We hope you enjoy this edition. We have tried to include a lot of valuable resource information you can use throughout the year.
Spring has sprung!

Welcome to the Executive Director’s Corner. I am so happy to write my first entry for the HANJ newsletter. As you have noticed, we have added some new features to the newsletter and we hope you are finding it beneficial to you and your family. We will continue to provide you great reading material, informative articles, updates on all things HANJ, and so much more!

Spring is a time where the tree leaves are turning green again, flowers are in bloom, and the anticipation of warmer days ahead. It is also a time at the HANJ where some of our most exciting programs and events take place. We are busy little bees!

Advocacy plays a big role in our mission. Right now, our Legislative efforts are in full force with two bills pending in the Trenton. One in particular, I would like to focus this article on, pertains to our state of New Jersey insurance grant program.

For over 30 years the HANJ has been awarded a grant from the New Jersey Department of Health which allows us to provide insurance policies, and copay assistance, to our members. We have worked very hard over recent years to keep up with the enactment of the Affordable Care Act and the expansion of Medicaid. In addition, the needs of the community have evolved. Whether it be the developments in von Willebrand disease, or the challenges with acquired hemophilia, we wanted to ensure this vital resource encompasses the community as it is today.

This is how Senate bill S3100 and Assembly bill A5186 was born. Passed on the Senate side and heading to the Assembly, this bill will expand the definition of Hemophilia to mean “a bleeding tendency resulting from a genetically determined [deficiency factor in the blood], hereditarily determined, or acquired factor deficiency in the blood”. The bill goes on to include qualitative platelet disorders and von Willebrand disease. By expanding the language of the existing insurance grant program, we will be able to ensure quality and access of care to the community TODAY. This bill in particular has taken a lot of hard work and expertise from many great friends of the Association, which brings me to our greatest friend of all…YOU.

Our membership is the driving force behind all we do. Our passion is to be certain our members can rest easy at night, knowing there are people out there fighting for their care, is at the heart of all our efforts. But we cannot do this alone. We need your help as we move through the most exciting and innovative time this community has ever seen. While anticipation is in the air for new treatment options and therapies, your support, along with your advocates at the HANJ are needed the most to educate the right people, shed light on the struggles some families face, and perhaps the most important question of all…how are these treatments going to be covered?

We are proud to hold the entire state of New Jersey in our hands. Legislative efforts in your home state directly benefit you and your family. This is why it is so important to stay on the pulse of all we do and be part of the trail we continue to blaze.

In June, we will be hosting a Legislative Day, where we will travel to the state capital, Trenton, New Jersey, to learn how the New Jersey Legislature works and use our voices to educate our lawmakers on the needs of the bleeding disorders community in New Jersey. Please be sure to keep an eye out for the upcoming notice of our Legislative Day, and please be sure to join us in Trenton. Our efforts are lost without the support of our members.

As we evolve with the community, it is crucial we stick together and come together as a voice of one. We often use the #bettertogether on our social media posts. Truer words have never been spoken.

Warmly,
Steph
constitutes endorsement by the HANJournal in no way.
Before 1985, roughly half of the nation’s 20,000 persons with hemophilia contracted HIV, the virus that causes AIDS, through tainted blood products. Wives and children were also infected. The crisis has been referred to as the worst medically induced catastrophe in this country.

In 2001, the Hemophilia Association of New Jersey commissioned New Jersey Artist Edward Adams to create a work of public art, dedicated to people who had been infected with the virus, and to those who had died. The Association, with the full support of the late Dr. Parvin Saidi, Professor of Hematology, Professor of Medicine, and Director of the New Jersey Regional Hemophilia Program, selected the entrance to the RWJ Clinical Academic building in New Brunswick as the ideal site for Mr. Adams’ work of art. Prayer Feather, is an eight-foot high bronze statue into which the artist enclosed the ashes or various writings, photos, and other mementos of those community members who had died of AIDS. The location had been selected because of its proximity to the RWJ Hemophilia Treatment Center, and because it would be in full view of patients, physicians, medical staff, medical students, and administrators. A fitting juncture for this living memorial. The street side of Prayer Feather is highly polished so that passersby, seeing their image, may reflect that AIDS can attack anyone. The other side, deeply textured, bears a wound symbolic of the pain and torment caused by the disease.

Prayer Feather memorializes the innocent victims whose memory remains in our hearts, honors those still struggling to survive, and reminds us that the mandate from this tragedy is clear: Forever Vigilant!!

LEST WE FORGET
By Elena Bostick
WHAT IS HEMOPHILIA
Forward
For many, many, years, the disease “Hemophilia” had very few Senior Citizens. People with Hemophilia simply did not live that long. Advances in the care, and treatment of Hemophilia have changed that prognosis. Today we have community members that are aging into Medicare. Wow!! That is progress, but it is progress for which we have paid a steep price.

