be understandably challenging for many reasons. Being proactive might mean thinking about hemophilia several days each week, which some people might find difficult.

In some patients, a hemophilia management plan may include prophylaxis, which means taking steps to prevent a problem before it happens. In hemophilia, this might include treatments to help prevent bleeding episodes.<sup>2</sup> Thinking ahead does take time, attention, and practice. Reaching out for support can make the process easier and can help with staying on track with treatment goals.

### Adhering to Your Care Plan

When patients follow their treatment plan, it is sometimes referred to as adherence. Following your care plan is an important part of avoiding complications. Over time, having bleeding episodes can cause damage to joints.<sup>3</sup> Recognizing symptoms and treating them, especially when a bleeding episode first starts, is important.<sup>2</sup>

When you are feeling well, it may not seem as though being adherent is very important. However, taking care of hemophilia and overall health while young can bring

benefits such as a better quality of life and avoiding complications when you're older.

### Being Part of the Team

Learning about hemophilia and asking questions of health care team members, such as doctors and nurses, will help in being prepared and in preventing and treating bleeds. When patients and caregivers create a treatment plan together, it's called shared decision-making. Being an active part of the health care team helps to make sure that the care plan fits into everyday life. The best plan for each person is going to be specific to them and the one that they will follow.

### Developing a Comprehensive Plan

Treating hemophilia includes more than just preventing and treating bleeding episodes. Consider other parts of an overall care plan including<sup>2</sup>:

- Getting regular checkups for overall health
- Learning to recognize a bleed
- Keeping a store of medical supplies on hand
- Knowing how to self-infuse
- Keeping a record of bleeds and treatments
- Getting proper nutrition and regular exercise

### Becoming Your Own Best Advocate

Shared decision-making, adherence, and self-care all play a role in living a healthier life with hemophilia. With the help of the health care team and parents or other caregivers, managing hemophilia can become a regular part of a normal day. Learning about hemophilia in order to be more self-reliant is empowering and can lead to a rewarding, healthy life.

**References:** 1. Suris JC, Michaud PA, Viner R. The adolescent with a chronic condition. Part I: developmental issues. *Arch Dis Child.* 2004;89(10):938-942. doi:10.1136/adc.2003.045369 2. Srivastava A, Santagostino E, Dougall A, et al. WFH Guidelines for the Management of Hemophilia, 3rd edition. *Haemophilia.* 2020;26(suppl 6):1-158. doi:10.1111/hae.14046 3. Lindvall K, Colstrup L, Wollter IM, et al. Compliance with treatment and understanding of own disease in patients with severe and moderate haemophilia. *Haemophilia.* 2006;12(1):47-51. doi:10.1111/j.1365-2516.2006.01192.x



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.**

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

Happy Summer 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 some updates, current programs, and plans with you. We hope you are all doing well!

**News:**

**Hemophilia Camp:** Summer camp at Double H Ranch and The Hole in The Wall Gang Camp are back in person this year! Camp can be an integral part of a patient's journey towards independence and both camps also offer family programming. For more information about camp, or if your child or family is interested in attending in the future, please contact our Social Worker, Emily.

**Ongoing Programs:**

**Travel Letters:** Do you have summer travel plans? 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.

**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:** Although school may be out for summer it is not too early to be prepared for your child's school or educational needs for the Fall. 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:** When was the last time you had your yearly visit? 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.

**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 and  
Children's Hospital  
of New Jersey**  
**201 Lyon's Avenue (E2)**  
**Newark, NJ 07112**  
**Main number:**  
**973-926-6511**  
**Social Worker:**  
**Emily Fusco, LSW**  
**Emily.Fusco@RWJbh.org**  
**973-926-4197**  
**973-391-0048 (fax)**

**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.**

**Your body may make antibodies against HEMLIBRA, which may stop HEMLIBRA from working properly. Contact your healthcare provider immediately if you notice that HEMLIBRA has stopped working for you (eg, increase in bleeds).**

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.

