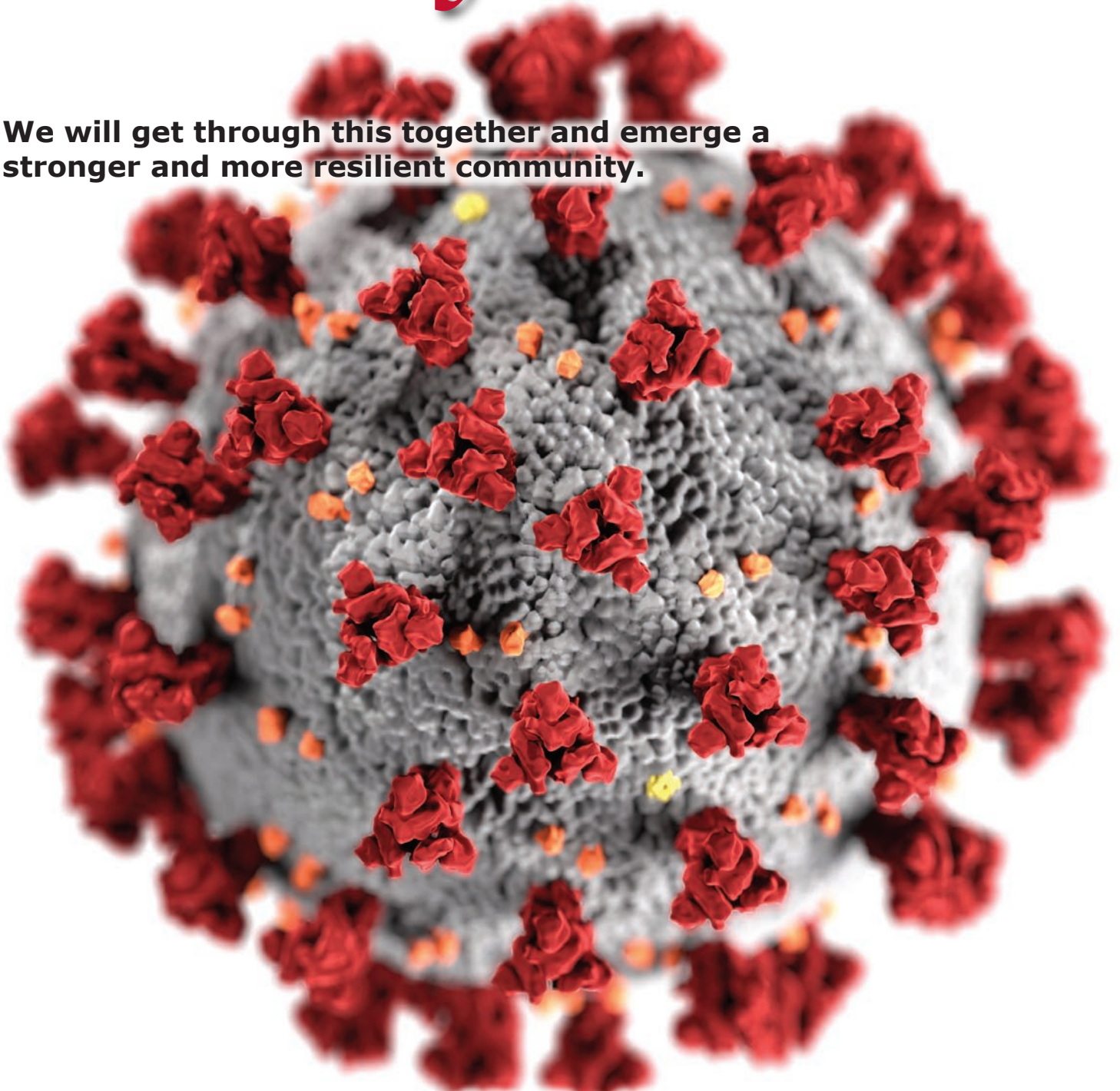


Spring 2020



# HANJournal

**We will get through this together and emerge a stronger and more resilient community.**



**COVID—19**

**It's what's on everyone's mind. Please see the message from HANJ's Medical Advisor, Jeff Lynch, MD on page 11.**

# BDRN & HANJ

## 340B Bleeding Disorders Program

In association with:

Rutgers: Robert Wood Johnson Medical School



### Bleeding Disorders Resource Network

BDRN's Mission is to improve the quality of life for people living with bleeding disorders.

At BDRN we are dedicated to serving and making a difference in the bleeding disorders community. We take a team approach to address each set of circumstances. Our commitment to improving the lives of those living with a bleeding disorder is what motivates us and is the essence of everything we do.

### Hemophilia Association of New Jersey

HANJ's mission is to improve the quality of life for persons with a bleeding disorder by providing and maintaining access to highly qualified medical treaters and successfully proven medical regimens.

- Ensure access to care
- Secure more comprehensive insurance coverage
- Ensure the NJ Standards of Care are met
- Provide financial grants to hemophilia and bleeding disorder patients
- Provide financial grants in support of the HTC's
- Provide education programs and reimbursement support to patients of New Jersey

### 340B Program

The 340B Program is a federal drug discount program. It entitles certain safety net providers and clinics, including hemophilia treatment centers, to a discounted price for covered outpatient drugs. Rutgers/RWJ has registered to participate in the 340B Program as a Covered Entity. This will allow Rutgers/RWJ to purchase factor and other drugs at a discount. While other grant fundings suffer cutbacks, Rutgers/RWJ is able to use the cost savings and other program revenues to fund the services it provides to its patients. Rutgers has selected BDRN as one of its contract pharmacies under the 340B Program. BDRN and HANJ have agreed to work together to provide certain services for the Rutgers program, including patient education and financial assistance services.



### Executive Director's Corner By Stephanie Lapidow

It is Spring here in New Jersey, and while we would typically be in the middle of our busiest fundraising season, instead we have sheltered in place.

COVID-19 has hit us hard in New Jersey, and the New Jersey/New York region is being referred to as a "hot spot" nationwide. Nobody could have expected or planned for what we are now facing. But the hard work and indomitable spirit of our staff and entire community means that everyone has adapted and adjusted quickly. The HANJ office became a remote and virtual operation on March 16. To ensure the health and safety of our staff and community members, as well as to comply with statewide mandates, we have postponed our events and created virtual platforms for engagement and resources. Because the health and wellness of our community is, and always has been, our top responsibility, this is not the "new normal" for us — it is simply our duty and responsibility, in service to our ongoing mission.

In addition, we are committed to keeping you as informed and updated as possible during and beyond the pandemic. We update our website daily with new virtual opportunities, event updates, and resources available to you. I encourage you to check our website, and also to **LIKE** us on **Facebook**, **FOLLOW** us on **Twitter**, and **CONNECT** with us on **LinkedIn**. We have increased our social media presence and would love for you to help us not only stay connected with you, but gain new members to our New Jersey family. By engaging with our social posts and providing feedback, you help us improve the ways in which we serve our community.

We recognize that this situation has affected so many of you, and that is why we have created the COVID-19 Relief Fund. If you or a family member need financial assistance during this time, please reach out to our Social Worker, Neidy Olarte. Neidy is prepared to help you get the assistance you need during these difficult times.

Several community members have asked how they can donate to help others who are struggling. All donations are used to support our New Jersey bleeding disorder families in need. Visit [www.hanj.org](http://www.hanj.org) and click the **DONATIONS** tab to help.

For the past two months, it seems as though we have all been on "pause" and waiting for life to resume. But actually, your life is happening right now, and we encourage you to live it! Even as we continue our responsible social-distancing practices, take the time to count your blessings, appreciate your loved ones, enjoy your hobbies, and stay active. We will get through this together, and emerge a much stronger and more resilient community.

Be well,  
Stephanie





HANJournal is published by the Hemophilia Association of New Jersey  
 197 Route 18 South  
 Suite 206 North  
 East Brunswick, NJ 08816.

Phone: 732-249-6000  
 Fax: 732-249-7999  
 Editor: Genevieve Christo  
 E-mail: info@hanj.org  
 Website: www.hanj.org

We welcome all letters and submissions for consideration.

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The Hemophilia Association of New Jersey was founded in August 1971 by 10 concerned families, and offers assistance to persons with hemophilia and their families from our office located in East Brunswick, New Jersey.

Our mission is to improve the quality of life for persons with a bleeding disorder by providing and maintaining access to highly qualified medical providers and successfully proven medical regimens.

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**Social Worker Update  
 By Neidy Olarte, MSW  
 Social Service Coordinator**

With all the uncertainty that the COVID-19 has brought to everyone's lives, it is important to find ways to stay calm, safe and well mentally, physically and emotionally. While safely social distancing, you may have noticed an increase in virtual programs from virtual learning, entertainment as well as having the option to visit your doctor virtually. If you enjoy social activities, these may be some options for you to consider while trying to keep some balance in your life. HANJ is sending weekly updates on some of those virtual opportunities in order to stay connected during this time. If we do not have your email address and you would like more information on how to stay connected, please reach out to us at [info@hanj.org](mailto:info@hanj.org). You can also contact us via Facebook as well as log into our website at [www.hanj.org](http://www.hanj.org) to view updates and additional resources offered to our community. If you have any suggestions on what programs you would like to see or if you have any ideas on programs you would like to share, please reach out to us. We would love to hear from you.

**Are you currently covered?**

If you are experiencing any changes such as loss of employment and if you have lost your insurance benefits due to COVID-19, please know that we are here to assist. The Hemophilia Association of New Jersey continues to offer Insurance Assistance to individuals with a bleeding disorder that have lost their health insurance. To see if you qualify for assistance, please contact us at the office at (732) 249-6000 or email me directly at [nolarte@hanj.org](mailto:nolarte@hanj.org). Please know that it is crucial to contact HANJ as soon as you know your coverage has ended, or will be ending. There is a time frame to be able to obtain insurance and if you wait too long to contact us, it may be difficult to get you covered. If

**Insurance Grant Program  
 &  
 Scholarship Application  
 Deadline  
 has been  
 extended  
 to  
 May 31, 2020**

you have any insurance questions, please feel free to reach out.