The hemophilias are bleeding disorders caused by an inherited absence, or abnormality, of any of the clotting factors. Hemophilia is a lifelong problem affecting the individual from birth until death. Because blood permeates all body tissues, hemophilia involves all body systems, and is an added complication to every other medical condition the individual with hemophilia may encounter.

Hemophilia afflicts one out of every 4,000 male births. It is estimated that at present there are 20,000 hemophiliacs in the United States. Until the last four decades, most persons with hemophilia did not reach adulthood; and of those who did, a life history of frequent, excruciatingly painful bleeding episodes involving the muscles and joints, with early and severe crippling, a typical picture. If a person with hemophilia happened to suffer another common medical problem, such as a bad sore throat or an abscessed tooth, it often became a crisis. Treatable conditions, like appendicitis or gallstones, were catastrophes and often fatal. Even more damaging than the medical problems, the physical disabilities of the child with hemophilia inevitably interfered with his education. This very often prevented him from becoming a gainfully employed and productive adult. The cost of hemophilia was enormous and suffered by the individual as well as society at large.

This picture has completely changed for two main reasons: 1) the availability of concentrated forms of recombinant clotting factors and 2) the recognition that medical care for this population must be provided in a centralized, coordinated, and comprehensive setting, by a team of specially trained and experienced care providers.

The New Jersey Regional Comprehensive Hemophilia Care Program was established in 1976, under the auspices of the Division of Hematology and Oncology of University of Medicine and Dentistry of New Jersey (UMDNJ, today’s Rutgers RWJ). It provides coordinated comprehensive care for patients with hemophilia through its major Comprehensive Centers at Rutgers Robert Wood Johnson Medical School, Saint Michael Medical Center, Newark Beth Israel Medical Center, and a freestanding Pediatric Hemophilia Clinic in Voorhees.

The hemophilic patient population, like any other large patient population, has a predictable incidence of all other medical and surgical diagnosis; however, these diagnosis are all impacted upon, and made more complex and costly by hemophilia. Clotting factor replacement is an absolute medical requirement. There is simply no alternative, regardless of, and in addition to whatever other medical needs he may have. When a hemophilia patient receives expert care, and expert clotting factor replacement, other medical and surgical problems become routine. Without appropriate expertise and support, all medical and surgical problems could become life threatening.

There is no question that modern hemophilia care, and especially clotting factor replacement, is expensive, but it is still a bargain when compared to the long-term medical, rehabilitative, psychosocial and welfare cost (in dollars as well as human suffering) of improper or inadequate hemophilia care.

By Elena Bostick
The Hemophilia Association of New Jersey’s Many Years of Accomplishments

Much has been learned in the nearly 48 years since the incorporation of the Hemophilia Association of New Jersey. One recurring theme has been that some of the best opportunities surface when times are seemingly at their most uncertain. This was true in the seventies with the creation of the first State Hemophilia Program in the nation; in the eighties with the passage of Hemophilia Insurance Legislation which eliminated lifetime limits; and again in the nineties with the enactment of Hemophilia Standards of Care. Persons with Hemophilia who reside in New Jersey know that in HANJ they have an organization that can respond. Individuals with hemophilia nationwide have come to understand that as well.

Forty-eight years ago, the goal of the HANJ was a cure for hemophilia. While that has not changed, today our daily focus must be to predict, prepare for, or prevent. To do so requires a clear understanding of what is needed, recognition as a credible and dedicated organization, and knowledgeable people to convey our message.

The value of HANJ is built upon the commitment of its people, and the relationships developed, over time, with leaders in all fields pertinent to hemophilia. This has included medical professionals, insurance industry representatives, pharmaceutical manufacturers, legislators, regulators, and, of course, consumers. We have created a pool of experts from different disciplines to draw upon when comprehensive solutions are needed.

Our challenge has been to preserve policies that work, try to make them work better, and be relentless about anything viewed as detrimental to the health and well-being of persons with hemophilia.

In order to be effective, consumers, and their representatives must be informed, present, and engaged. We seek to impart the lessons we have learned to others representing the hemophilia community. The whole can only be as strong as the sum of its parts.

A brief synopsis of our history follows:

2011 HANJ begins quarterly meetings with Medicaid officials to ensure that hemophilia treatment, patient care, and patient choice are not compromised as a result of healthcare cuts. These meetings include: The Director of NJ Medicaid, the Medical Director, the Pharmacy Director, representatives from NJ HTC’s, and others as needed, and have led to a comprehensive, cooperative, and effective relationship. Quarterly meetings continue to this day, and are utilized to air issues of mutual concern, and avoid any disruption of medical benefits to eligible persons with bleeding disorders.

2011 HANJ participates in Rutgers Center for State Health Policy Focus Groups to determine effect of ACA on hemophilia in New Jersey.