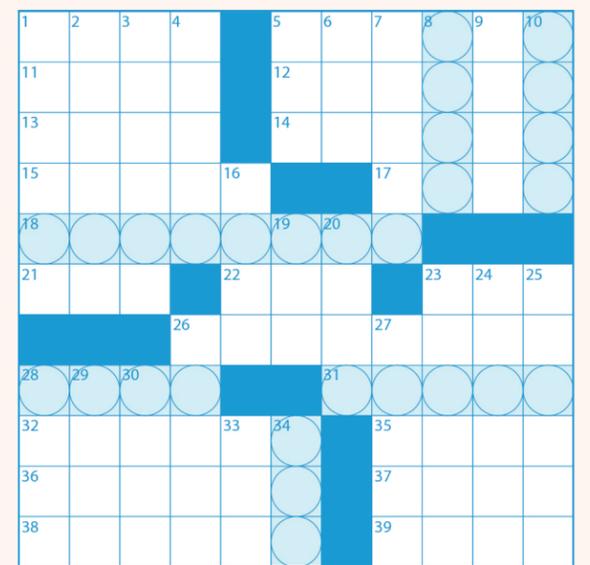
This Medication Guide has been approved by the U.S. Food and Drug Administration  
Revised: 12/2021



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**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 people with hemophilia A without factor VIII inhibitors\*

\*According to IQVIA claims data from various insurance plan types from April 2020 - May 2021 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 October 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 enthusiasm
29. Brontë heroine Jane
30. Old Portuguese coins
33. Opposite of WNW
34. More than \_\_\_\_ thousand patients have been treated with HEMLIBRA worldwide†

**SOLUTIONS**

30. Reis, 33. ESE, 34. ten  
25. steels, 26. polos, 27. photo, 28. zeal, 29. Eyre,  
16. lira, 19. bus, 20. rest, 23. mortal, 24. Creole,  
5. CPU, 6. has, 7. arena, 8. side, 9. M51s, 10. shot,  
Down: 1. catchy, 2. adore, 3. serums, 4. kneel,  
35. Oreo, 36. arose, 37. tall, 38. lessen, 39. oles  
26. passport, 28. zero, 31. three, 32. eyelid,  
18. HEMLIBRA, 21. yrs, 22. rare, 23. MCS,  
13. fore, 14. used to, 15. crew, 17. nest,  
Across: 1. cash, 5. charms, 11. Aden, 12. parish,

Discover more at [HEMLIBRA.com/answers](http://HEMLIBRA.com/answers)

**INDICATION & IMPORTANT SAFETY INFORMATION**

**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.**



# What Our Parents Leave Us

Gary McClain, MS, PhD, LMCH, CEAP

I was looking at my schedule for this month and I noticed that Father's Day is coming up, and we just celebrated Mother's Day in May. I don't have my parents here anymore, and holidays always bring up a lot of memories of times we spent together. I am flooded with memories of what I learned from them, what I wish I had learned from them, as well as what was best about our relationships. And, like most people, those questions of why they made some of the choices they made, and thoughts about what they could and should have done differently, come up. It's just human nature to gaze into that rear view mirror and revisit the influence that our parents had on our lives.

Getting older has given me an opportunity to see the bigger picture. As I established my own life as a grown-up, I began to understand what my parents struggled with. Like trying to make financial ends meet. That was always a big one. Raising kids in a time when the values they grew up with were changing. And of course, their own strengths and limitations as humans. As I understood them better as an adult, I was also able to understand the choices they made.

After all, parents are human. Good, bad, imperfect... sometimes terribly damaged.

I hear a lot of stories here about parents and how they treated their children. Some of the stories I hear are just awful. Stories about unspeakable abuse, both physical and emotional.

Constant criticism, unpredictable behavior, or complete lack of involvement. Parents who were too troubled themselves to be parents. Some of us have been left with a lot of damage, no doubt about it.

