Winter 2025-2026

HANJournal

The quarterly news journal of the Hemophilia Association of New Jersey

HEMOPHILIA ASSOCIATION OF NEW JERSEY

Happy New Year

Hemophilia Association of New Jersey and Rutgers RWJ Hemophilia Treatment Center jointly hosted the Winterfest & Resource Fair on Tuesday, December 9th. Everyone had a great time!

See photos on page 5

HANJournal
the quarterly publication of the Hemophilia Association of New Jersey

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HEMOPHILIA ASSOCIATION OF NEW JERSEY

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.

A Message from the HANJ President

Lisa Maniaci

As we close out 2025, I want to extend my deepest gratitude on behalf of our entire organization. This has been a year marked by community, commitment, and meaningful progress—and none of it would have been possible without you. Whether you attended an educational workshop, joined us for our Annual 5k Run/1 Mile Walk, participated in a family event, supported our advocacy efforts, or contributed to our fundraisers, your presence and generosity strengthened our mission every step of the way.

Thank you to every individual, family, volunteer, healthcare partner, and sponsor who gave their time, energy, and resources to our events and fundraisers this year. Each effort—large or small—directly impacts the bleeding disorders community of New Jersey by helping us ensure access to care, emergency assistance, education, and support services for those who need them most.

As we look to 2026, we are energized by the opportunities ahead. In the coming year, we hope you will join us in one or more of the following:

Ways to Stay Involved and Make an Impact

- **Year-End Giving:** Your tax-deductible contributions help us continue providing essential programs and direct support to individuals and families navigating life with hemophilia and other bleeding disorders.
- **Event Participation & Sponsorship:** Our 2026 calendar is filled with educational programs, community gatherings, and fundraising events where your involvement makes a meaningful difference.
- **Volunteer Engagement (My Favorite):** From event support to community outreach, we welcome volunteers who want to lend their skills, compassion, and leadership.
- **Advocacy Efforts:** Your voice matters. By standing with us on key policy issues, you help protect access to treatment and resources for the entire bleeding disorders community.
- **In-Kind Support:** Professional services, supplies, and partnerships from businesses and individuals help stretch our resources further and expand our reach.

Your continued dedication empowers us to fulfill our mission—and ensures that no one in New Jersey faces a bleeding disorder alone.

As we celebrate this season of reflection and generosity, please accept my heartfelt thanks for the role you've played in strengthening our community. I look forward to the year ahead and the impact we will create together.

With gratitude and warmest wishes,

Lisa

FEMALES & BLEEDING FAB WOMEN'S RETREAT & CONFERENCE

FRIDAY, FEBRUARY 6TH-
SATURDAY, FEBRUARY 7, 2026
COURTYARD MARRIOTT
BY EDGEWATER NYC
3 PEMBROKE PLACE
EDGEWATER, NJ 07020

This retreat will feature educational sessions, social activities, health and wellness workshops, breakout sessions, and much more!

TO REGISTER:
EMAIL: CINDY HANSEN
CHANSEN@HANJ.ORG
PH: 732-249-6000
REGISTER BY: JAN. 12TH 2026

Winterfest - December 9, 2025

Hemophilia Association of New Jersey and Rutgers RWJ Hemophilia Treatment Center jointly hosted the Winterfest & Resource Fair on Tuesday, December 9th. There was a buffet dinner, camp craft table - resource table, photo booth, a Holiday Fun Balloon Artist, Face Painting and a DJ. Everyone had a great time!

St. Michael's Medical Center

Joanne Rodriguez, CSW

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:
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 for everyone. You can contact us at (973) 877-5342 Monday through Friday to schedule yours.

Physical Therapy:
If you need Physical Therapy let us know during you re-evaluation process for us to make an appointment that is convenient for you.

Patient Education:
Our patients are always welcome to ask questions about New Therapies and Insurance updates. If 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:
We have individualized sessions which will provide you with 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. If you or anyone you know needs help, please know that you are not alone. There's help for you and others:

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

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

From our St. Michael's Family to yours, we wish you a Merry Christmas and a Happy New Year. Stay Safe and be blessed!