**Program Extensions:**

We have extended a few deadlines for some of our programs. If you receive insurance assistance through our **Insurance Grant Program**, please note we have extended the **deadline from April 30, 2020 to May 31, 2020**. If you have any questions regarding your application, you can call the office or email me directly at [nolarte@hanj.org](mailto:nolarte@hanj.org). Our Scholarship Application deadline has also been extended. We have extended the **Scholarship Application deadline from April 30, 2020 to May 31, 2020**. If you are interested in applying for any of our scholarships, please visit our website at [www.hanj.org](http://www.hanj.org) to obtain a copy of the scholarship applications as well as to view our requirements. If you would like for us to send you a copy of our scholarship application or if you have any questions regarding the HANJ scholarships, you can contact us at the office or contact me directly at: [nolarte@hanj.org](mailto:nolarte@hanj.org). We also have a list of additional scholarship resources that you can obtain from our website.

I hope everyone is staying safe and practicing social distancing the best way they can. If you or a family member is essential personnel going to work, we thank you and greatly appreciate your service.

**Contact Neidy Olarte, MSW  
 Social Service Coordinator at:  
 Email—[nolarte@hanj.org](mailto:nolarte@hanj.org)  
 HANJ Office Phone (732) 249-6000**

## WHAT'S HAPPENING

### New Jersey Hemophilia Treatment Centers

#### Rutgers Robert Wood Johnson Medical School Hemophilia Treatment Center

##### **RUTGERS RWJ MEDICAL SCHOOL HEMOPHILIA TREATMENT CEN- TER DURING COVID19:**

The Rutgers RWJ Hemophilia Treatment Center (HTC) recognizes that the global health crisis we are facing today with COVID-19 is of particular concern for patients and their families who rely on clinical coordination of care, factor and home care nursing. We would like to assure you that the HTC remains operational and is able to provide care for our patients with bleeding disorders. In order to minimize risk to patients & staff and to abide by the state of New Jersey's stay at home mandate, clinic visits are currently being conducted via telemedicine. HTC nurses are available during regular clinic hours (8:30-4:30) to take calls as is the case during normal operations. Please do not hesitate to contact the clinic with any concerns or issues that you may have.

Contact can be made with the Rutgers HTC at the usual telephone numbers:  
For Nurses: 732-235-6542 or 732-235-6531  
For Social Worker: 732-235-6533

Additionally, the HTC is working with the specialty pharmacies to minimize disruption of home care services. Prescriptions are being dispensed at their usual quarterly schedule and as needed on demand. If you have a concern regarding your prescription, please contact the HTC as soon as possible.

##### **Programs & School Visits:**

Currently educational programs & school visits are postponed in order to comply with the COVID19 New Jersey stay at home mandate. School visits should resume in the fall. Please contact Lisa Cohen, MSW at [cohenlr@rwjms.rutgers.edu](mailto:cohenlr@rwjms.rutgers.edu) or by phone at 732-235-6533 if you anticipate a need for a school visit in the fall.



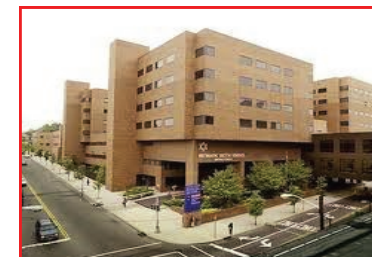
***We urge all of our patients to abide by the state of New Jersey's social distancing and stay at home mandates and the CDC guidelines in order to minimize the risk to themselves, their family members and the public. If these measures are not adhered to, the devastation of COVID19 will continue to grow.***

**Please  
Stay  
Home!**



**Rutgers RWJ Medical School  
Hemophilia Treatment Center  
125 Paterson Street, 5th Flr, Ste5200  
New Brunswick, NJ 08901  
For appointments:(732) 235-7226  
Nurse Direct Line for  
Medical Issues: (732) 235-6531  
Social Worker: Lisa Cohen, MSW,LSW  
(732) 235-6533  
[cohenlr@rwjms.rutgers.edu](mailto:cohenlr@rwjms.rutgers.edu)**

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



Happy Spring from the staff at the Comprehensive Hemophilia Treatment Center at Newark Beth Israel Medical Center and Children's Hospital of New Jersey! We are happy to share with you the latest news from our treatment center.

##### **NEWS:**

**Hemophilia Camp:** Camps have been canceled this year due to the COVID-19 outbreak. **If you have any questions, please contact our Social Worker, Erica.**

**Scholarships:** Scholarships are now available. Please be mindful of the deadlines to submit the applications and the eligibility criteria for each scholarship. Also, please remember to complete your FAFSA forms as early as possible to secure available funds. **If you have any questions about scholarships, internships, or coordinating your care away from home please contact our Social Worker, Erica.**

##### **ONGOING PROGRAMS:**

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

**Treatment Logs:** The HTC is aiming to get all patients (who treat their bleeding disorder with medication) to track their infusions and/or treatment in a treatment log. 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. ATHNadvoy is a web-based application that allows patients, or their caregivers, to record any and all treatment related to their bleeding disorder in a user friendly way directly

through their smart phone, tablet, laptop, or computer. When a user creates an account, they choose their treatment center; linking the patient and the HTC, and allowing the HTC to have access to view a patient's treatment log. **For more information, or to sign up, please contact our Social Worker, Erica.**

**School Visits:** As the school year continues, we know that you might need forms completed, letters for school, or school visits scheduled. School visits are a wonderful opportunity for our HTC to provide education and outreach to your child's school or daycare about hemophilia and other bleeding disorders. Whether the visit is with the staff at your child's school, the daycare staff, or even the child study team, a school visit opens the lines of communication between the child's school or daycare and the HTC. **If you are going to want a school visit scheduled for your child's school or daycare center, or need a letter for school or forms completed, please contact Erica, our Social Worker.** Erica 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

Programs as part of the Veteran's Health Care Act of 1992. Across the United States almost all of the HTC's participate in 340B Programs. Depending on their healthcare coverage, patients may have a variety of pharmacy options to choose from. Our HTC is contracted with three different home care companies; Accredo, BDRN, and Option Care Health/Bioscrip. Patients who are not currently using one of these three companies may voluntarily switch if their insurance company allows. Participation in the 340B Program is voluntary. **Please contact our Program Manager, Phyllis, for further information.**



**Comprehensive Evaluations:** It is really important to schedule and attend an annual comprehensive evaluation at the HTC. The annual evaluation is an essential component in the provision of an individual's comprehensive care. Members of the HTC treatment team will complete medical, musculoskeletal, psychosocial and laboratory evaluations to assess the patient's current health and to develop a treatment plan for the upcoming year. Education and referrals for medical and psychosocial services will also be provided as needed. At the time of an annual evaluation, patients will be asked to participate in the ATHN (American Thrombosis & Hemostasis Network) Data Set. This is a voluntary program conducted by HTC's with support from ATHN to improve the health of people with coagulation disorders. Patients will also be educated about any other available studies that they might be eligible to participate in. **Please note that any individual receiving medication through the HTC to treat their bleeding disorder must be seen by the HTC on an annual basis.**



**Travel Letters:**

Are you going to be travelling? Are you going to need a travel letter? If you answered yes to either of those questions, this information is for you. **Please remember to let the HTC staff know if you are going to need a travel letter at least two weeks prior to your scheduled trip** so you can rest assured that your letter is in your hand as you embark on your journey.

**Manufacturer Factor Programs:**

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

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

**Newark Beth Israel Medical Center and Children's Hospital of New Jersey Hemophilia Treatment Center  
201 Lyons Ave. (E2)  
Newark, NJ 07112  
Main Number: (973) 926-6511  
Social Worker:  
Erica Stuppler, LCSW  
(973) 926-4197  
Erica.Stuppler@RWJbh.org  
Fax: (973) 391-0048**



**COVID-19:**

We want you to know that although we are going through a very difficult time, we are here for you. Our main concern is everyone's safety but please do not hesitate to give us a call. We are still here servicing our community the best way that we can. Remember to stay safe. Do not go out unless it is extremely necessary. Call your doctors if any concerns or issues arise. **Remember Hand Washing is the most important measure at this time.**

**Here 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. Let's come together and help by staying home to protect our families and one another.**



**St. Michael's Medical Center**

**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.

**St. Michael's Medical Center Hemophilia Treatment Center  
111 Central Ave., Bldg. M2  
Newark, NJ 07102  
Patient's call: (973) 877-5340 or (973) 877-5341 or (973) 877-5342  
Social Worker: Joanne Rodriguez, CSW (973) 877-2967  
JRodriguez27@primehealthcare.com  
Fax (973) 877-5466**



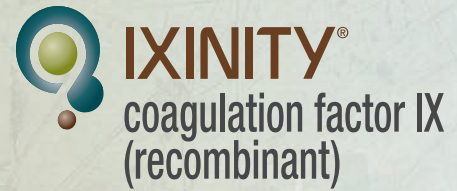
The Hemophilia Association of New Jersey provides MedicAlert Memberships and IDs for patients with hemophilia and vWD.

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.

# IMPORTANT ANNOUNCEMENT

For greater dosing flexibility...



NOW AVAILABLE IN A CONVENIENT  
**3000 IU SINGLE-USE VIAL**



# NOW THAT'S BIG ASSAY NEWS!

## MORE IX IN LESS TIME

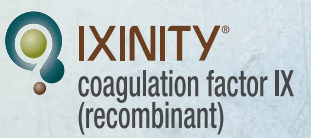
For patients requiring higher doses, the **NEW IXINITY 3000 IU assay** may help reduce reconstitution time.



Talk to your IXINITY rep or visit [IXINITY.com](http://IXINITY.com)



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

I sincerely hope this newsletter finds you and your family healthy and safe. Currently everything in our lives seems to be impacted by the COVID19 pandemic. We, in New Jersey, are of course in one of the most severely impacted areas. Hopefully by the time you read this there will be some good news.

While having a bleeding disorder by itself does not make us more susceptible to the virus, any additional medical condition caused by or made worse by a bleeding disorder does place us in a higher risk category. It is important to maintain our health and observe measures to lower the risk of becoming infected.

As from the beginning of the crisis the core preventative measures are:

- Maintain social distancing of six feet or greater and avoid crowded locations
- Wash your hands frequently for 20 seconds.
- Clean household surfaces frequently
- If you are sick stay home and isolate from family members

And as of 4/10 New Jersey residents are required to wear a face covering while in any store.

Distancing measures also relate to medical care visits. If you have a scheduled visit at your HTC or other physician office, it is recommended to contact them and see if the visit can be safely postponed or if telemedicine is an option. Bleeding disorder patients are being requested to not over order factor products but certainly to maintain an

## For information [www.covid19.nj.gov](http://www.covid19.nj.gov)

adequate supply of product at home.

The major product manufacturers have stated that they do not anticipate a disruption in the availability of supplies.

For those on plasma derived products or other human blood related therapies the regulatory agencies consider the blood supply to be safe. There has not been a detection of any Corona-type virus in the blood supply chain.

The knowledge regarding treatment and prevention of COVID 19 is developing rapidly. It is important to keep aware of the latest recommendations.

New Jersey regularly updates local and State information at:  
[www.covid19.nj.gov](http://www.covid19.nj.gov)

HFA (Hemophilia Federation of America) maintains information specific to the bleeding community at:  
[www.hemophiliafed.org](http://www.hemophiliafed.org)

NHF (National Hemophilia Foundation) is the leading/largest/only national non-profit organization dedicated to finding better treatments and cures for inheritable bleeding disorders and to preventing the complications of these disorders through education, advocacy, and research. Check their website at:  
[www.hemophilia.org](http://www.hemophilia.org)

Please take all necessary precautions for yourself and your family. Looking forward to seeing everyone at a HANJ event in the near future.

Jeff Lynch, MD  
HANJ Medical Advisor



## Hemophilia Association of New Jersey Mission Statement

**Our mission is to improve the quality of life for persons with bleeding disorders by providing and maintaining access to highly qualified medical providers and successfully proven medical regimens.**

## Coping With Hemophilia as a Family: Suggestions for Managing the Family Dynamic



For more information, visit  
[b2byourvoice.com](http://b2byourvoice.com) to download  
*Hemophilia B: A Family Perspective*.

This content is brought to you by Pfizer.

### Hemophilia Affects the Whole Family

Despite improvements in the medical management of bleeding disorders, raising a child living with hemophilia still affects the lives of everyone in the family. It's important to address the needs of caregivers and family members as well as acknowledge how a diagnosis of hemophilia alters family dynamics.<sup>1</sup>

Hemophilia is a complex disorder that requires treatment for a lifetime. If hemophilia is new to the family, feelings of uncertainty about coping with day-to-day management can occur. In particular, infusing factor may initially be upsetting to the child and stressful for the caregiver who is experiencing challenges with the process.<sup>1</sup>

"One thing we learned was that growing up is a learning process for all children, whether they have hemophilia or not."

— Jill L.

Mother of 2 sons with hemophilia B

### Discipline and Limits

It's important for parents and other caregivers to support one another in the daily care of the child, including talking about emotions and overcoming hemophilia-related challenges together.<sup>2</sup> Some of these challenges can include providing discipline and setting limits. Parents and caregivers are often advised to address these issues in the same way they would for children who are not diagnosed with a bleeding disorder.

**References:** 1. Beeton K, Neal D, Watson T, Lee CA. Parents of children with haemophilia—a transforming experience. *Haemophilia*. 2007;13(5):570-579. 2. Wiedebusch S, Pollmann H, Siegmund B, Muthny FA. Quality of life, psychosocial strains and coping in parents of children with haemophilia. *Haemophilia*. 2008;14(5):1014-1022. 3. National Hemophilia Foundation. Steps for Living website. Discipline. [www.stepsforliving.hemophilia.org/first-step/family-life/discipline](http://www.stepsforliving.hemophilia.org/first-step/family-life/discipline). Accessed July 12, 2019. 4. Rivard G-E, Blanchette V, Hilliard P, Mulder K, Zourikian N. Management of bleeds. In: *All About Hemophilia: A Guide for Families*. Montréal, Québec: Canadian Hemophilia Society; 2010: 4-1-4-32. 5. Cassis FRMY. *Psychosocial Care for People With Hemophilia*. Montréal, Québec: World Federation of Hemophilia; 2007.

### Some suggestions from the National Hemophilia Foundation that may help in caring for a child with hemophilia include<sup>3</sup>:

- Praise your child when he or she reports a bleed to a caregiver
- Reinforce that having a bleeding disorder that requires treatment is not a punishment
- Openly discuss the potential effects of behavior and activities
- Never punish your child for having a bleed

One major concern that parents or caregivers may face is knowing when a child is having a bleed. In some cases, bleeds can be tricky to identify, as a child may exhibit one or more of the following signs or symptoms of a muscle bleed<sup>4</sup>:

- Holding a part of the body in an awkward position or reluctance to use that part of the body
- Complaining of pain or a tingling sensation in the injured area
- The injured area feels warm, swollen, and/or firm to the touch

It's important to recognize that caring for a child with hemophilia may create changes to which the family must become accustomed. Lifestyle modifications are a part of living with hemophilia, and sometimes these changes extend to the entire family. However, these adjustments represent opportunities for positive change through learning and self-awareness.<sup>5</sup>



Patient Affairs Liaisons are Pfizer employees who are dedicated solely to providing support to the community. Your Pfizer Patient Affairs Liaison is available to help you access the support and information you need. To find your Patient Affairs Liaison, go to [hemophiliavillage.com/support/patient-affairs-liaison-finder](http://hemophiliavillage.com/support/patient-affairs-liaison-finder) or call Pfizer Hemophilia Connect at 1.844.989.HEMO (4366).



# What you need to know about coronavirus disease 2019 (COVID-19)

## What is coronavirus disease 2019 (COVID-19)?

Coronavirus disease 2019 (COVID-19) is a respiratory illness that can spread from person to person. The virus that causes COVID-19 is a novel coronavirus that was first identified during an investigation into an outbreak in Wuhan, China.

## Can people in the U.S. get COVID-19?

Yes. COVID-19 is spreading from person to person in parts of the United States. Risk of infection with COVID-19 is higher for people who are close contacts of someone known to have COVID-19, for example healthcare workers, or household members. Other people at higher risk for infection are those who live in or have recently been in an area with ongoing spread of COVID-19. Learn more about places with ongoing spread at <https://www.cdc.gov/coronavirus/2019-ncov/about/transmission.html#geographic>.

## Have there been cases of COVID-19 in the U.S.?

Yes. The first case of COVID-19 in the United States was reported on January 21, 2020. The current count of cases of COVID-19 in the United States is available on CDC's webpage at <https://www.cdc.gov/coronavirus/2019-ncov/cases-in-us.html>.

## How does COVID-19 spread?

The virus that causes COVID-19 probably emerged from an animal source, but is now spreading from person to person. The virus is thought to spread mainly between people who are in close contact with one another (within about 6 feet) through respiratory droplets produced when an infected person coughs or sneezes. It also may be possible that a person can get COVID-19 by touching a surface or object that has the virus on it and then touching their own mouth, nose, or possibly their eyes, but this is not thought to be the main way the virus spreads. Learn what is known about the spread of newly emerged coronaviruses at <https://www.cdc.gov/coronavirus/2019-ncov/about/transmission.html>.

## What are the symptoms of COVID-19?

Patients with COVID-19 have had mild to severe respiratory illness with symptoms of

- fever
- cough
- shortness of breath

## What are severe complications from this virus?

Some patients have pneumonia in both lungs, multi-organ failure and in some cases death.

## How can I help protect myself?

People can help protect themselves from respiratory illness with everyday preventive actions.

- Avoid close contact with people who are sick.
- Avoid touching your eyes, nose, and mouth with unwashed hands.
- Wash your hands often with soap and water for at least 20 seconds. Use an alcohol-based hand sanitizer that contains at least 60% alcohol if soap and water are not available.

## If you are sick, to keep from spreading respiratory illness to others, you should

- Stay home when you are sick.
- Cover your cough or sneeze with a tissue, then throw the tissue in the trash.
- Clean and disinfect frequently touched objects and surfaces.

## What should I do if I recently traveled from an area with ongoing spread of COVID-19?

If you have traveled from an affected area, there may be restrictions on your movements for up to 2 weeks. If you develop symptoms during that period (fever, cough, trouble breathing), seek medical advice. Call the office of your health care provider before you go, and tell them about your travel and your symptoms. They will give you instructions on how to get care without exposing other people to your illness. While sick, avoid contact with people, don't go out and delay any travel to reduce the possibility of spreading illness to others.

## Is there a vaccine?

There is currently no vaccine to protect against COVID-19. The best way to prevent infection is to take everyday preventive actions, like avoiding close contact with people who are sick and washing your hands often.

## Is there a treatment?

There is no specific antiviral treatment for COVID-19. People with COVID-19 can seek medical care to help relieve symptoms.



CS 314937-A 03/20/2020

[cdc.gov/COVID19](http://cdc.gov/COVID19)

# Lo que necesita saber sobre la enfermedad del coronavirus 2019 (COVID-19)

## ¿Qué es la enfermedad del coronavirus 2019 (COVID-19)?

La enfermedad del coronavirus 2019 (COVID-19) es una afección respiratoria que se puede propagar de persona a persona. El virus que causa el COVID-19 es un nuevo coronavirus que se identificó por primera vez durante la investigación de un brote en Wuhan, China.

## ¿Pueden las personas en los EE. UU. contraer el COVID-19?

Sí. El COVID-19 se está propagando de persona a persona en partes de los Estados Unidos. El riesgo de infección con COVID-19 es mayor en las personas que son contactos cercanos de alguien que se sepa que tiene el COVID-19, por ejemplo, trabajadores del sector de la salud o miembros del hogar. Otras personas con un riesgo mayor de infección son las que viven o han estado recientemente en un área con propagación en curso del COVID-19.

## ¿Ha habido casos de COVID-19 en los EE. UU.?

Sí. El primer caso de COVID-19 en los Estados Unidos se notificó el 21 de enero del 2020. La cantidad actual de casos de COVID-19 en los Estados Unidos está disponible en la página web de los CDC en <https://www.cdc.gov/coronavirus/2019-ncov/cases-in-us.html>.

## ¿Cómo se propaga el COVID-19?

Es probable que el virus que causa el COVID-19 haya surgido de una fuente animal, pero ahora se está propagando de persona a persona. Se cree que el virus se propaga principalmente entre las personas que están en contacto cercano unas con otras (dentro de 6 pies de distancia), a través de las gotitas respiratorias que se producen cuando una persona infectada tose o estornuda. También podría ser posible que una persona contraiga el COVID-19 al tocar una superficie u objeto que tenga el virus y luego se toque la boca, la nariz o posiblemente los ojos, aunque no se cree que esta sea la principal forma en que se propaga el virus. Infórmese sobre lo que se sabe acerca de la propagación de los coronavirus de reciente aparición en <https://www.cdc.gov/coronavirus/2019-ncov/about/transmission-sp.html>.

## ¿Cuáles son los síntomas del COVID-19?

Los pacientes con COVID-19 han tenido enfermedad respiratoria de leve a grave con los siguientes síntomas:

- fiebre
- tos
- dificultad para respirar

## ¿Cuáles son las complicaciones graves provocadas por este virus?

Algunos pacientes presentan neumonía en ambos pulmones, insuficiencia de múltiples órganos y algunos han muerto.

## ¿Qué puedo hacer para ayudar a protegerme?

Las personas se pueden proteger de las enfermedades respiratorias tomando medidas preventivas cotidianas.

- Evite el contacto cercano con personas enfermas.
- Evite tocarse los ojos, la nariz y la boca con las manos sin lavar.
- Lávese frecuentemente las manos con agua y jabón por al menos 20 segundos. Use un desinfectante de manos que contenga al menos un 60 % de alcohol si no hay agua y jabón disponibles.

## Si está enfermo, para prevenir la propagación de la enfermedad respiratoria a los demás, debería hacer lo siguiente:

- Quedarse en casa si está enfermo.
- Cubrirse la nariz y la boca con un pañuelo desechable al toser o estornudar y luego botarlo a la basura.
- Limpiar y desinfectar los objetos y las superficies que se tocan frecuentemente.

## ¿Qué debo hacer si he regresado recientemente de un viaje a un área con propagación en curso del COVID-19?

Si ha llegado de viaje proveniente de un área afectada, podrían indicarle que no salga de casa por hasta 2 semanas. Si presenta síntomas durante ese periodo (fiebre, tos, dificultad para respirar), consulte a un médico. Llame al consultorio de su proveedor de atención médica antes de ir y dígame sobre su viaje y sus síntomas. Ellos le darán instrucciones sobre cómo conseguir atención médica sin exponer a los demás a su enfermedad. Mientras esté enfermo, evite el contacto con otras personas, no salga y postergue cualquier viaje para reducir la posibilidad de propagar la enfermedad a los demás.

## ¿Hay alguna vacuna?

En la actualidad no existe una vacuna que proteja contra el COVID-19. La mejor manera de prevenir infecciones es tomar medidas preventivas cotidianas, como evitar el contacto cercano con personas enfermas y lavarse las manos con frecuencia.

## ¿Existe un tratamiento?

No hay un tratamiento antiviral específico para el COVID-19. Las personas con el COVID-19 pueden buscar atención médica para ayudar a aliviar los síntomas.

# Symptoms of Coronavirus (COVID-19)

## Your symptoms can include the following:

### Fever



### Cough



### Shortness of breath



If you have COVID-19, you may have mild (or no symptoms) to severe illness.

Symptoms can appear 2-14 days after you are exposed to the virus that causes COVID-19.

Seek medical attention immediately if you or someone you love has **emergency warning signs**, including:

- Trouble breathing
- Persistent pain or pressure in the chest
- New confusion or not able to be woken
- Bluish lips or face

This list is not all inclusive. Please consult your medical provider for any other symptoms that are severe or concerning.



[cdc.gov/COVID19-es](https://cdc.gov/COVID19-es)



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



# SÍNTOMAS DE LA ENFERMEDAD DEL CORONAVIRUS 2019

Los pacientes con COVID-19 han presentado enfermedad respiratoria de leve a grave.

Los síntomas\* pueden incluir

FIEBRE



TOS



\*Los síntomas pueden aparecer de 2 a 14 días después de la exposición.

DIFICULTAD PARA RESPIRAR



Consulte a un médico si presenta síntomas y ha estado en contacto cercano con una persona que se sepa que tiene el COVID-19, o si usted vive o ha estado recientemente en un área en la que haya propagación en curso del COVID-19.



[cdc.gov/COVID19-es](https://cdc.gov/COVID19-es)

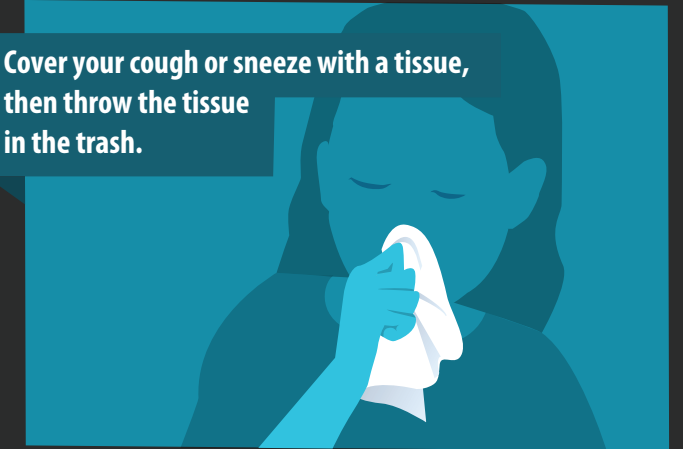
# Stop the Spread of Germs

Help prevent the spread of respiratory diseases like COVID-19.

Avoid close contact with people who are sick.



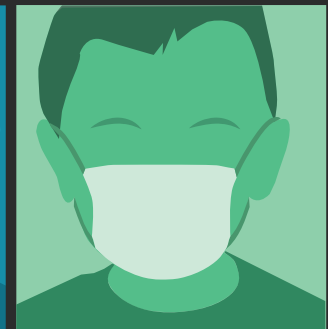
Cover your cough or sneeze with a tissue, then throw the tissue in the trash.



Avoid touching your eyes, nose, and mouth.



When in public, wear a cloth face covering over your nose and mouth.



Clean and disinfect frequently touched objects and surfaces.



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



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



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

# DETENGA LA PROPAGACIÓN DE LOS MICROBIOS

Ayude a prevenir la propagación de enfermedades respiratorias como el COVID-19

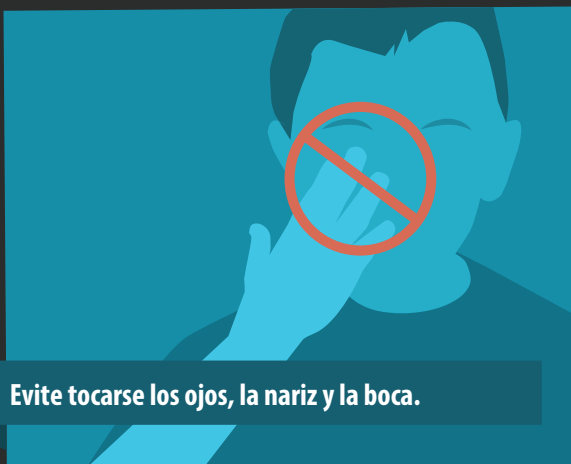
Evite el contacto cercano con las personas enfermas.



Cúbrase la nariz y la boca con un pañuelo desechable al toser o estornudar y luego bótelo a la basura.



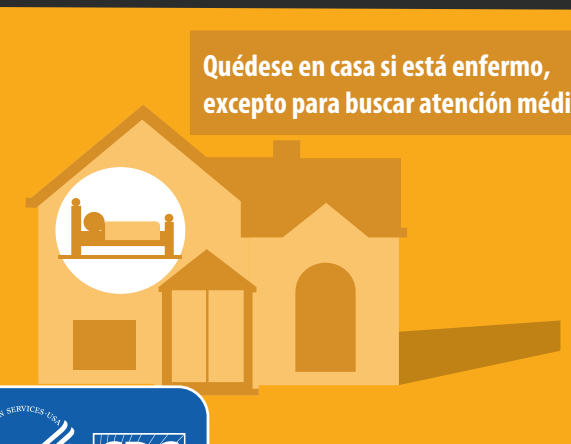
Evite tocarse los ojos, la nariz y la boca.



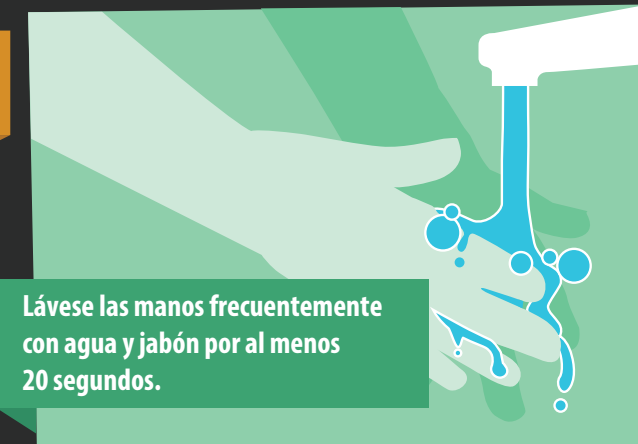
Limpie y desinfecte los objetos y las superficies que se tocan frecuentemente.



Quédese en casa si está enfermo, excepto para buscar atención médica.



Lávese las manos frecuentemente con agua y jabón por al menos 20 segundos.



[cdc.gov/COVID19-es](https://www.cdc.gov/COVID19-es)



314915-B

## LIFE HAPPENS

AND ADVATE WILL BE THERE WHEN IT DOES

ADVATE has over 15 years of treatment experience in the real world and provides clinically proven bleed protection\* for patients with hemophilia A.<sup>1</sup>

**ADVATE**  
[Antihemophilic Factor (Recombinant)]  
REAL LIFE. REAL BLEED PROTECTION.\*

AdvateRealLife.com

\*In clinical trials, ADVATE demonstrated the ability to help prevent bleeding episodes using a prophylaxis regimen. Not an actual patient.

### Prophylaxis with ADVATE prevented bleeds<sup>1</sup>

- ADVATE was proven in a pivotal clinical trial to prevent or reduce the number of bleeding episodes in children and adults when used regularly (prophylaxis)
- The efficacy of ADVATE was studied in a multicenter, open-label, prospective, randomized, 2-arm controlled trial of 53 previously treated patients with severe to moderately severe hemophilia A. Two different ADVATE prophylaxis regimens (standard, 20–40 IU/kg every 48 hours, or pharmacokinetic-driven, 20–80 IU/kg every 72 hours) were compared with on-demand treatment. Patients underwent 6 months of on-demand treatment before 12 months of prophylaxis
  - 98% reduction in median annualized bleeding rate (ABR) from 44 to 1 when 53 patients in the clinical study switched from on-demand to prophylaxis
  - 0 bleeds in 42% (22/53) of patients during 1 year on prophylaxis

### ADVATE Important Information

#### What is ADVATE?

- ADVATE is a medicine used to replace clotting factor (factor VIII or antihemophilic factor) that is missing in people with hemophilia A (also called “classic” hemophilia).
- ADVATE is used to prevent and control bleeding in adults and children (0-16 years) with hemophilia A. Your healthcare provider (HCP) may give you ADVATE when you have surgery.
- ADVATE can reduce the number of bleeding episodes in adults and children (0-16 years) when used regularly (prophylaxis).

ADVATE is not used to treat von Willebrand disease.

#### DETAILED IMPORTANT RISK INFORMATION

##### Who should not use ADVATE?

Do not use ADVATE if you:

- Are allergic to mice or hamsters.
- Are allergic to any ingredients in ADVATE.

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

##### What should I tell my HCP before using ADVATE?

Tell your HCP if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Are breastfeeding. It is not known if ADVATE passes into your milk and if it can harm your baby.

Reference: 1. ADVATE Prescribing Information.

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#### What should I tell my HCP before using ADVATE? (continued)

- Are or become pregnant. It is not known if ADVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADVATE may not work for you).

#### What important information do I need to know about ADVATE?

- You can have an allergic reaction to ADVATE. Call your HCP right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.
- Do not attempt to infuse yourself with ADVATE unless you have been taught by your HCP or hemophilia center.

#### What else should I know about ADVATE and Hemophilia A?

- Your body may form inhibitors to factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop ADVATE from working properly. Talk with your HCP to make sure you are carefully monitored with blood tests for the development of inhibitors to factor VIII.

#### What are possible side effects of ADVATE?

- Side effects that have been reported with ADVATE include: cough, headache, joint swelling/aching, sore throat, fever, itching, unusual taste, dizziness, hematoma, abdominal pain, hot flashes, swelling of legs, diarrhea, chills, runny nose/congestion, nausea/vomiting, sweating, and rash. Tell your HCP about any side effects that bother you or do not go away or if your bleeding does not stop after taking ADVATE.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit [www.fda.gov/medwatch](https://www.fda.gov/medwatch), or call 1-800-FDA-1088.

Please see Important Facts about ADVATE on the following page and discuss with your HCP.

For Full Prescribing Information, visit [www.ADVATE.com](https://www.ADVATE.com).





## [Antihemophilic Factor (Recombinant)]

### Important facts about

#### ADVATE [Antihemophilic Factor (Recombinant)]

This leaflet summarizes important information about ADVATE. Please read it carefully before using this medicine. This information does not take the place of talking with your healthcare provider, and it does not include all of the important information about ADVATE. If you have any questions after reading this, ask your healthcare provider.

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

Do not attempt to do an infusion to yourself unless you have been taught how by your healthcare provider or hemophilia center.

You must carefully follow your healthcare provider's instructions regarding the dose and schedule for infusing ADVATE so that your treatment will work best for you.

#### What is ADVATE?

ADVATE is a medicine used to replace clotting factor (factor VIII or antihemophilic factor) that is missing in people with hemophilia A (also called "classic" hemophilia). The product does not contain plasma or albumin. Hemophilia A is an inherited bleeding disorder that prevents blood from clotting normally.

ADVATE is used to prevent and control bleeding in adults and children (0-16 years) with hemophilia A.

Your healthcare provider may give you ADVATE when you have surgery. ADVATE can reduce the number of bleeding episodes in adults and children (0-16 years) when used regularly (prophylaxis).

ADVATE is not used to treat von Willebrand disease.

#### Who should not use ADVATE?

You should not use ADVATE if you:

- Are allergic to mice or hamsters.
- Are allergic to any ingredients in ADVATE.

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

#### How should I use ADVATE?

ADVATE is given directly into the bloodstream.

You may infuse ADVATE at a hemophilia treatment center, at your healthcare provider's office or in your home. You should be trained on how to do infusions by your healthcare provider or hemophilia treatment center. Many people with hemophilia A learn to infuse their ADVATE by themselves or with the help of a family member.

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

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

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

#### What should I tell my healthcare provider before I use ADVATE?

You should tell your healthcare provider if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Are breastfeeding. It is not known if ADVATE passes into your milk and if it can harm your baby.
- Are pregnant or planning to become pregnant. It is not known if ADVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADVATE may not work for you).

#### What are the possible side effects of ADVATE?

You can have an allergic reaction to ADVATE.

Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.

Side effects that have been reported with ADVATE include:

cough	headache	joint swelling/aching
sore throat	fever	itching
unusual taste	dizziness	hematoma
abdominal pain	hot flashes	swelling of legs
diarrhea	chills	runny nose/congestion
nausea/vomiting	sweating	rash

Tell your healthcare provider about any side effects that bother you or do not go away

These are not all the possible side effects with ADVATE. You can ask your healthcare provider for information that is written for healthcare professionals.

#### What else should I know about ADVATE and Hemophilia A?

Your body may form inhibitors to factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop ADVATE from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to factor VIII.

Medicines are sometimes prescribed for purposes other than those listed here. Do not use ADVATE for a condition for which it is not prescribed. Do not share ADVATE with other people, even if they have the same symptoms that you have.

**The risk information provided here is not comprehensive. To learn more, talk with your health care provider or pharmacist about ADVATE. The FDA-approved product labeling can be found at [www.ADVATE.com](http://www.ADVATE.com) or 1-877-825-3327.**

**You are encouraged to report negative side effects of prescription drugs to the FDA. Visit [www.fda.gov/medwatch](http://www.fda.gov/medwatch), or call 1-800-FDA-1088.**

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Issued: 12/2018

S47030

## Pharmaceutical Resources for Bleeding Disorders Free Factor & Co-Pay/Deductible Assistance

Manufacturer	Program Name & Contact Information	Details
<b>Aptevo Therapeutics</b>	IXINITY Savings Program  <a href="http://ixinity.com/save-on-IXINITY">http://ixinity.com/save-on-IXINITY</a>  1 (855) 494-6489	<ul style="list-style-type: none"> <li>• Must have valid prescription for IXINITY</li> <li>• Must have commercial insurance</li> <li>• No monthly limits unless limit total is reached.</li> <li>• No income requirements</li> <li>• Co-pay program can be used retroactively for up to 12 months</li> <li>• Limit Total \$12,000</li> </ul> <p><b>Free Trial</b>—Starter Kit— Your IXperience; on the go, no matter where your next adventure takes you. With your FREE trial of IXINITY, you'll receive 1 month of free treatment up to 20,000 IU.</p> <p>After that, if you're covered by commercial insurance, you may continue to pay nothing out-of-pocket for IXINITY regardless of income.</p> <p>Download and complete the IXINITY FREE Trial Form and bring to your doctor to get started. Questions? Connect with a Hemophilia Territory Manager.</p> <p>This program helps deliver treatment to those in need, even if they don't have insurance. If you are uninsured or experience a lapse in coverage, this program may cover you. Learn more about the IXINITY Patient Assistance Program. Call your IXperience Concierge at 1-855-IXINITY (1-855-494-6489).</p>
<b>Bayer</b>	<a href="http://www.jivi.us.com">www.jivi.us.com</a> <a href="http://www.kogenatefs.com">www.kogenatefs.com</a> <a href="http://www.kovaltry-us.com">www.kovaltry-us.com</a>  1 (800) 288-8374	<p><b><u>IXINITY Patient Assistance Programs:</u></b></p> <ul style="list-style-type: none"> <li>• <b>\$0 Product Co-pay Program:</b> You may receive up to \$12,000 in assistance per year, regardless of income.</li> <li>• <b>Lab Monitoring Co-pay Program for Jivi antihemophilic factor (recombinant), PEGylated-aucl:</b> You may be able to receive up to \$250 per year to apply towards out-of-pocket costs for laboratory monitoring of Jivi</li> <li>• <b>Free Trial Program:</b> Enroll today for up to 6 free doses of Jivi, Kovaltry, or Kogenate FS</li> <li>• <b>Loyalty Program:</b> 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.</li> <li>• <b>Live Helpline Support:</b> Consult with an expert in insurance. Multiple languages, including Spanish, are available.</li> </ul>

Manufacturer	Program Name & Contact Information	Details
<b>CSL Behring</b>	<p>www.cslbehringassurance.com</p> <p>www.cslbehring.com/patients/support/support-and-assistance</p>	<ul style="list-style-type: none"> <li>• <u>CSL Behring Assurance Program</u>: Contact a <i>CSL Behring Assurance Program</i> Care Coordinator at 1 (866) 415-2164</li> <li>• <u>CSL Behring Patient Care Coordination Center</u>: 1 (844)727-2752</li> <li>• <u>My Source CSL Support Line</u> — 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           <ul style="list-style-type: none"> <li>* <a href="http://www.idelvion.com">www.idelvion.com</a>: My Access Co-pay Support Program: 30-day free trial and, if eligible, co-pay support up to \$12,000.</li> <li>* <a href="http://www.afstyla.com">www.afstyla.com</a>: My Access Co-pay Support Program: All insured patients are eligible for 30-day free trial and co-pay support up to \$12,000.</li> </ul> </li> </ul>
<b>Genentech</b>	<p>1 (866) 422-2377</p> <p><a href="http://www.genentech-access.com/hemlibra">www.genentech-access.com/hemlibra</a>: Information related to HEMLIBRA Access and patients inquiring about HEMLIBRA 1 (877) 436-3683</p> <p>www.HEMLIBRA.COM</p>	<ul style="list-style-type: none"> <li>• <b>The Hemlibra Co-pay Program</b> helps people with commercial health insurance. This might be a plan you get through your employer or one you purchased through a Health Insurance Marketplace like HealthCare.gov. To qualify, you must also meet other criteria.</li> <li>• <b>Independent Co-pay Assistance Foundations:</b> If you need help with the co-pay for your Genentech medicine, HEMLIBRA Access Solutions can refer you to an independent co-pay assistance foundation. Independent co-pay assistance foundations help patients with public or commercial health insurance. Call HEMLIBRA Access Solutions at (877) 233-3981 for a referral.</li> <li>• <b>Genentech Patient Foundation</b> gives free Genentech medicine to people who don't have insurance coverage or who have financial concerns. Visit <a href="https://hemlibra.com/patient/patient-resources/financial-support.html">https://hemlibra.com/patient/patient-resources/financial-support.html</a> for more information.</li> </ul>
<b>Grifols</b>	<p><b>FACTORS FOR HEALTH</b></p> <p>1 (844) MY-FACTOR (693-2286)</p> <p>www.grifolspatientcare.com</p>	<ul style="list-style-type: none"> <li>• The <u>\$0 Copay Program</u>, wherein eligible patients or caregivers may pay as little as \$0 for prescriptions.</li> <li>• The <u>Free Trial Program</u> for eligible patients who are new to treatments from Grifols.</li> <li>• <u>Benefits investigation and support</u> services to help you coordinate with your insurer.</li> <li>• The <u>Patient Assistance Program (PAP)</u> for patients with no coverage or lapsed coverage.</li> <li>• <u>Care Coordination</u> to help you access and stay on treatment.</li> </ul>
<b>Kedrion</b>	<p>1 (855) 353-7466</p> <p>www.koate-dvi.com</p>	<p><u>Kedrion Connect</u>: Created to help provide eligible KOATE® [Anti-hemophilic Factor (Human)] patients with financial support. There are two programs under Kedrion Connect to assist eligible patients:</p> <ul style="list-style-type: none"> <li>• <u>Co-pay Assistance</u> – Helps eligible patients with their co-pay costs. The Co-pay card covers up to \$16,000 per calendar year.</li> <li>• <u>Insurance Premium Support Program</u> – Helps with private insurance premiums and assistance for those who qualify.</li> </ul>

Manufacturer	Program Name & Contact Information	Details
<b>Novo Nordisk</b>	<p>www.MyNovoSecure.com</p> <p>Novo Nordisk NovoSecure Hotline 1 (844) NOVOSSEC Or 1 (844) 668-6732</p> <p>www.novonordisk-us.com</p> <p><a href="https://www.novoeight.com">https://www.novoeight.com</a> <a href="https://www.novosevenrt.com">https://www.novosevenrt.com</a> <a href="https://www.rebinyn.com">https://www.rebinyn.com</a> <a href="https://www.tretten.com">https://www.tretten.com</a></p>	<p><u>Novo Nordisk Co-pay Assistance Program</u> – Save up to \$12,000 annually on co-pay, deductible, and coinsurance costs, regardless of income.</p> <p><u>Product Assistance Program</u> – <a href="http://www.mynovosecure.com/support/continue_your_treatment.html">http://www.mynovosecure.com/support/continue_your_treatment.html</a></p> <p><u>Product Assistance Program (PAP)/Trial Program</u> – Download the application at <a href="http://www.mynovosecure.com/support.continue_your_treatment.html">www.mynovosecure.com/support.continue_your_treatment.html</a></p>
<b>Octapharma</b>	<p>www.wilateusa.com</p>	<ul style="list-style-type: none"> <li>• <b>Bridge Program</b> – Free trial program for Wilate (5,000 units/30 day supply). Application form at: <a href="http://www.wilateusa.com/images/PDF_Files/wilateBridgeProgramEnrollmentForm_102512.pdf">http://www.wilateusa.com/images/PDF_Files/wilateBridgeProgramEnrollmentForm_102512.pdf</a></li> <li>• <b>NUWIQ® Co-Pay Assistance Program</b> Offers eligible patients a savings up to \$12,000 per year on the out-of-pocket costs associated with treatment <a href="http://www.nuwiquisa.com/factor-viii-patient-assistance-program/">http://www.nuwiquisa.com/factor-viii-patient-assistance-program/</a></li> <li>• <b>NUWIQ® Free Trial Program</b> Eligible patients can receive treatment with NUWIQ at no cost. (Not to exceed 6 doses, or approximately 20,000 IUs) <a href="http://www.nuwiquisa.com/factor-8-free-trial/#Free-Trial-Program">http://www.nuwiquisa.com/factor-8-free-trial/#Free-Trial-Program</a></li> <li>• Find us online at: <a href="http://www.NUWIQUUSA.com">www.NUWIQUUSA.com</a></li> <li>• <b>Octapharma Reimbursement Hotline</b> <a href="mailto:usreimbursement@octapharma.com">usreimbursement@octapharma.com</a> Tel: (800) 554-4440 Fax: (800) 554-6744</li> <li>• <u>Wilate Co-Pay Assistance Program</u> -- 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) 554-4440.</li> </ul>
<b>Pfizer</b>	<p>www.hemophiliavillage.com</p>	<ul style="list-style-type: none"> <li>• <u>Trial Prescription Program for Eligible Patients</u>- 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 <a href="http://www.HemophiliaVillage.com">www.HemophiliaVillage.com</a></li> <li>• <u>Pfizer Factor Savings Card</u> – Up to \$12,000 annual support for co-pay, deductible and coinsurance costs. If you have questions, please call 888-240-9040 or send questions to Pfizer Factor Savings Program, 2250 Perimeter Park Drive, Suite 300, Morrisville, NC 27560, or visit <a href="http://www.HemophiliaVillage.com">www.HemophiliaVillage.com</a></li> <li>• <u>Pfizer RxPathways</u> – A comprehensive assistance program that provides eligible patients (insured, uninsured, and underinsured) with a range of support services (<a href="https://pparx.org">https://pparx.org</a>). Call Pfizer Hemophilia Connect at 1-866-706-2400 for more information or visit website <a href="http://www.PfizerRxPathways.com">www.PfizerRxPathways.com</a></li> </ul>

Manufacturer	Program Name & Contact Information	Details
Pfizer continued ...		<ul style="list-style-type: none"> <li>• <a href="#">Reimbursement Support Services for Eligible Patients</a> – Benefit Verifications, Prior Authorization Assistance and Appeals Assistance. Call Pfizer Hemophilia Connect at 1-844-989-HEMO (4366) for more information.</li> <li>• If you're having trouble finding the Pfizer program that's right for you, call 1-844-989-PATH (7284) and speak with a Medicine Access Counselor who can work with you to map out your path to prescription assistance.</li> </ul>
Sanofi Genzyme (formerly Bioverativ)	<p>Learn about all the resources, support and financial assistance options available to you at the links below. Eligible patients need to be a resident of the United States, you do not have to be a citizen of the United States to receive assistance.</p> <p><a href="https://www.eloctate.com/resources/financial-assistance.aspx">https://www.eloctate.com/resources/financial-assistance.aspx</a> or call: (855) 693-5628 (Hem A)</p> <p><a href="https://www.alprolix.com/resources/financial-assistance.aspx">https://www.alprolix.com/resources/financial-assistance.aspx</a> or call: (855) 692-5776 (Hem B)</p> <p><b>Email:</b> MyEloctateCoordinator@sanofi.com <b>or</b> MyAlprolixCoordinator@sanofi.com</p>	<p>Eloctate and Alprolix both offer the following assistance programs:</p> <ul style="list-style-type: none"> <li>• <a href="#">Free Trial Plus Program</a> –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.</li> <li>• <a href="#">Factor Access Program</a> – Helps patients with factor access even if your insurance coverage is interrupted.</li> <li>• <a href="#">Co-Pay Assistance Program</a> – Provides up to \$12,000 co-pay/co-insurance assistance for eligible patients who use Eloctate or Alprolix. No income requirements!</li> </ul>
Takeda(formerly Shire)	<p><a href="https://www.hematologysupport.com/copay-assistance/">https://www.hematologysupport.com/copay-assistance/</a> (888) 229-8379</p> <p><a href="http://www.hematologysupportpro.com">www.hematologysupportpro.com</a> (855) 229-8379 Fax: (866) 467-7740</p>	<p><b>Patient Support &amp; Affordability Resources</b></p> <ul style="list-style-type: none"> <li>• Co-Pay Assistance</li> <li>• Insurance, Education &amp; Resources</li> </ul> <p><b>Hematology Support Center: One stop resource for Hematology resources (Medical Professionals):</b></p> <ul style="list-style-type: none"> <li>• <a href="#">Assistance Programs</a> - Available to eligible patients who have a US mailing address with no insurance or a gap in coverage (eligibility and application requirements) No longer require documentation of US citizenship.</li> <li>• <a href="#">Freedom of Choice</a> – Eligible patients can receive free sample dose of eligible Takeda's hemophilia products along with educational resources.</li> <li>• <a href="#">Co-Pay Assistance Program</a> –Non-Financial Needs Based Program (Commercial insurance only)</li> <li>• Reimbursement Resources</li> </ul>

Non-Pharmaceutical Assistance Programs		
Organization	Contact Information	Details
<b>The Colburn-Keenan Foundation, Inc.</b> PO Box 811 Enfield, CT 06083 Email: admin@colkeen.org	www.colkeen.org  Toll free Phone: (800) 966-2431  Fax: (888) 345-0259	Provides financial assistance programs to individuals and families living with chronic conditions, with priority placed on those living with bleeding disorders.
<b>HFA Helping Hands</b> Hemophilia Federation of America (HFA) 999 N. Capitol Street NE, Suite 201 Washington, DC 20002 Email: info@hemophiliafed.org	www.hemophiliafed.org/ programs/helping-hands  Phone: (202) 675-6984 Toll Free: (800) 230-9797 Fax: (202) 675-6983  <a href="http://www.hemophiliafed.org/our-role-and-programs/assisting-and-advocating/financial-assistance/helping-hands-emergency-assistance/">http://www.hemophiliafed.org/our-role-and-programs/assisting-and-advocating/financial-assistance/helping-hands-emergency-assistance/</a>	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 <u>diagnosed bleeding disorders</u> . Each year, Helping Hands aids hundreds of families with emergency/urgent funding to assist in crisis situations such as housing, transportation, and utility bills. Helping Hands cannot cover any medical expenses including medical bills, dental bills, insurance premiums, co-payments, deductibles, medications, factor, etc. Please visit <a href="#">HFA's Navigating Patient Assistance Programs</a>
<b>Hope for Hemophilia</b> PO Box 77728 Baton Rouge, LA 70879	(888) 529-8023  Fax (888) 835-1449  info@hopeforhemophilia.com www.hopeforhemophilia.org	Patient Resource Program and Direct Financial Assistance Program.
<b>Patient Services Inc.</b> P.O. Box 5930 Midlothian, VA 23112 Email: uneedpsi@uneedpsi.org	www.patientservicesinc.org  1-(800) 366-7741 Fax 1-(804) 744-9388	PSI helps chronically ill patients. <ul style="list-style-type: none"> <li>• <b>Premium Assistance, Copayment Assistance, Infusion and Nursing Services &amp; Travel Assistance:</b> Call 1 (800) 366-7741 for further information.</li> <li>• <b>PSI.-A.C.C.E.S.S. Legal Hotline (PSI – Patient Services, Inc.)</b> Supports patients with Social Security Disability and Supplemental Security Income benefits via legal counseling. Call 1 (877) 851-9065 www.patientservicesinc.org</li> </ul>

**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

Organization	Contact Information	Details
<b>211 United Way</b> United Way Worldwide 701 N. Fairfax Street Alexandria, VA 22314	(703) 836-7112  Dial 211  www.unitedway.org www.211.org http://www.211.org	Provides free and confidential information and referrals to local services including housing, food, employment, healthcare, counseling, and more. Check the website of call your local United Way.  Links to additional resources in your local area for specific needs.
<b>The Assistance Fund</b>	1 (855) 845-3663 https://tafcares.org	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.
<b>Needy Meds</b> NeedyMeds, Inc. PO Box 219 Gloucester, MA 01931 info@needymeds.org	Helpline: 1(800) 503-6897 www.needymeds.org	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.
<b>Patient Access Network Foundation (PAN)</b> P.O. Box 30500 Bethesda, MD 20824  Email: info@panfoundation.org	www.panfoundation.org  1 (866) 316-7263 Fax 1 (866) 316-7261	<b>Assistance Programs:</b> Offers nearly 70 disease-specific assistance programs to help patients pay for their out-of-pocket costs, such as deductibles, co-pays and coinsurance, travel expenses and health insurance premiums. Contact PAN by phone or email for more information.
<b>Patient Advocate Foundation (PAF)</b> PAF 421 Butler Farm Road Hampton, VA 23666	1 (800) 532-5274 www.patientadvocate.org	Provides case management and assistance in accessing health insurance. Co-pay assistance programs are available.
<b>RxAssist</b>  <b>info@rxassist.org</b>	www.rxassist.org/contact	Can help you learn about ways to use pharmaceutical company programs and other resources to help reduce your medication costs.
<b>RxHope</b>	https://www.rxhope.com/about.aspx	A web-based information resource to help low-income US residents access patient assistance programs.
<b>RxOutreach</b>	1(888) 796-1234 www.rxoutreach.org	A fully licensed non-profit mail order pharmacy that offers a patient assistance program that provides discounts on prescription drugs.
<b>United Healthcare Children's Foundation</b> UnitedHealthcare Children's Foundation MN017-W400 PO Box 41 Minneapolis, MN 55440-0041 email: customerservice@uhccf.org (mailto:customerservcie@uhccf.org)	1-855-698-4223 www.uhccf.org	Provides medical grants to help children gain access to health-related services not covered, or not fully covered, by a commercial health insurance plan. <i>You do not need to have United Healthcare to be eligible.</i>

## Federal/State Resources

Organization	Contact Information	Details
<b>AIDSinfo</b> – A Service of the US Dept. of Health and Human Services  Email: ContactUs@aidsinfo.nih.gov	(800) 448-0440 toll free www.aidsinfo.nih.gov	Offering information on HIV/AIDS treatment, prevention and research.
<b>CDC – Centers for Disease Control and Prevention</b>	(800) 232-4636 toll free www.cdc.gov	24/7: Saving Lives, Protecting People-A current list of hemophilia Treatment centers can be found on this website.
<b>Get Covered NJ</b>	https://nj.gov/governor/getcoverednj/faqs/	Information on ways to get health insurance as well as help with health coverage enrollment.
<b>Healthcare</b>	(800) 318-2596 www.healthcare.gov	Information for people who need health insurance and want to apply for or enroll in the Marketplace.
<b>HFA – Hemophilia Federation of America</b>  email: info@hemophiliafed.org	(800) 230-9797 www.hemophiliafed.org	A national nonprofit organization that assists and advocates for the bleeding disorders community.
<b>Medicare</b>	(800) 633-4227 www.medicare.gov	Information for people with Medicare, Medicare open enrollment, and benefits
<b>NHF – National Hemophilia Foundation</b>	(212) 328-3700 www.hemophilia.org	Dedicated to finding better treatments and cures for inheritable bleeding disorders and to preventing the complications of these disorders through education, advocacy and research.
<b>New Jersey Family Care</b>	(800) 701-0710 www.njfamilycare.org	New Jersey's publicly funded health insurance program - includes CHIP, Medicaid and Medicaid expansion populations.
<b>New Jersey State Website</b>	www.nj.gov	NJ state website where you can find resources offered in the state of NJ.
<b>State Health Insurance Assistance Program (SHIP)</b>	(800) 792-8820 https://www.state.nj.us/humanservices/doas/services/ship/	Provides free help to New Jersey Medicare beneficiaries who have problems with, or questions about their health insurance.
<b>WFH – World Federation of Hemophilia</b>  email: wfh@wfh.org	(514) 875-7944 www.wfh.org	Providing global leadership to improve and sustain care for people with inherited bleeding disorders.



## Explore HEAD-TO-HEAD Pharmacokinetic (PK) Study Data

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

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

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

**Jivi**  
antihemophilic factor  
(recombinant) PEGylated-aui1  
LET'S GO

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## Hemophilia Association of New Jersey Upcoming 2020 Events

*Due to the current Coronavirus Pandemic, HANJ has rescheduled many events to keep our Community safe. Please make note of the new dates below.*

### Hemophilia Association of New Jersey Annual Meeting

Thursday, October 8th, 2020

### 41st Dennis Keelty Memorial Golf Classic

Monday, October 19th, 2020

### Testimonial Dinner—Man of the Year: Kevin Cummings

President of Investors Bank

Friday, October 30th, 2020

### Hemophilia Awareness 5K Run/Walk

Heavenly Farms

East Brunswick, NJ

Sunday, November 8th, 2020

### 2021

### Summer Camp Wellness Gathering

Sunday, June 13th, 2021

### Educational Programs

All Educational Programs are being presented virtually for now. Please check the website for upcoming programs.



**Straight from the Kitchen of Our HANJ  
Program Assistant  
Cindy Hansen  
(while she works from home during the Pandemic)  
Tomato Ditalini Soup**

**Ingredients**

1 cup diced onions  
1/2 cup diced celery  
2 tsp. minced fresh garlic  
2 Tbsp. extra-virgin olive oil  
2 cans diced tomatoes in juice (14.5 oz. each)  
4 cups vegetable broth  
1/2 cup dry ditalini pasta  
Salt and fresh ground pepper to taste (or you can use red pepper flakes in place of fresh ground pepper— if you like a little heat)  
Chopped fresh parsley  
Grated Parmesan cheese



**Directions**

- 1.) Sauté onions, celery, and garlic in oil in a large saucepan or Dutch oven over medium heat, 4 to 5 minutes.
- 2.) Add tomatoes, broth, and pasta; bring to a boil. Cook soup until pasta is al dente, 10 minutes. Season soup with salt and pepper (or red pepper flakes). Garnish servings of soup with parsley and Parmesan cheese.

**Absolutely, delicious!**

**MARK  
YOUR CALENDAR**

**NEW DATE:**

**MONDAY, OCTOBER 19, 2020**

**PLAINFIELD C.C.**

**DENNIS KEELTY**

**41<sup>st</sup> MEMORIAL GOLF CLASSIC**

**TO BENEFIT**

**HEMOPHILIA ASSOCIATION**

**OF NEW JERSEY**



**WASHINGTON DAYS**

**By: Porus Pavri**

This year was my third year participating in NHF's (National Hemophilia Foundation) Washington Days. For those of you who don't know, Washington Days is a three day event. People from all around the country arrive in Washington on a Wednesday in March. There is a dinner and briefing that evening. On Thursday morning, participants sit down for breakfast with other members from their state, followed by another briefing. After eating, each group leaves for their legislative appointments at Capitol Hill. Finally, on Friday, everyone is dismissed after a wrap up breakfast session. Around 500 to 600 people attend Washington Days. It comprises of people with bleeding disorders, their spouses, parents, grandparents, children, friends and of course chapter leaders.

The first year I went was in 2017. This was a new experience for our family. We didn't know what to do and what to expect. It was pretty simple though. We were following the lead of advocacy captains and experienced participants from our state. We mostly listened in that year. When asked, my parents spoke about our struggles and experiences dealing with a bleeding disorder. I remember that year, while we were waiting for the rest of the New Jersey group to join us for our next appointment, we found ourselves waiting outside of Speaker Nancy Pelosi's office. Her staff was so good. They saw my discomfort and my Red Tie and offered me a seat in their office. Shortly after, one of the staff members took us into Speaker Pelosi's office and allowed my sister and me to sit in her chair and hold the gavel. That meant a lot to us. That gavel was mostly important because it was the gavel of



the first woman speaker and it was the gavel that was used to pass the Affordable Care Act (ACA) also called Obama Care. That was the highlight of my visit to Washington that year.

Success of the visit in 2017 motivated us to register for the event again in 2018. Except this time we were more prepared. We had posters made with pictures of my swollen knee (which is my target joint) and elbows, of me taking physical therapy, of me and my family raising awareness and funds through the walks, etc. We feel those pictures helped us narrate our story a lot better. Legislative aides were interested to hear our story and most of them genuinely cared and wanted to help us. This year we were fighting to keep the ACA alive. If ACA was repealed, benefits like pre-existing disorders, life time caps, and children staying on their parent's insurance till the age of 26 would have all gone. We also advocated for Medicare expansion, Appropriations Bill, and HTC participation in 340B programs. In 2018, we were lucky to meet New Jersey Senator Cory Booker, Fifth District (which is my district) Representative Josh Gottheimer and Eleventh District Representative Rodney Frelinghuysen.







2019 was a gap year and we were back in 2020. Yes, that was the last event we went to before the whole COVID-19 virus situation started. By now we were a pro at this!! This year we advocated for the SNF Bill. We wanted Medicare to include Skilled Nursing Facilities for people living with a bleeding disorder. This was especially important to our adult population. Although we didn't get to meet any Senators or Representatives, we were a great group and had a fun day. This year was special because the Executive Director of HANJ, Ms. Stephanie Lapidow was in our group. She strongly advocated for our community while giving each of us an opportunity to tell our story. We had a grandmother in our group, parents with a teen child, parents of a young child, and an adult living with a bleeding disorder, so we had hemophilia stories to share from multiple perspectives. It was interesting to learn about the advancements in care for

people with bleeding disorders from back in those days till now. I wish to continue going to Washington to advocate for our wonderful community and I encourage anyone that is interested to go and participate at least once. Trust me, you won't regret it.

*A little info about Porus: Porus has not only dealt with hemophilia but has dealt with the worse nightmare of someone with a bleeding disorder after getting inhibitors. While majority of the children his age were dealing with common cold, and scabs from falling off a bike, Porus was dealing with needles, ports, limited extensions of his limbs, and worst of all pain. Playing sports was a dream for this boy, but forget about contact sports, riding a bike was difficult as his knee wouldn't allow his leg to make that full rotation. Porus is currently a freshman at Northern Highlands Regional High School and lives in Allendale with his parents and sister Farah who are all highly involved in raising awareness and funds for the bleeding disorder community.*



## 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 HANJ directly.

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 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.

**GO SEEK. GO EXPLORE. GO AHEAD.**

PEOPLE LIKE YOU. STORIES LIKE YOURS.  
Explore more at [HEMLIBRAjourney.com](https://www.hemlibra.com/HEMLIBRAjourney.com)

**Discover your sense of go. Discover HEMLIBRA®**

### 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. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent or factor VIII, and the dose and schedule to use for breakthrough bleed treatment. HEMLIBRA may cause 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-lee-bruh)**  
**(emicizumab-kxwh)**  
**injection, for subcutaneous use**

**What is the most important information I should know about HEMLIBRA?**

**HEMLIBRA increases the potential for your blood to clot. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent or factor VIII (FVIII) and the recommended dose and schedule to use for breakthrough bleed treatment.**

**HEMLIBRA may cause the following serious side effects when used with activated prothrombin complex concentrate (aPCC; FEIBA®), including:**

- **Thrombotic microangiopathy (TMA).** This is a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs. Get medical help right away if you have any of the following signs or symptoms during or after treatment with HEMLIBRA:
 

- confusion	- stomach (abdomen) or back pain
- weakness	- nausea or vomiting
- swelling of arms and legs	- feeling sick
- yellowing of skin and eyes	- decreased urination
- **Blood clots (thrombotic events).** Blood clots may form in blood vessels in your arm, leg, lung, or head. Get medical help right away if you have any of these signs or symptoms of blood clots during or after treatment with HEMLIBRA:
 

- swelling in arms or legs	- cough up blood
- pain or redness in your arms or legs	- feel faint
- shortness of breath	- headache
- chest pain or tightness	- numbness in your face
- fast heart rate	- eye pain or swelling
	- trouble seeing

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

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

**What is HEMLIBRA?**

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children, ages newborn and older, with hemophilia A with or without factor VIII inhibitors.

Hemophilia A is a bleeding condition people can be born with where a missing or faulty blood clotting factor (factor VIII) prevents blood from clotting normally.

HEMLIBRA is a therapeutic antibody that bridges clotting factors to help your blood clot.

**Before using HEMLIBRA, tell your healthcare provider about all of your medical conditions, including if you:**

- are pregnant or plan to become pregnant. It is not known if HEMLIBRA may harm your unborn baby. Females who are able to become pregnant should use birth control (contraception) during treatment with HEMLIBRA.
- are breastfeeding or plan to breastfeed. It is not known if HEMLIBRA passes into your breast milk.

**Tell your healthcare provider about all the medicines you take,** including prescription medicines, over-the-counter medicines, vitamins, or herbal supplements. Keep a list of them to show your healthcare provider and pharmacist when you get a new medicine.

**How should I use HEMLIBRA?**

**See the detailed "Instructions for Use" that comes with your HEMLIBRA for information on how to prepare and inject a dose of HEMLIBRA, and how to properly throw away (dispose of) used needles and syringes.**

- Use HEMLIBRA exactly as prescribed by your healthcare provider.
- **Stop (discontinue) prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis.**
- **You may continue prophylactic use of FVIII for the first week of HEMLIBRA prophylaxis.**
- HEMLIBRA is given as an injection under your skin (subcutaneous injection) by you or a caregiver.

- Your healthcare provider should show you or your caregiver how to prepare, measure, and inject your dose of HEMLIBRA before you inject yourself for the first time.
- Do not attempt to inject yourself or another person unless you have been taught how to do so by a healthcare provider.
- Your healthcare provider will prescribe your dose based on your weight. If your weight changes, tell your healthcare provider.
- You will receive HEMLIBRA 1 time a week for the first four weeks. Then you will receive a maintenance dose as prescribed by your healthcare provider.
- If you miss a dose of HEMLIBRA on your scheduled day, you should give the dose as soon as you remember. You must give the missed dose as soon as possible before the next scheduled dose, and then continue with your normal dosing schedule. **Do not** give two doses on the same day to make up for a missed dose.
- HEMLIBRA may interfere with laboratory tests that measure how well your blood is clotting and may cause a false reading. Talk to your healthcare provider about how this may affect your care.

**What are the possible side effects of HEMLIBRA?**

- See "What is the most important information I should know about HEMLIBRA?"

**The most common side effects of HEMLIBRA include:**

- redness, tenderness, warmth, or itching at the site of injection
- headache
- joint pain

These are not all of the possible side effects of HEMLIBRA.

Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

**How should I store HEMLIBRA?**

- Store HEMLIBRA in the refrigerator at 36°F to 46°F (2°C to 8°C). Do not freeze.
- Store HEMLIBRA in the original carton to protect the vials from light.
- Do not shake HEMLIBRA.
- If needed, unopened vials of HEMLIBRA can be stored out of the refrigerator and then returned to the refrigerator. HEMLIBRA should not be stored out of the refrigerator for more than a total of 7 days or at a temperature greater than 86°F (30°C).
- After HEMLIBRA is transferred from the vial to the syringe, HEMLIBRA should be used right away.
- Throw away (dispose of) any unused HEMLIBRA left in the vial.

**Keep HEMLIBRA and all medicines out of the reach of children.**

**General information about the safe and effective use of HEMLIBRA.**

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use HEMLIBRA for a condition for which it was not prescribed. Do not give HEMLIBRA to other people, even if they have the same symptoms that you have. It may harm them. You can ask your pharmacist or healthcare provider for information about HEMLIBRA that is written for health professionals.

**What are the ingredients in HEMLIBRA?**

**Active ingredient:** emicizumab-kxwh

**Inactive ingredients:** L-arginine, L-histidine, poloxamer 188, and L-aspartic acid.

Manufactured by: Genentech, Inc., A Member of the Roche Group,  
 1 DNA Way, South San Francisco, CA 94080-4990  
 U.S. License No. 1048

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 For more information, go to [www.HEMLIBRA.com](http://www.HEMLIBRA.com) or call 1-866-HEMLIBRA  
 This Medication Guide has been approved by the U.S. Food and Drug Administration  
 Revised: 10/2018



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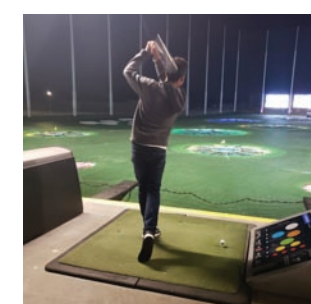
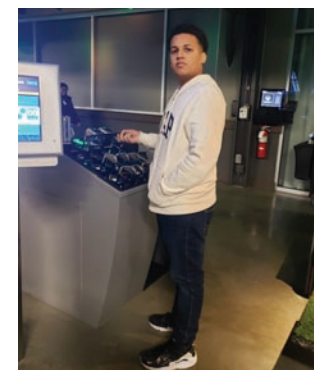
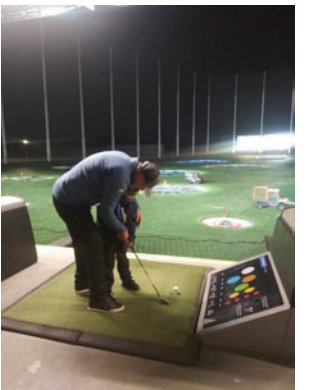
## TopGolf Educational Event

Thursday, January 9, 2020

HANJ in partnership with CSL Behring, sponsored the Top Golf Educational Event. It was a huge success. We had 50 attendees, including members, some new families and HANJ staff. We were delighted to have some new families come out and join us.

Everyone enjoyed the buffet, presentation and especially golfing with Perry Parker.

The Presentation, **Believing in Yourself; Helping Children Find Their Passion in Life** by Perry Parker was well received and of interest to the attendees. Perry held a golf clinic and helped all our members with their swing technique. We look forward to more events as soon as we can. Please check your mail, email and our website for future events.



Hemophilia Association of New Jersey

# HEMOPHILIA RUN/WALK

*Community is in Our Blood!*



## 5K Run and 1 Mile Fun Walk



**SUNDAY**  
**Nov. 8, 2020**

Rain or Shine!

Registration **8:30 AM**

**East Brunswick**  
**Community Arts Center**

721 Cranbury Rd., East Brunswick, NJ 08816



### ~ FAMILY FRIENDLY EVENT ~

Children's Activities • Refreshments • BBQ • Lunch • Entertainment

#### INDIVIDUAL RUNNER OR WALKER

	Earlybird Special*	After Nov. 2nd	Day of Run
5K Participants:	<b>\$25</b>	<b>\$30</b>	<b>\$35</b>
5K Participants 5 & under:	<b>FREE!</b>		
1 Mile Walkers:	<b>Only \$15</b>		
1 Mile Walkers 5 & under:	<b>FREE!</b>		

USATF sanctioned  
race for 5K Run



Free T-Shirts for all  
pre-registered participants!

\*In order to be guaranteed a Run t-shirt, you must register  
by 11:59pm on Oct. 18th. Other shirt sizes not guaranteed.

Strollers, wheelchairs and  
all dogs welcome.

Please register online at [runsignup.com/hanj](https://runsignup.com/hanj)

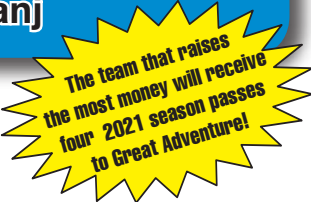
or scan the QR Code below to access the run/walk portal

#### 4 ways to Get Involved:

- Register as an Individual
- Join a Team - Walk and Raise Donations!
- Make your own Team & recruit friends to Walk!
- Make a Donation to the Walk!

#### Schedule:

- 8:30AM Registration
- 9:30AM 5K Start
- 9:45AM 1 Mile Walk Start
- 12:00PM Event Ends



Scan QR Code for direct  
access to Run/Walk Portal



*"To make a donation" or for other events, please visit [www.hanj.org](http://www.hanj.org)  
Call 732.249.6000 for a Registration Packet.*