It seems to me that an important part of growing up is accepting your parents for who they are or were. I am not saying that coming to this place in your life is without pain. It can be really painful. It might mean accepting that your parents were troubled, damaged people who inflicted pain and suffering on their own children. It might mean accepting that your parents seemed to be focused someplace other than on their children, that their own challenges were so great that they couldn't quite figure out how to be the parents their children needed. Or maybe they didn't or couldn't care. On the other hand, you might be wondering why your parents didn't spend more time helping you to become the people that they seemed to be. Or maybe you are one of the fortunate ones, and your parents did the best they could and did a pretty good job of things, now that you think about it. The kind of parents many of you are trying to be.

Parents leave all kinds of legacies. Physical and mental illness may also be passed on from parents to children. So, the gifts they give us may not exactly be gifts we would have chosen to receive. Like a bleeding disorder. Or maybe, why do we all seem to be so depressed in this family?

Whatever you experienced, there is no denying that the homes we grew up in have a big impact on who we are as adults. And that can result in a lot of feelings – proud and happy on one hand; angry, frustrated, ashamed, sad, scared, on the other hand. Probably a mix of feelings.

I often meet with clients who continue to experience conflict with their parents as adults, who continue to expect the impossible from their parents, who want their parents to take care of them in ways that they can't, or who want validation from parents who can't or won't give it, or who want to make their parents acknowledge events from the past that they can't or won't acknowledge.

## What Our Parents Leave Us continued

Coming to terms with your childhood is a process. It takes doing some work with yourself, and it might take doing some work with someone who is trained to help you. So, what I am giving you is not intended as a formula. Instead, here are some ideas to think about to help you get some perspective on the role your parents have played in your life.

**Understanding.** Who were these people who were your parents? Were they both willing and able to be parents? What struggles did they have in their own lives, as children, and as adults? These are hard questions to ask, and you may not be able to learn many of the answers. But understanding who your parents were – who they weren't – can help you to begin to understand the impact they had on your life, and why they made the choices that they made.

**Acknowledgment.** You may have fallen into a pattern of blaming your parents for everything that isn't right in your life, fairly or unfairly. Or you may want only to focus on their better qualities and not on the flaws that all humans have. Or it may just be too painful to think about what must have been going on with them and what they did to you. Coming to terms with your childhood begins with looking at it for what it was, the good, the not-so-good maybe even the terrible. And that means acknowledging the role that your parents have played in your life. And it can also help to acknowledge that people are who they are. That means they may not be willing to change the way they think, feel, or behave. To expect otherwise is to create more frustration and unhappiness for yourself.

**Healing.** Life happens. Some of it is fair, and some of it isn't fair. Some of it is just plain tragic. But you are not doomed to repeat the lives of your parents. You are not doomed to continue to live with the damage from your childhood. You are not doomed to live the same lifestyle habits and experience the same outcomes as your parents, or to raise your children the way that you were raised. You can choose to move on, to take what you want to take with you, and leave behind what needs to be left behind. To let go and leave the pain behind. To heal.

**Compassion.** One of the greatest blessings of having a perspective on the past is coming into yourself. Knowing who YOU are. Without all of the conflict and the anger about the past, and without all of the negative labels you may have picked up along the way. Have compassion for yourself.

Give yourself the gentle encouragement that you may not have received from others in the past. Let go of the self-criticism and blame, along with the resentment.

Show yourself some compassion. After all, it begins inside. Loving and accepting ourselves helps to heal the damage left by people we needed to love and accept us and who couldn't.

**Possibilities.** Some of us learned about possibilities from our parents, some of learned only limitations. Grab on to the responsibility for being the best person possible in the here and now. Turn off the voices of limitation and open yourself up to what is possible in your life. What you can be, what you can do, the people you can have in your life to share it with. I often tell my clients that when they were children, they were only "this high" and they had very few options, if any. Now they are "this high" – a lot taller – and they have a lot more options. Update your view of yourself and what is possible for your life.

**Help.** Like I said earlier on, getting a perspective on your childhood and the role that your parents played isn't accomplished in a few easy steps. It is a process and, in some ways, a lifelong process. But that doesn't mean you won't see progress along the way, changes that will make your life that much less stressful, more fulfilling. Getting support along the way is the key. People who help to keep you grounded in the present – who you are now – and what's possible. Talking to a mental health professional can help you to gain a perspective on your childhood experiences, including how you were affected by your parents, and help you to develop some new, and healthier, ways to live your life. Don't go through this alone.