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)

WHAT'S NEXT?
YOU DECIDE.

At Genentech, we're committed to supporting the hemophilia A community in ways that go beyond treatment and focus on you as a person. From sharing real stories and experiences from our Patient Ambassadors, to an educational rap anthem for a hemophilia A treatment, to one-on-one support from a team of experts, we're here to help you take on what comes next.

SCAN THE QR CODE TO SEE HOW GENENTECH AND THE HEMOPHILIA A COMMUNITY ARE EMBRACING WHAT'S NEXT, TOGETHER.

GENENTECH IN HEMOPHILIA | Genentech *A Member of the Roche Group*

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

Phyllis Kandl, MA, CSW

Happy Holidays and Happy New Year from the team 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 important updates, current programs, and future plans with you. We hope you are all doing well!

News:

New Staff: When you call the HTC, expect to hear the kind and friendly voice of Yocasta Peña, our new Program Secretary who has become an indispensable member of our HTC team!

Scholarships: Keep an eye out for educational scholarships which will soon be 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 the HTC staff.**

Hemophilia Camp: This past summer we had many new and returning campers who attended camp at Hole in the Wall Gang Camp and Double H Ranch Camp. Applications will soon open for the upcoming camp session(s) in 2026 and can be found on holeinthewallgang.org and doublehranch.org. Camp can be an integral part of a patient's journey toward independence, and family weekends can be beneficial for the whole family. **For more information about camp and family weekends, or if your child or family is interested in attending camp in the future, please contact Dan, our Social Worker, at the HTC.**

Ongoing Programs:

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

School Letters/Visits: As students are in the middle of the school year, we know that you might need forms completed, letters, or virtual school visits scheduled. While school visits will be virtual, they are a wonderful opportunity for our HTC to provide education and outreach to your child's school or daycare staff about hemophilia and other bleeding disorders. **If you are going to want a school visit scheduled for your child's school or daycare center, or need a letter for school/forms completed, please contact Dan, our Social Worker.** Dan 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.

Treatment Logs: Don't forget to log! The mobile app **Robust Health** allows patients and their caregivers to track infusions, treatments, and bleeds directly through their smartphone or tablet in a user-friendly log that shares this information seamlessly with your care team here 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. When creating a Robust Health account, make sure to choose Newark Beth Israel Medical Center as the treatment center during setup. **For more information, or to sign up, please contact our Social Worker Dan.**

Comprehensive Evaluations: It is very 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. **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. To schedule your comprehensive evaluation appointment, please call our HTC at (973) 926-6511.**

Travel Letters: Are you planning a trip and need a travel letter? **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 or vacation.** We like to make sure that you have your travel letter in hand before you embark on your journey.

Epic/MyChart: Our hospital is using Epic, which allows us to use MyChart to communicate directly with our patients. Please be aware of texts and emails asking you to enroll in MyChart. Enrolling will allow you to request refills, confirm appointments, receive letters, and will make communication with our HTC staff much easier.

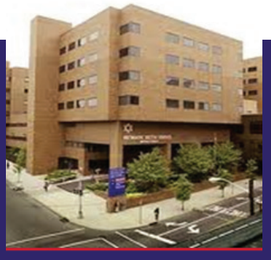
Research: At the time of an annual evaluation, patients will be asked to participate in various studies and surveillance projects depending on eligibility. These include:

- ATHNdataset (American Thrombosis & Hemostasis Network) and ATHN Transcends: Hemophilia Natural History Arm and substudies.
- Pregnancy AND Anticoagulation (PANDA) Study, part of the Venous thromboembolism Network U.S. (VENUS) Prospective Cohort Study of Management of Anticoagulation around Delivery.