2010 HANJ continues to absorb the cost of its uninsured members, $900,000 in 2010/2011 alone.

2009 HANJ initiates quarterly meetings with HTC Social Workers in an effort to facilitate discussion on ongoing issues and concerns affecting persons with hemophilia, as well as to review and prepare for challenges ahead. These meetings continue to this day.

2007 Governor Corzine signs off on the Women with Bleeding Disorders Task Force final report and recommendations. The Task Force reconvenes in April to begin developing programs and services recommended through the report.

2004 The Governor's Women with Bleeding Disorders Task Force meet through 2006. The final report is submitted for Governor Corzine's signature.

2003 HANJ pursues an Executive Order to study the prevalence and complications of women with bleeding disorders. Governor James McGreevey signs order.

2000 HANJ Standards of Care legislation requires HMO/Managed Care insurers comply with certain standards in the provision of benefits to patients with hemophilia.

1997 HANJ has language inserted into state HMO regulations that secures access to and reimbursement for care of Hemophilia Treatment Centers.

1996 HANJ legislation opens a one year window to the NJ Statue of Limitations for those HIV infected individuals wishing to pursue the Justice System.

1993 HANJ funds deficit to insurance premium grant and we still do so today despite skyrocketing costs and premium rate hikes.

1987 HANJ receives state grant to purchase insurance premiums for members not eligible for entitlements or group insurance.

1986 HANJ legislative effort leads to NJ requirement that all insurers cover home care factor under the basic plan. This eliminated lifetime limits.

1985 HANJ obtains social services grant from NJ State Department of Health.

1983 HANJ legislative effort leads to Blue Cross payment of heat treated products.

1981 HANJ legislative effort leads to major medical open enrollment.

1977 Federal funding for NJ treatment centers obtained.

1973 State program pays for in-home use of clotting factor.

1972 HANJ legislative efforts lead to the first state hemophilia program for uninsured, persons with hemophilia and health service contracts for HTC's.

Meeting the challenges since 1971.
JOINT RESOLUTION NO. 2

A Joint Resolution designating March of each year as “Bleeding Disorders Awareness Month” in New Jersey.

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

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

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

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

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

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

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

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

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

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

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

Be it Resolved by the Senate and General Assembly of the State of New Jersey:

C.36:2-325 “Bleeding Disorders Awareness Month,” March; designated.
1. March of each year is designated as “Bleeding Disorders Awareness Month” in New Jersey in order to increase public awareness about bleeding disorders, generate a greater understanding of all inheritable bleeding disorders, and foster a greater sense of community and shared purpose among individuals with inheritable bleeding disorders and the general public.

C.36:2-326 Annual observance.
2. The Governor is respectfully requested to annually issue a proclamation designating March as “Bleeding Disorders Awareness Month” in New Jersey, and calling upon public officials and the citizens of the State to observe the month with appropriate activities and programs.

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

4. This joint resolution shall take effect immediately.

Approved March 20, 2018.

Hemophilia Association of New Jersey
Mission Statement
Our mission is to improve the quality of life for persons with a bleeding disorder by providing and maintaining access to highly qualified medical providers and successfully proven medical regimens.
Managing Depression A Challenge In Primary Care Settings, Study Finds

By Shefali Luthra March 7, 2016, Kaiser Health News, (KHNN) is a nonprofit national health policy news service.

Often referred to as the “common cold of mental health,” depression causes about 8 million doctors’ appointments a year. More than half are with primary care physicians. A new study suggests those doctors may not be the best to treat the condition due to insurance issues, time constraints and other factors.

The paper, published Monday in the March issue of Health Affairs, examines how primary care doctors treat depression. More often than not, according to the study, primary care practices fall short in teaching patients about managing their care and following up regularly to track their progress. That approach is considered most effective for treating chronic illnesses.

That’s important. Most people with depression seek help from their primary care doctors, the study notes. Why? Patients often face “shortages and limitations of access to psychiatrists,” the authors write. For example, patients sometimes have difficulty locating psychiatrists nearby or those who are covered by their insurance plans. Plus, there’s stigma: Patients sometimes feel nervous or ashamed to see a mental health specialist, or believe there are barriers to accessing one.

Meanwhile, physicians and health experts have increasingly been calling for mental health conditions — such as depression and anxiety — to be treated like physical illnesses. Historically, these have been handled separately and, experts say, without the same attention and care as things like high blood pressure and heart disease.

The researchers compared strategies for treating depression with those used for asthma, diabetes and congestive heart failure. They surveyed more than 1,000 primary care practices across the country to determine how often doctors’ offices used five specific steps — considered “best practices” — to manage patients’ chronic conditions. They include employing nurse care managers, keeping a registry of all patients with a condition that requires regular follow-up, reminding patients to comply with their treatment regimens, teaching them about their illnesses and giving doctors feedback. Those approaches track with recommendations from the Department of Health and Human Services Agency for Healthcare Research and Quality.

On average, the practices surveyed were least likely to follow those protocols when treating depression. About a third kept registries of patients with depression, and the other steps were less commonly used. Less than 10 percent of practices, for instance, reminded patients about their treatments or taught them about the condition.

Doctors were most likely to use those best practices for treating diabetes. Most practices followed at least one of the strategies for managing chronic illness.

“The approach to depression should be like that of other chronic diseases,” said Dr. Harold Pincus, vice chair of psychiatry at Columbia University’s College of Physicians and Surgeons and one of the study’s co-authors. But “by and large, primary care practices don’t have the infrastructure or haven’t chosen to implement those practices for depression.” Pincus is also director of quality and outcomes research at New York Presbyterian Hospital.

That’s a problem, said Dr. Tara Bishop, an associate professor of healthcare policy and research at Weill Cornell Medical College, the study’s main author. Effectively treating any chronic illness requires working with patients beyond single visits. For depression, that means things like following up to see if medication is working, or if a dose should be adjusted.

“When we treat high blood pressure, the blood pressure may start at 150 over 95, and then it’s monitored over time until it gets to a level that’s being aimed for,” said Dr. Jeffrey Borenstein, president of the Brain and Behavior Research Foundation. The foundation funds mental health research but was not involved with this study. “If somebody has depression, their symptoms need to be monitored until it gets to a level that the depression is lifted.”

Depression can contribute to other health problems, like pulmonary disease or diabetes, Bishop said. It can make people less productive at work or less able to have healthy relationships. Unchecked, it can result in suicide.

“If we actually treat depression as a chronic illness and use the level of tools we’re using for diabetes, then we’ll be able to better treat patients — and help them live healthier lives and more productive lives,” she said.

The study didn’t delve into why the gap exists between depression and other medical conditions. But the authors pointed to potential explanations. One is that there’s been a decades-long push to improve how doctors treat diabetes — an effort that has almost been “the poster child” for how to monitor and treat a long-term illness, Pincus said.

And there are time pressures. Diagnosing a patient with depression — and following up regularly — can take more time than a diabetes blood test or insulin check. Cramming that into a 15-minute visit can get difficult, Bishop said, especially as doctors are increasingly asked to do more with less time.

Plus, she said, while there’s been an effort nationally for the medical profession to better address mental wellness, individual physicians may still struggle.

“It’s almost like a subconscious divide of mental health issues versus physical health issues,” she said. That may also contribute to why the treatment of depression sometimes falls short.

Some cited money as a key obstacle. Dr. Wanda Filer, president of the American Academy of Family Physicians, noted that, despite federal law, it’s still difficult to get insurers to pay for mental health care. That circumstance, she said, could discourage or impede primary care doctors from taking a comprehensive approach to treating it.

“Most depression cases we can manage quite easily — family physicians are well-trained to manage this particular condition,” said Filer, also a practicing family doctor in York, Pennsylvania. The problem is that there are all these barriers to improving mental health.”

But Bishop said that, as doctors and policymakers take a broader interest in the issue, those barriers could come down and change how doctors practice.

“We’re starting to realize that mental health care, and depression in particular, are very important illnesses. They affect a large part of our population, and they have a lot of repercussions for patients and society,” she said.

Mental Health Services

Suicide Prevention Line 1-800-273-8255 Suicidepreventionlifeline.org

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

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

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

NJ Connect for Recovery 1-844-822-0586 Groundlink www.njconnectforrecovery.org

The Crisis Text Line text 741741 when you are feeling depressed or suicidal. A crisis worker will text you back immediately and continue to text with you. Many people don’t like talking on the phone and would be more comfortable texting. It’s a FREE and confidential service to ANYONE - teens, adults, etc. - who live in the U.S. and it is available 24/7.

2-1-1
How Hemophilia is Inherited

The following examples show how the hemophilia gene can be inherited. It is important to note that in one-third of people with hemophilia, there is no family history of the disorder.

1. In this example, the mother is a carrier of the hemophilia gene, and the father does not have hemophilia.
   - There is a 50% chance that each son will have hemophilia.
   - There is a 50% chance that each daughter will be a carrier of the hemophilia gene.

2. In this example, the father has hemophilia, and the mother does not carry the hemophilia gene.
   - All daughters will carry the hemophilia gene.
   - No sons will have hemophilia.

3. In this example, the father does not have hemophilia, and the mother does not carry the hemophilia gene.
   - None of the children (daughters or sons) will have hemophilia or carry the gene.

The Hemophilia Association of New Jersey provides MedicAlert Memberships and IDs for patients with hemophilia and VWD.

Medical ID jewelry is essential for people with bleeding disorders. Wearing a Medical ID ensures emergency responders and hospital staff have the most up-to-date medical information the moment they need it, to make informed decisions about treatment and care.

For more information and an order form, please contact Cindy Hansen at HANJ at 732-249-6000 or chansen@hanj.org.
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 may cause serious side effects when used with activated prothrombin complex concentrate (aPCC; FEIBA®), including:
  - thrombotic microangiopathy (TMA), which 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 or legs
    - yellowing of skin and eyes
    - stomach (abdominal) 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:
  - cough up blood
  - feel faint
  - headache
  - numbness in your face
  - eye pain or swelling
  - fast heartbeat
  - joint pain
  - chest pain or tightness
  - shortness of breath
  - faintness
  - feeling sick
  - nausea or vomiting
  - back pain

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.

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 breakthrough bleeds and serious side effects when used with activated prothrombin complex concentrate (aPCC; FEIBA®), including thrombotic microangiopathy (TMA), and blood clots (thrombotic events). 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.

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

Medication Guide

HEMLIBRA® (hem-les-bruh) (emicizumab-kvch)
Injection, for subcutaneous use

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.

How should I use HEMLIBRA?

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.

• Do not attempt to inject yourself or another person unless you have been taught 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® once a week for the first four weeks. Then you will receive a maintenance dose as prescribed by your healthcare provider.

How should I store HEMLIBRA?

• 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 dispose of unused 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 68°F (20°C).

• After HEMLIBRA® has been transferred from the vial to the syringes, 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 should 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-kvch
Inactive ingredients: L-leucine, polysorbsate 80, and L-leucine acid.

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Page 18
Genentech 1st page

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EM/151984/1106
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What is the most important information I should know about HEMLIBRA?

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  - Thrombotic microangiopathy (TMA), which 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 or legs
    - yellowing of skin and eyes
    - stomach (abdominal) or back pain
    - nausea or vomiting
    - feeling sick
    - decreased urination

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Please see Brief Summary of Medication Guide on following page for Important Safety Information, including Serious Side Effects.
## Pharmaceutical Resources for Bleeding Disorders
### Free Factor & Co-Pay/Deductible Assistance Programs

<table>
<thead>
<tr>
<th>Manufacturer</th>
<th>Program Name &amp; Contact Information</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Akorn Pharmaceuticals</strong></td>
<td>1 (844) 202-5909</td>
<td>Patient Assistance Programs: This needs-based program assists patients in accessing Amicar. Programs include co-pay assistance for patients with commercial insurance coverage and a needs-based support program for those patients without commercial insurance. These are newly created programs to support your access to the product and reduce co-pay obligation automatically at participating pharmacies.</td>
</tr>
<tr>
<td><strong>Aptevo Therapeutics</strong></td>
<td>IXINITY Savings Program <a href="http://ixinity.com/save-on-IXINITY">http://ixinity.com/save-on-IXINITY</a></td>
<td>- Must have valid prescription for IXINITY - Must have commercial insurance - No monthly limits unless limit total is reached. - No income requirements - Co-pay program can be used retroactively for up to 12 months - Limit Total $12,000</td>
</tr>
<tr>
<td><strong>Bayer</strong></td>
<td><a href="http://www.jivi.com">www.jivi.com</a> <a href="http://www.kogenatefs.com">www.kogenatefs.com</a> <a href="http://www.kovaltry-us.com">www.kovaltry-us.com</a></td>
<td>$9 Product Co-Pay Program: You may receive up to $12,000 in assistance per year, regardless of income. - Lab Monitoring Co-Pay Program for Jivi antihemophilic factor (recombinant), PEGylated-dux: You may be eligible to receive up to $250 per year to apply towards out-of-pocket costs for laboratory monitoring of Jivi - 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. - Live Helpline Support: Consult with an expert in insurance, multiple languages, including Spanish, are available.</td>
</tr>
<tr>
<td><strong>CSL Behring</strong></td>
<td><a href="http://www.csblehringassurance.com">www.csblehringassurance.com</a> <a href="http://www.csblehring.com/patients/support/support-and-assistance">www.csblehring.com/patients/support/support-and-assistance</a></td>
<td>CSL Behring Assurance Program: Contact a CSL Behring Assurance Program Care Coordinator at 1 (866) 415-2164 - CSL Behring Patient Assistance Program: 1(844) 727-2752 - My Source Hotline for My Source Care Coordinator - My Source Hotline Program to assist with deductibles/co-pays associated with Helixate and Humate-P, Idelvion and Afstyla up to $12,000 annually. 1 (800) 676-4266 - <a href="http://www.idelvion.com">www.idelvion.com</a>: 30-day free trial and, if eligible, co-pay support up to $12,000. - <a href="http://www.afstyla.com">www.afstyla.com</a>: All insured patients are eligible for 30-day free trial and co-pay support up to $12,000, if eligible.</td>
</tr>
<tr>
<td><strong>Grifols</strong></td>
<td>1 (844) MY-FACTOR (693-2286) <a href="http://www.grifolspatientcare.com">www.grifolspatientcare.com</a></td>
<td>- 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.</td>
</tr>
<tr>
<td><strong>Kedrion</strong></td>
<td>1 (855) 353-7466 <a href="http://www.koate-divi.com">www.koate-divi.com</a></td>
<td>Kedrion Connect: Created to help provide eligible patients with financial support. There are two programs under Kedrion Connect to assist eligible patients: - Co-pay Assistance – Helps eligible patients with their copay 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.</td>
</tr>
</tbody>
</table>
Octapharma

Manufacturer: Octapharma
Information: www.wilateusa.com

- Bridge Program - Free trial program for Wilate (5,000 units/30 day supply). Application form at: http://www.wilateusa.com/images/DOF_Files/wilateBridgeProgram_enrollmentForm_102512.pdf
- NUWIQ® Co-Pay Assistance Program Offers eligible patients a savings up to $12,000 per year on the out-of-pocket costs associated with treatment. http://www.nuwiquasa.com/factor-8-free-trial/#Free-Trial-Program
- Find us online at: www.NUWIQUSA.com
- Octapharma Reimbursement Hotline: useimbursement@octapharma.com Tel: (800) 554-6744 Fax: (800) 554-6744
- Wilate Co-Pay Assistance Program -- Savings of up to $6,000 per year on the out-of-pocket costs associated with your therapy. For more information or to enroll, contact the Octapharma Support Center at 1-800-554-6744.
- Trial Prescription Program for Eligible Patients - Allows patients to get a one-time, one-month supply up to 20,000 IU of Pfizer factor product delivered at no cost to him or her. Call Pfizer Hemophilia Connect at 1-844-989-HEMO (4366) for more information or visit the website www.HemophiliaVillage.com
- Pfizer Factor Savings Card - Up to $12,000 annual support for co-pay, deductible and coinsurance costs for Beneﬁx and Xyntha regardless of income. Call Pfizer Hemophilia Connect at 1-844-989-HEMO (4366) for more information or visit the website www.HemophiliaVillage.com
- Pfizer RxPathways - A comprehensive assistance program that provides eligible patients (insured, uninsured, and underinsured) with a range of support services. Call Pfizer Hemophilia Connect at 1-844-989-HEMO (4366) for more information or visit the website www.PfizerRxPathways.com

Pfizer

Manufacturer: Pfizer
Information: www.hematologysupportpro.com

- Freedom of Choice - Eligible patients can receive free sample dose of eligible Shire’s hemophilia products along with educational resources.
- Co-Pay Assistance Program – Non-Financial Needs Based Program (Commercial insurance only)
- Reimbursement Resources
- Product Information

Sanofi Genzyme (formerly Bioverativ)

Manufacturer: Sanofi Genzyme (formerly Bioverativ)
Information: www.NUWIQUSA.com

- NUWIQ® Free Trial Program Eligible patients can receive treatment with NUWIQ at no cost. (Not to exceed 6 doses, or approximately 20,000 IUs) http://www.nuwiquasa.com/factor-8-free-trial/#Free-Trial-Program
- Find us online at: www.NUWIQUSA.com
- NUWIQ® Co-Pay Assistance Program – Provides up to $12,000 co-pay/insurance assistance for eligible patients who use Eloctate or Alprolix. No income requirements!
- Painate 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 $12,000 co-pay/insurance assistance for eligible patients who use Eloctate or Alprolix.
  - No income requirements!

Pfizer continued ...

Manufacturer: Pfizer
Information: www.hematologysupport.com

- Pfizer Hemophilia Connect offers Appeals Support on Behalf of Eligible Patients - Service includes claim denial review and research, Nurse-drafted appeals on behalf of Pfizer Patients, Submission of appeal directly to the payer on behalf of patient, Timely follow-up with payer on appeal status until outcome is received. Call Pfizer Hemophilia Connect at 1 (844) 989-HEMO (4366) for more information.

Takeda

Manufacturer: Takeda
Information: www.hematologysupport.com

- Patient Support Resources
  - Co-Pay Assistance
  - Insurance, Education & Resources

Medical Professional Support Resources

Hematology Support Center: One-stop Resource for Hematology Resources (Medical Professionals):
- Assistance Programs – Available to eligible patients with no insurance or a gap in coverage (eligibility and application requirements)
- Freedom of Choice – Eligible patients can receive free sample dose of eligible Shire’s hemophilia products along with educational resources.
- Co-Pay Assistance Program – Provides up to $12,000 co-pay/insurance assistance for eligible patients who use Eloctate or Alprolix. No income requirements!
Non-Pharmaceutical Assistance Programs

<table>
<thead>
<tr>
<th>Organization</th>
<th>Contact Information</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hope for Hemophilia</td>
<td>(888) 529-8023</td>
<td>Provides financial assistance programs to individuals and families living with chronic conditions, with priority placed on those living with bleeding disorders.</td>
</tr>
<tr>
<td>The Colburn-Kean Foundation, Inc.</td>
<td><a href="http://www.colkeeen.org">www.colkeeen.org</a></td>
<td>Provides financial assistance programs to individuals and families living with chronic conditions, with priority placed on those living with bleeding disorders.</td>
</tr>
<tr>
<td>Caring Voice Coalition (CVC)</td>
<td><a href="http://www.caringvoice.org">www.caringvoice.org</a></td>
<td>Factor XIII deficiency program</td>
</tr>
<tr>
<td>HFA Helping Hands</td>
<td><a href="http://www.hemophiliafed.org/programs/helping-hands">www.hemophiliafed.org/programs/helping-hands</a></td>
<td>Hemophilia Federation of America is a national non-profit organization that assists, educates and advocates for the bleeding disorders community. HFA’s Helping Hands Emergency Assistance is designed to establish a rapid, non-invasive source of relief for emergency situations or urgent needs to persons who are affected by diagnosed bleeding disorders. Each year, Helping Hands aids hundreds of families with emergency/jurgent 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 HFA’s Navigating Patient Assistance Programs chart to find other financial resources.</td>
</tr>
</tbody>
</table>

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

Additional Resources

<table>
<thead>
<tr>
<th>Organization</th>
<th>Contact Information</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>211 United Way</td>
<td>(703) 836-7112</td>
<td>Provides free and confidential information and referrals to local services including housing, food, employment, healthcare, counseling, and more. Check the website of your local United Way.</td>
</tr>
<tr>
<td>The Assistance Fund</td>
<td>(855) 845-3663</td>
<td>The Assistance Fund (TAF) is an independent charitable assistance foundation that helps patients and families facing high medical out-of-pocket costs by providing financial assistance for their co-payments, co-insurance, deductibles and other health-related expenses. Go to their website to confirm eligibility and other resources.</td>
</tr>
<tr>
<td>Needy Meds</td>
<td>1 (800) 503-6897</td>
<td>A national non-profit organization that maintains a website of free information on programs that help people who can’t afford medications and healthcare costs.</td>
</tr>
<tr>
<td>Patient Advocate Foundation (PAF)</td>
<td>1 (800) 532-5274</td>
<td>Provides case management and assistance in accessing health insurance. Co-pay assistance programs are available.</td>
</tr>
<tr>
<td>RxHope</td>
<td><a href="https://www.rxhope.com/about.aspx">https://www.rxhope.com/about.aspx</a></td>
<td>A web-based information resource to help low-income US residents access patient assistance programs.</td>
</tr>
<tr>
<td>RxOutreach</td>
<td>(888) 796-1234</td>
<td>A patient assistance program that provides discounts on prescription drugs.</td>
</tr>
<tr>
<td>United Healthcare</td>
<td>1-855-696-4223</td>
<td>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.</td>
</tr>
</tbody>
</table>
How should I use Rebinyn®?

• Rebinyn® is given as an infusion into the vein.
• Call your healthcare provider right away if your bleeding does not stop after taking Rebinyn®.
• Do not stop using Rebinyn® without consulting your healthcare provider.

What are the possible side effects of Rebinyn®?

• Common side effects include swelling, pain, rash, redness at the location of the infusion, itching.
• Tell your healthcare provider about any side effect that bothers you or that does not go away.

Common Side Effects Include:

• Swelling, pain, rash, or redness at the location of infusion.

Other Possible Side Effects:

• You could have an allergic reaction to Rebinyn®. Call your healthcare provider right away if you get any of the following signs of an allergic reaction: hives, chest tightness, wheezing, difficulty breathing, and/or swelling of the face.

Tell your healthcare provider if you are pregnant or plan to become pregnant. The total time of storage at room temperature is 1000 IU per vial.

How can I store Rebinyn®?

Do not attempt to do an infusion yourself unless you are trained. An infusion should be given only by someone trained in the care of people with hemophilia B. Rebinyn® is an injectable medicine used to replace Factor IX that is missing in patients with hemophilia B.

Rebinyn® is a pilot who hikes and camps in his spare time. Clayton lives with hemophilia B.

Tell your healthcare provider if you are pregnant or planning to become pregnant.

If you forget to use Rebinyn®

If you forget a dose, do not take the missed dose when you remember. Do not take a double dose to make up for a missed dose. Make up for the missed dose as soon as possible.

What if I take too much Rebinyn®

Always call your healthcare provider if you think you or someone else may have taken too much Rebinyn®. Do not share Rebinyn® with other than those listed here. Do not use Rebinyn® for a condition for which it is not prescribed. Do not share Rebinyn® with other people, even if they have the same symptoms that you have.

You should not use Rebinyn® if you:

• are allergic to Factor IX or any of the other ingredients of Rebinyn®.
• have ever had an allergic reaction to hamster proteins.

Who should not use Rebinyn®?

• have injections or infusions at home.

Who should use Rebinyn®?

• is an emergency treatment right away if you get any of the following signs of an allergic reaction: hives, chest tightness, wheezing, difficulty breathing, and/or swelling of the face.

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

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Blood Brotherhood  
For Adult Men with Hemophilia

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

If you’d like to join the Blood Brotherhood group and attend one of our events, please reach out to Peter Marcano (petermarcano@gmail.com / (201) 401-7080) or Rajh Odi (odi.apd@gmail.com / (862) 215-7944) or HANJ directly.

DONATE! DONATE! DONATE!
Please show your support by donating to The Hemophilia Association of New Jersey. Every single dollar counts!

Your donations go towards providing crucial programs to support persons with hemophilia in New Jersey.

Please make your check out to The Hemophilia Association of New Jersey or HANJ. We are a non-profit 501(c) organization. You will receive a receipt when we receive your donation for tax purposes.

Name: ______________________________________________________
Address: ____________________________________________________
City: _______________________________ State: _______Zip: ________

Phone: Cell/Home : _____________________
Amount of Donation: _____________________

You can always donate on our website at www.hanj.org
Thank You! Your Donations Make A Big Difference!

HANJ has partnered with the Hemophilia Federation of America (HFA) to offer the Blood Brotherhood program. Blood Brotherhood is a men’s group open to adult men (21+) with bleeding disorders. The purpose of this group is to provide an opportunity for older men with bleeding disorders to connect with their peers in a fun, relaxed setting. There is NO COST to attend any Blood Brotherhood event and once you sign up, there is no obligation to attend every event.

HANJ Pharmaceutical Educational Programs

We partner with a Pharmaceutical Company to host each program. Please join us for member gathering, some good food, and education you won’t want to miss!

On April 17th, 2019, HANJ partnered with Sanofi Genzyme to bring the program titled “Braving Change” presented by Aliana Soto of Sanofi Genzyme. It was a very informative and engaging presentation. Aliana talked about resilience in the face of change and included ways to help adapt to difficult circumstances. The family-style dinner provided at Maggiano’s in Bridgewater, New Jersey, was delicious and plentiful. Everyone in attendance had a very enjoyable evening.

On March 20th, 2019, HANJ partnered with Genentech, to bring the program titled “The Science of Optimism” at Season’s 52 Restaurant in Cherry Hill, New Jersey. We wanted to reach out to members that live in South Jersey. We had 25 in attendance. The speaker, Dr. Judy Saltzberg, Ph.D. emphasized that anyone can learn to be optimistic and offered information on building an optimistic mindset. The program was very informative and everyone had a wonderful evening.

These educational programs are a time for our members and their families and friends to get together to meet one another and enjoy the program along with a nice dinner. You will be sure to bring some knowledge away from any program you attend. We would love to hear from you. If you have an idea for a program we will work on bringing that one to one of our programs. Just contact us at info@hanj.org and we will work to present your program of interest.

Upcoming Pharmaceutical Educational Programs

June 19th, 2019
“The Science of Connection”
Presented by Genentech

July 17th, 2019
“Empowered: Tools for Self Advocacy”
Presented by Pfizer

August 2019
Details to come soon.
Presented by Bayer

September 2019
“Evaluating Your Insurance Options”
Presented by Sanofi Genzyme

November 2019
Details to come soon.
Presented by CSL Behring

December 2019
Details to come soon.
Presented by Novo Nordisk

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Hemophilia Association of New Jersey
Upcoming Events

Annual Meeting
Thursday, May 30, 2019

Dennis Keelty Memorial Classic
Monday, June 17, 2019

27th Annual Kelly Brothers Scholarship Benefit
In Memory of Bob & Dennis
Saturday, August 17, 2019

Fall Educational Symposium
October 2019
Date to be decided

Casino Night
Saturday, October 26, 2019

PACT Workshop
November 2019
27th Annual
Kelly Brothers Scholarship Benefit
In Memory of Bob & Dennis
Saturday, August 17, 2019

Friendly Sons of the Shillelagh
15 Oak Street, Old Bridge, NJ
2:00 PM - 6:00 PM

$25 per Adult (Children free)

Includes:
Food, Draft Beer, Wine, Soda, Water
DJ & Games for Kids

Any questions please call 732-679-5679

If unable to attend, donations greatly appreciated.

Checks can be sent to:
Hemophilia Association of NJ or H.A.N.J
197 Route 18 South, Suite 206 North
East Brunswick, NJ 08816