So... what did we get from our parents? Life! Let's all make the best of the life we've been given!



*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.*

# The Ultramarathon Runner With Hemophilia B

Michael Caggianno

Exercise has always been a big part of our lives. Whether it be going for a walk or weight lifting, it has generally been promoted throughout history. For hemophiliacs though, the history has been different. Ricardo Ramirez is an ultramarathon runner with Hemophilia B severe.

## History of Hemophilia and Exercise

Until about the 1970s, those who suffered from hemophilia were taught to avoid any physical activity and sports. There was, and still is, a perceived risk of injury. However, during the mid 70s, public opinion on exercise for hemophiliacs started to take a turn. Now, multiple hemophilia organizations like the National Hemophilia Foundation, (NHF), actually suggest low risk exercise for patients with hemophilia.



Michael Caggianno is a college student and HANJ community member attending the University of Miami who has hemophilia A severe. Michael founded HemoTalk.com where he shares hemophilia-related news and inspirational stories to inspire others with bleeding disorders to accomplish their goals. You can follow Michael on Instagram: @hemotalk

## Running With Hemophilia

Ricardo Ramirez says that he runs ultramarathons for his enjoyment. Ultramarathons are categorized as races that are more than a regular marathon, 26.2 miles (42km), and they generally start at 31 miles (50km). Ultramarathons is an accomplishment that the runner can be proud of, as achieving something that was before beyond the runner's capability is incredibly fulfilling. Ricardo runs ultramarathons because he wants to demonstrate to the hemophilia community that hemophiliacs are able to be active and participate in things that they enjoy.

## How Did Ricardo Ramirez Get Started Running?

Ricardo said that because of the effects of an inactive lifestyle and being overweight, he feared injury. Obesity may be a significant risk factor for those with hemophilia. When he started to become physically active, he started with walking and eventually began running in the park with a group. The American Council on Exercise suggests that "finding friends with whom you can exercise" can be a motivator for exercise.

## How Does Ricardo Manage His Hemophilia?

Ricardo says that, "Having hemophilia impacted me by making me fearful to not engage in activities which may cause bleeds but that had a negative impact on my health so I decided to take control and start to improve upon my activity level in a sport that was non-impact and as safe as possible with my condition." He still safely and effectively manages his hemophilia B, as he injects himself three times a week and may perform an infusion before, during, and/or after hard events. He also checks with his hematologist for clearance before racing. Ricardo says that because running is a low impact activity at base, and it is easy to adjust your trainings according to how your body is feeling and would encourage others with hemophilia to consider running as a means of exercise. Of course, it is important to talk with your hematologist or treatment center before engaging in any physical activity.

## Advice for Hemophiliacs

When Ricardo was asked the question, "If you could tell other hemophiliacs anything that want to pursue something they love like running, what would you tell them?" he encourages those with hemophilia to pursue their passions, but to do it safely, with an understanding of proper treatment. He says, "My recommendation for hemophiliacs that want to pursue their passions is to get connected, get treatment and listen to your body. Being connected with a local hemophilia chapter to ensure you are receiving all of the support and services available is very important. They are an excellent resource."

Ricardo also stresses how important proper treatment and connecting with a hematologist regularly is. Getting the proper treatment is essential. He emphasizes that "Most importantly; listen to your body. Take it easy when you need to and be patient with yourself. It is okay if you need to take light days, just enjoy the outdoors and fresh air!" Ricardo started just by walking and running around a park with a group, so going outdoors is already a great step for exercise.



Ricardo at the 2020 marathon

Ricardo Ramirez  
Ricardo Ramirez has completed and won a 200 mile (321km), race, which is the longest race he has ran, and is currently training for the Badwater135 which is a non-stop 135 mile (217km) race from Death Valley to Mt. Whitney, California, in the "peak of the summer." It is world-renowned as the toughest foot race in the world and it attracts runners globally to test their determination.