These are voluntary programs conducted by HTCs 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. **For more information about these studies and how to get involved, please contact our Research Nurse, Cynthia, at (973) 926-6511.**

Manufacturer Factor Programs: Manufacturers have programs available to help patients continue to receive products during a lapse of insurance coverage. They also offer co-pay assistance programs. Each program has enrollment requirements and many require yearly re-enrollment. Enrollment in these programs can be beneficial. **For more information, please contact your home care company or our Financial Coordinator, Cassandra.**

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



Newark Beth Israel Medical Center and Children's Hospital of New Jersey
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Newark, NJ 07112
Main number:
973-926-6511
Social Worker:
Saila Javed, LCSW
Saila.Javed@RWJbh.org
973-926-4197
973-391-0048 (fax)

Rutgers Robert Wood Johnson Medical School Hemophilia Treatment Center

Lisa Cohen, MSW, LSW

Winter 2025

The Rutgers RWJMS Hemophilia Treatment Center (HTC) continues to focus on the provision of comprehensive care for our bleeding disorder and thrombosis patients amidst the changing healthcare landscape. The HTC is fully operational with primarily in person clinical care while tele-health visits are still available. Contact can be made with the Rutgers RWJMS HTC by calling the general clinic line to reach the nurses at 732-235-6542.

Welcome! Cori Nunziata, MSW has joined the Rutgers' team as the program's Social Work Coordinator. She can be reached directly at 732-235-6533.

Gene Therapy: The Rutgers HTC is pleased to be able to provide the most current treatment options for our patients. Provision of gene therapy is available to patients with hemophilia A or B who meet the eligibility requirements as defined by the product's manufacturer. If you are interested in learning more about this, please reach out to the HTC directly by contacting Frances Maceren, RN at 732-235-6542.

Educational Programming: The Rutgers HTC, in collaboration with the Hemophilia Association of New Jersey, has planned several education programs for the upcoming year (2025-2026). A variety of programming is being developed for parents of teens with bleeding disorders, Latino community members, adult men with bleeding disorders, transition age teens & elementary age children and their families. Stay tuned for more details!

School Visits: School visits continue virtually. If you anticipate the need for a school in-service program, please contact the Cori Nunziata, MSW at 732-235-6533.

Studies: Rutgers has one clinical trial that is currently enrolling patients - Genetic Analyses of Patients with Incomplete Plasminogen Activator Inhibitor (PAI). The purpose of this research is to identify differences in the genes associated with PAI-1 in patients with low PAI-1 activity. Rutgers also has two upcoming pediatric studies that will be enrolling patients in the coming months.

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Hemophilia Treatment Center
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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

WIN TICKETS TO SUPER BOWL LX!

BUY A RAFFLE TICKET FOR A CHANCE TO WIN:

GRAND PRIZE:

2 TICKETS TO SUPER BOWL LX
SUNDAY, FEBRUARY 8, 2026

Which Includes:

4 DAYS/3 NIGHTS HOTEL ACCOMMODATIONS AND ROUND TRIP AIRFARE FOR 2 TO SANTA CLARA, CALIFORNIA

SECOND PRIZE:

$500 GIFT CARD FOR BEST BUY

You can scan the QR CODE * and buy your tickets on-line through Saturday January 17th.
** Day of purchases must be in person at Miller's Woodbridge Ale House.*

DONATION: $25.00

www.hanj.org/events

Proceeds go to:
Hemophilia Association of New Jersey
197 Route 18 South, Suite 201 North
East Brunswick, NJ 08816

To provide crucial programs to support persons living with hemophilia in New Jersey.

Raffle drawing will be held:
Sunday, January 18, 2026
8 PM
Miller's Woodbridge Ale House

- *winner need not be present to win*
- *prizes are non-transferable*

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:

- **SuperBowl Raffle Pull**
  Sunday, January 18th
  Miller's Ale House in Woodbridge, NJ
- **HANJ Virtual Scholarship Seminar**
  Wednesday, January 28th at 6pm
- **FAB - Females and Bleeding Conference/Retreat**
  Friday, February 6th - Saturday, February 7th
  Courtyard Marriott by Edgewater NYC
  Octapharma is the Exclusive Sponsor
- **Rutgers RWJ Transitions Program - Virtual**
  Gary McClain, PhD, Therapist
  Date to be decided
- **Community Connections**
  Sunday, March 22nd
  Bowling at Palmeras Entertainment