Ricardo has an Instagram where he documents his journey not only with running but also with hemophilia. You can follow Ricardo on Instagram @1171ricardo.

# Travel Safe with a Bleeding Disorder

*Handy tips from the CDC*

Traveling with a bleeding disorder, such as hemophilia, can be stressful and challenging knowing that a bleed can happen at any time. Plan ahead to help manage bleeding episodes and medical emergencies that occur while away from home.

Before You Leave for a Trip:

- Talk to your doctor about your travel plans to make sure you are in healthy condition to travel.
- Ask your doctor if there are any recommended vaccinations based on your travel plans. Vaccinations, such as hepatitis A and B vaccines, are highly recommended for people with bleeding disorders.

What to Pack:



- Ask your doctor for a travel letter that describes your bleeding disorder and the medicine you take.
- Your travel letter will allow transportation security officials to make sure your medicine and medical supplies are allowed while traveling.

If you are traveling internationally, consider having an additional copy of the travel letter written in the primary language spoken in the country you are visiting.



## A list of hospitals

- Make a list of hospitals or hemophilia treatment centers (HTCs) and their contact information that are along your travel route.
- Use the HTC directory for a list of HTCs in the United States. For a list of HTCs worldwide, use the World Federation of Hemophilia's Global Treatment Centre Directory [external icon](#).



## Medicine and medical supplies

- Medicine and medical supplies are exempt from airline baggage restrictions.
- Clearly label all medicine and medical supplies and pack them separately in a carry-on bag. If items are safely stored in your carry-on, you will be able to use your items at any time, and you will have your items with you in case your checked luggage is delayed or lost.
- If there are any items that should not be exposed to X-rays, request your items to be physically inspected by the transportation security official.
- Unexpected travel delays can happen. Pack extra amounts of medicine and supplies in the event that your return home is delayed.

Pack these medical supplies in your carry-on or in a bag you have with you at all times:

- ✦ Vials of factor medicine
- ✦ Diluent (A liquid used to form or thin a solution. Normal saline or sterile water are diluents that can be mixed with the factor powder.)
- ✦ Reconstitution device (A device used to “reconstitute” or mix factor with a liquid (usually water), called a diluent, before it can be infused or given to a person with hemophilia. Factor is stored in powdered form because it rapidly loses its power once mixed into a solution.)
- ✦ Syringes (Needles)
- ✦ Alcohol and cotton pads
- ✦ Disinfectant (A product that destroys bacteria or other harmful agents)
- ✦ Containers to dispose of your used syringes (Sharps)



## Medical and contact information

- Keep a copy of your important medical and contact information with you.
- Consider wearing a medical ID emblem if traveling alone to help inform medical personnel if you become unconscious or unable to communicate during an emergency.

# Social Worker Update

Neidy Olarte, MSW  
Social Service Coordinator

## What can HANJ programs offer me?



For the past five years, we have expanded our educational programs to include many topics of interest to the bleeding disorder community. We work closely with members of the community through our Publicity and Education Committee, as well as send out surveys to address any topics of interest. We want to make sure that the needs of the community are met and by providing the opportunity for these educational programs, it helps guide us on how we can offer the best services and help the community become stronger as well as offer our support during different life stages.

Since we know our members are spread throughout NJ, we try our best to travel to different locations and try to reach out to as many individuals as we can. I know in the past 3 years; we were all faced with many challenges. COVID-19 was something that no one intended to experience, yet here we are. During this time, we wanted to continue to find a way to connect with our members, and fortunately, virtual programs were the next best thing to being able to continue our work and connect with each other.

While we are not 100% in the clear, we have been able to cautiously and safely start live programs and hope that we can continue to provide live educational opportunities going forward to continue with our mission to provide educational opportunities to our members.

By attending our educational programs, you can help to ensure our continued educational efforts. We create these programs with you in mind and by attending our programs, it gives us guidance that we are working in the right direction. Providing feedback on current or future programs. We cannot grow or improve affectively without the input of the community we are trying to reach, so I you feel there is a topic we should address that it is very important to you, please reach out we are more than happy to receive your feedback. We have a wonderful community of individuals that possess many talents and experiences that we would love to learn about and help share with other community members. If you would like to collaborate in a program, or be one of our presenters, please reach out. Finally, we are always seeking out volunteers. What better way to give back than to be part of our efforts to grow? Volunteers are so important to our organization and the reason we can offer these program opportunities.

You can visit our website for the most up to date program schedule and reach out to us if you are interested in volunteering or being part of one of our many committees. I hope to hear from you soon as well as see you at one of our upcoming programs!!

## The Annual Dennis Keelty Memorial Golf Classic Plainfield Country Club May 23, 2022



## A wonderful day of golf and camaraderie!

For more photos, scan QR Code:





# Explore HEAD-TO-HEAD

Pharmacokinetic (PK) Study Data

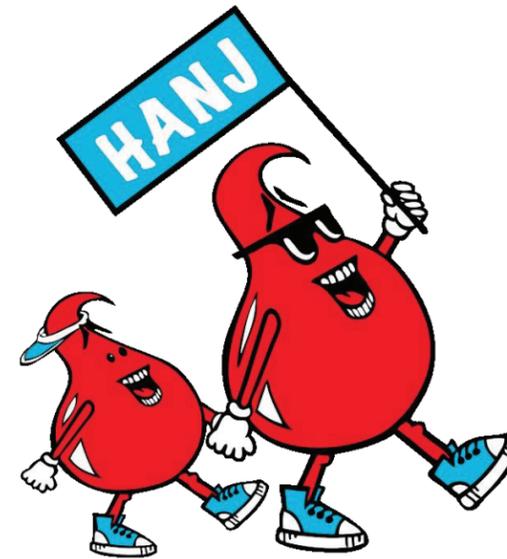
See half-life, clearance and other PK data from the crossover study comparing **Jivi**<sup>®</sup> and **Eloctate**<sup>®</sup>.

Visit [PKStudies.com](http://PKStudies.com) to find out more.

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



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**EVENT SCHEDULE**  
8:00 AM REGISTRATION OPENS  
9:00 AM 5K RUN & 1 M WALK START  
11:00 AM AWARDS CEREMONY  
11:30 AM LUNCH AND FAMILY FUN TIME

# 5K RUN & 1 M WALK

EAST BRUNSWICK COMMUNITY CENTER

**SATURDAY, SEPTEMBER 24**  
MEDALS AND T-SHIRTS FOR ALL PARTICIPANTS

JOIN FELLOW WALKERS, RUNNERS, AND VOLUNTEERS AS WE RAISE AWARENESS ABOUT HEMOPHILIA AND FUND OUR MISSION WHICH PROVIDES HOPE AND MUCH NEEDED ASSISTANCE TO THE HEMOPHILIA COMMUNITY.

FOR MORE INFORMATION CALL  
732-249-6000

OR DROP US EMAIL TO  
[mloub@hanj.org](mailto:mloub@hanj.org)

SCAN QR CODE  
TO REGISTER:



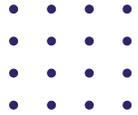

## MedicAlert Seatbelt ID Holder

The seatbelt medical ID holder keeps your medical info easily accessible.



HANJ will cover the cost of the MedicAlert seatbelt ID holder for our registered members.

If you would like a seatbelt ID holder, please contact Cindy Hansen at 732-249-6000.



# JOIN US AT THE SUMMER WELLNESS GATHERING!

**Saturday, July 16th**  
**Eagles Landing Day Camp**  
**12 PM - 4 PM**



You will not want to miss this event!

We have planned a very special day for you this year at our Summer Wellness Gathering. The day will be chock-filled with: exhibit booths, interesting workshops, a delicious catered lunch, all the fun you can imagine at Eagle's Landing - and of course, the camaraderie we share when we get together.

Eagle's Landing has ALL the fun one camp can offer including a beautiful 20-acre facility with 4 sparkling pools, a spray park, soccer and softball fields, 3 full-size basketball courts, a sand volleyball court, and a 9-hole mini-golf course.

To learn more and to register, scan the QR Code:

