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.

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

**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. You can also contact us via Facebook as well as log into our website at 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 us directly at 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 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.

Our Scholarship Application deadline has also been extended. We have extended the Scholarship Application deadline from May 31, 2020 to May 31, 2020. If you are interested in applying for any of our scholarships, please visit our website at 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. 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

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 CENTER 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 using the telephone numbers below:

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 or by phone at 732-235-6533 if you anticipate a need for a school visit in the fall.

Please Stay Home!

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.

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

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

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

St. Michael’s Medical Center

St. Michael’s Medical Center is 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.

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.

SCHOLARSHIPS:

We know a lot of our patients are now entering college and might be in need of financial assistance. So 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.

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. So please do not hesitate to call and ask for information, help, and assistance.

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.

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

For more information and an order form, please contact Cindy Hansen at HANJ at (732) 249-6000 or chansen@hanj.org.

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.
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 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

HFA (Hemophilia Federation of America) maintains information specific to the bleeding community at: 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

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.
Some suggestions from the National Hemophilia Foundation that may help in caring for a child with hemophilia include:

- 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 that growing up is a learning process for all children, whether they have hemophilia or not. Both children need support and discipline.

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. 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:

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 highest 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.?


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 is also 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, 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.

cdc.gov/COVID19

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.1

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.1

“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

What you need to know about coronavirus disease 2019 (COVID-19)
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 infección 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 sospecha 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.?

¿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 puede ser posible que una persona contraiga el COVID-19 de una persona infectada tose o estornuda. Sin embargo, se cree que esta es la principal forma en que se propaga el virus. Informes sobre lo que se sabe acerca de la propagación de los coronavirus de reciente aparición en [https://www.cdc.gov/coronavirus/2019-ncov/resources-transmissions.html](https://www.cdc.gov/coronavirus/2019-ncov/resources-transmissions.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 puede 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.
- Limpie y desinfecte los objetos y las superficies que se tocan frecuentemente.

¿Cuánto tiempo puede durar 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. Lleve al consultorio de su proveedor de atención médica antes de ir y diga 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 posponga cualquier viaje para reducir la posibilidad de propagar la enfermedad a los demás.

¿Existe 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.

Si ha viajado recientemente a partir de un área con propagación del COVID-19, notifique al 211 o 211es el número de 211 para obtener información y ayuda.

 Siri: ¿Cómo se propaga el COVID-19?
 Siri: ¿Cuáles son los síntomas del COVID-19?
 Siri: ¿Existe una vacuna contra el COVID-19?
 Siri: ¿Existe un tratamiento para el COVID-19?
 Siri: ¿Qué puedo hacer para ayudar a protegerme?
 Siri: ¿Por cuánto tiempo debo quedarme en casa si he regresado de un viaje a un área con propagación del COVID-19?
 Siri: ¿Cómo puedo contactar a los centros de atención médica?
 Siri: ¿Cuáles son las complicaciones graves de la enfermedad del coronavirus 2019 (COVID-19)?
 Siri: ¿Existe una vacuna contra el COVID-19?
 Siri: ¿Existe un tratamiento para el COVID-19?
 Siri: ¿Qué puedo hacer para ayudar a protegerme?
 Siri: ¿Por cuánto tiempo debo quedarme en casa si he regresado de un viaje a un área con propagación del COVID-19?
 Siri: ¿Cómo puedo contactar a los centros de atención médica?
 Siri: ¿Cuáles son las complicaciones graves de la enfermedad del coronavirus 2019 (COVID-19)?
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
- DIFICULTAD PARA RESPIRAR

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

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.

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/COVID19-es
 CDC.gov/coronavirus
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).

Prophylaxis with ADVATE prevented bleeds\(^1\):
- ADVATE was proven in pivotal clinical trial to prevent or reduce the number of bleeding episodes in children and adults when used regularly (prophylaxis).
- In clinical trials, ADVATE demonstrated the ability to help patients nerdly achieve using prophylactic regimens of ADVATE every 48 hours. In pharmacokinetic-driven, 20–40 IU/kg every 24 hours. Data from 20–80 IU/kg every 72 hours were compared with on-demand treatment. Patients underwent 1 week 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).

What should I tell my HCP before using ADVATE?

Tell your HCP if you:
- 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).
- Have a history of allergic reactions to ADVATE or any of its ingredients.
- Have or develop any other 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 milk, eggs, fish, shellfish, tree nuts, peanuts, wheat, soy, or Tree nuts.

What are possible side effects of ADVATE?
- Call your HCP right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or shortness of breath, or if you feel like fainting.
- If you have a severe reaction, call 911 or get to a hospital right away.
- 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 shortness of breath, difficulty breathing, high blood pressure, dizziness, nausea or fainting.
- Do not attempt to infuse yourself with ADVATE unless you have been taught by your HCP or hemophilia center.
- Do not attempt to infuse yourself with ADVATE unless you have been taught by your HCP or hemophilia center.

What should I tell my HCP before using ADVATE? (continued)
- Have or become pregnant. It is not known if ADVATE may harm your unborn baby.
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- Have a history of allergic reactions to ADVATE or any of its ingredients.
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- Do not attempt to infuse yourself with ADVATE unless you have been taught by your HCP or hemophilia center.

What should I tell my HCP before using ADVATE? (continued)
- Have 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).
- Have a history of allergic reactions to ADVATE or any of its ingredients.
- Have or develop any other 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 milk, eggs, fish, shellfish, tree nuts, peanuts, wheat, soy, or Tree nuts.

What are possible side effects of ADVATE?
- Call your HCP right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or shortness of breath, or if you feel like fainting.
- 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 shortness of breath, difficulty breathing, high blood pressure, dizziness, nausea or fainting.
- Do not attempt to infuse yourself with ADVATE unless you have been taught by your HCP or hemophilia center.
What is the 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 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
- 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 of 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 healthcare provider or pharmacist about ADVATE. The FDA-approved product labeling can be found at www.advate.com or 1-855-825-3327.

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

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Baxalta US Inc.
Lexington, MA 02421 USA
U.S. License No. 2320
Issued: 12/2014

SA7928

Pharmaceutical Resources for Bleeding Disorders

Free Factor & Co-Pay/Deductible Assistance

Manufacturer
Aptevo Therapeutics

Program Name & Contact Information
IXINITY Savings Program
http://ixinity.com/save-on-ixinity
1 (855) 494-6489

Free Trial—Starter Kit—Your Experience

IXINITY Patient Assistance Programs:

Bayer
www.jivi.us.com
www.kogenatefs.com
www.kovaltry-us.com
1 (800) 288-8374

IXINITY

• 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

IXINITY Savings Program
• $0 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 factor VIII

IXINITY 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.
<table>
<thead>
<tr>
<th>Manufacturer</th>
<th>Program Name &amp; Contact Information</th>
<th>Details</th>
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</thead>
<tbody>
<tr>
<td>CSL Behring</td>
<td><a href="http://www.cslbehring.assurance.com">www.cslbehring.assurance.com</a></td>
<td>• CSL Behring Assurance Program: Contact a CSL Behring Assurance Program Care Coordinator at 1 (866) 415-2164</td>
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<td><a href="http://www.cslbehring.com/patients/support/support-and-assistance">www.cslbehring.com/patients/support/support-and-assistance</a></td>
<td>• CSL Behring Patient Care Coordination Center: 1 (844)727-2752</td>
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<td>• My Source CSL Support Line — My Source Hotline Program to assist with deductibles/co-pays associated with Helixate and Humate-P, Idelvion and Afsyta up to $12,000 annually. 1 (800) 676-6266</td>
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<td>• <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.</td>
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<tr>
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<td></td>
<td>• <a href="http://www.afsytal.com">www.afsytal.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.</td>
</tr>
<tr>
<td>Genentech</td>
<td>1 (866) 422-2377</td>
<td>The Hemlibra Co-pay Program helps people with commercial health insurance. This might be a plan you get through your employer or one you purchased through a Health Insurance Marketplace like HealthCare.gov. To qualify, you must also meet other criteria.</td>
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<td><a href="http://www.genentech-access.com/hemlibra">www.genentech-access.com/hemlibra</a></td>
<td>Independent Co-pay Assistance Foundations: If you need help with the co-pay for your Genentech medicine, HEMLIBRA Access Solutions can refer you to an independent co-pay assistance foundation. Independent co-pay assistance foundations help patients with public or commercial health insurance. Call HEMLIBRA Access Solutions at (877) 233-3981 for a referral.</td>
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<td><a href="http://www.HEMLIBRA.COM">www.HEMLIBRA.COM</a></td>
<td>Genentech Patient Foundation 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.</td>
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<tr>
<td>Grifols</td>
<td>FACTORS FOR HEALTH 1 (844) MY-FACTOR (693-2286)</td>
<td><a href="http://www.grifolspatientcare.com">www.grifolspatientcare.com</a></td>
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<td>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.</td>
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<td>The Patient Assistance Program (PAP) for patients with no coverage or lapse coverage.</td>
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<td>Care Coordination to help you access and stay on treatment.</td>
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<tr>
<td>Kedrion</td>
<td>1 (855) 353-7466</td>
<td><a href="http://www.koate-dvi.com">www.koate-dvi.com</a></td>
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<td>Co-pay Assistance – Helps eligible patients with their co-pay costs. The Co-pay card covers up to $16,000 per calendar year.</td>
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<td>Insurance Premium Support Program – Helps with private insurance premiums and assistance for those who qualify.</td>
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<td>Octapharma</td>
<td><a href="http://www.wilateusa.com">www.wilateusa.com</a></td>
<td>Pfizer Connect to assist eligible patients:</td>
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<td>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. 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></td>
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<td>NUWIQ® Free Trial Program Eligible patients can receive treatment with NUWIQ at no cost. (Not to exceed 6 doses, or approximately 20,000 IU)</td>
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<td>To enroll, contact the Octapharma Support Center at 1-800-554-4440.</td>
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<td>OCTAPHERMA REIMBURSEMENT HOTLINE <a href="mailto:USEIMBURSEMENT@octapharma.com">USEIMBURSEMENT@octapharma.com</a> Tel: 800-554-4440</td>
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<td>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 1-800-554-4440.</td>
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<td>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 <a href="http://www.HemophiliaVillage.com">www.HemophiliaVillage.com</a></td>
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<td>Pfizer Factor Savings Card – Up to $12,000 annual support for co-pay, deductible and coinsurance costs. If you have questions, please call 888-240-9040 or send questions to Pfizer Factor Savings Program, 2250 Perimeter Park Drive, Suite 300, Morrisville, NC 27560, or visit <a href="http://www.HemophiliaVillage.com">www.HemophiliaVillage.com</a></td>
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<td>Pfizer RePathways – 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>). (see Pfizer Hemophilia Connect at 1-866-706-2400 for more information or visit website <a href="http://www.PfizerRePathways.com">www.PfizerRePathways.com</a>)</td>
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<tr>
<td>Novo Nordisk</td>
<td><a href="http://www.MyNovoSecure.com">www.MyNovoSecure.com</a> 1 (844) NOVOSEC Or 1 (844) 668-6732</td>
<td><a href="http://www.novonordisk-us.com">www.novonordisk-us.com</a></td>
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<td><a href="http://www.rebinyn.com">www.rebinyn.com</a></td>
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<td><a href="http://www.hemophiliavillage.com">www.hemophiliavillage.com</a></td>
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<td><a href="http://www.nuwiqusa.com">www.nuwiqusa.com</a></td>
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<td>OCTAPHERMA REIMBURSEMENT HOTLINE <a href="mailto:USEIMBURSEMENT@octapharma.com">USEIMBURSEMENT@octapharma.com</a> Tel: 800-554-4440</td>
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</tr>
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</table>
**Manufacturer**

**Pfizer continued...**

**Sanofi Genzyme (formerly Bioverativ)**

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.

https://www.eloctate.com/resources/financial-assistance.aspx or call: (855) 692-5626 (Hem A)

https://www.alprolix.com/resources/financial-assistance.aspx or call: (855) 692-5776 (Hem B)

Email: MyEloctateCoordination@sanofi.com or MyAlprolixCoordinator@sanofi.com

Eloctate and Alprolix both offer the following assistance programs:

- **Free Trial Plus Program** - Eligible patients may apply for a free 30-day trial of medicine. Patients could also receive free factor for up to 1 year, if needed.

- **Factor Access Program** - Helps patients with factor access even if your insurance coverage is interrupted.

- **Co-Pay Assistance Program** - Provides up to $12,000 co-pay/co-insurance assistance for eligible patients who use Eloctate or Alprolix. No income requirements!

**Takeda (formerly Shire)**

https://www.hematologysupportpro.com/copay-assistance/

(888) 229-8379

www.hematologysupportpro.com
(855) 229-8379
Fax: (866) 467-7740

Eloctate and Alprolix both offer the following assistance programs:


- **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.

**Details**

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

Hematology Support Center: One stop resource for Hematology resources (Medical Professionals):

- **Assistance Programs** - 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.

- **Freedom of Choice** - Eligible patients can receive free sample dose of eligible Takeda’s hemophilia products along with educational resources.

- **Co-Pay Assistance Program** - Non-Financial Needs Based Program (Commercial insurance only)

- **Reimbursement Resources**

**Non-Pharmaceutical Assistance Programs**

**Organization**

The Colburn-Keenan Foundation, Inc.
PO Box 811
Enfield, CT 06083
Email: admin@colkeen.org

HFA Helping Hands
Hemophilia Federation of America (HFA)
999 N. Capitol Street NE, Suite 201
Washington, DC 20002
Email: info@hemophiliafed.org

Hope for Hemophilia
PO Box 77728
Baton Rouge, LA 70879

Patient Services Inc.
P.O. Box 5930
Midlothian, VA 23112
Email: uneedpsi@uneedpsi.org

**Contact Information**

www.colkeen.org
Toll free Phone: (800) 966-2431
Fax: (888) 345-0259

www.hemophilafed.org/
programs/helping-hands
Phone: (202) 675-6984
Toll Free: (800) 230-9797
Fax: (202) 675-6983

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

(888) 529-8023
Fax: (888) 835-1449
info@hopeforhemophilia.com
www.hopeforhemophilia.org

www.patientservicesinc.org
1-(800) 366-7741
Fax 1-(804) 744-9388

**Details**

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

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/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 HFA’s Navigating Patient Assistance Programs.

Patient Resource Program and Direct Financial Assistance Program.

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

**PSI helps chronically ill patients.**

- **Premium Assistance, Copayment Assistance, Infusion and Nursing Services & Travel Assistance:** Call 1 (800) 366-7741 for further information.

- **PSI - A.C.C.E.S.S. Legal Hotline (PSI - Patient Services, Inc.)** Supports patients with Social Security Disability and Supplemental Security Income benefits via legal counseling. Call 1 (877) 851-9065 www.patientservicesinc.org
## Additional Resources

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<tr>
<th>Organization</th>
<th>Contact Information</th>
<th>Details</th>
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<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 call your local United Way.</td>
</tr>
<tr>
<td>The Assistance Fund</td>
<td>1 (855) 845-3663 <a href="https://tafcares.org">https://tafcares.org</a></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>Helpline: 1(800) 503-6897 <a href="http://www.needymeds.org">www.needymeds.org</a></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>
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<tr>
<td>Patient Access Network Foundation (PAN)</td>
<td><a href="http://www.panfoundation.org">www.panfoundation.org</a></td>
<td>Assistance Programs: 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.</td>
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<tr>
<td>Patient Advocate Foundation (PAF)</td>
<td>1 (800) 532-5274 <a href="http://www.patientadvocate.org">www.patientadvocate.org</a></td>
<td>Provides case management and assistance in accessing health insurance. Co-pay assistance programs are available.</td>
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<tr>
<td>RxAssist</td>
<td><a href="http://www.rxassist.org/contact">www.rxassist.org/contact</a></td>
<td>Can help you learn about ways to use pharmaceutical company programs and other resources to help reduce your medication costs.</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>1(888) 796-1234 <a href="http://www.rxoutreach.org">www.rxoutreach.org</a></td>
<td>A fully licensed non-profit mail order pharmacy that offers a patient assistance program that provides discounts on prescription drugs.</td>
</tr>
<tr>
<td>United Healthcare Children’s Foundation</td>
<td>1-855-698-4223 <a href="http://www.uhcff.org">www.uhcff.org</a></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>

## Federal/State Resources

<table>
<thead>
<tr>
<th>Organization</th>
<th>Contact Information</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>CDC – Centers for Disease Control and Prevention</td>
<td>(800) 232-4636 toll free <a href="http://www.cdc.gov">www.cdc.gov</a></td>
<td>Information on ways to get health insurance as well as help with health coverage enrollment.</td>
</tr>
<tr>
<td>Get Covered NJ</td>
<td><a href="https://nj.gov/governor/getcoverednj/faqs/">https://nj.gov/governor/getcoverednj/faqs/</a></td>
<td>Information for people who need health insurance and want to apply for or enroll in the Marketplace.</td>
</tr>
<tr>
<td>Healthcare</td>
<td>(800) 318-2596 <a href="http://www.healthcare.gov">www.healthcare.gov</a></td>
<td>A national nonprofit organization that assists and advocates for the bleeding disorders community.</td>
</tr>
<tr>
<td>HFA – Hemophilia Federation of America</td>
<td>(800) 230-9797 <a href="http://www.hemophiliafed.org">www.hemophiliafed.org</a></td>
<td>Information for people with Medicare, Medicare open enrollment, and benefits.</td>
</tr>
<tr>
<td>Medicare</td>
<td>(800) 633-4227 <a href="http://www.medicare.gov">www.medicare.gov</a></td>
<td>Dedicated to finding better treatments and cures for inheritable bleeding disorders and to preventing the complications of these disorders through education, advocacy and research.</td>
</tr>
<tr>
<td>NHF – National Hemophilia Foundation</td>
<td>(212) 328-3700 <a href="http://www.hemophilia.org">www.hemophilia.org</a></td>
<td>New Jersey’s publicly funded health insurance program - includes CHIP, Medicaid and Medicaid expansion populations.</td>
</tr>
<tr>
<td>New Jersey Family Care</td>
<td>(800) 701-0710 <a href="http://www.njfamilycare.org">www.njfamilycare.org</a></td>
<td>Offers free help to New Jersey Medicare beneficiaries who have problems with, or questions about their health insurance.</td>
</tr>
<tr>
<td>New Jersey State Website</td>
<td><a href="http://www.nj.gov">www.nj.gov</a></td>
<td>Providing global leadership to improve and sustain care for people with inherited bleeding disorders.</td>
</tr>
<tr>
<td>State Health Insurance Assistance Program (SHIP)</td>
<td>(800) 792-8820 <a href="https://www.state.nj.us/humanservices/doa/services/ship/">https://www.state.nj.us/humanservices/doa/services/ship/</a></td>
<td></td>
</tr>
<tr>
<td>WFH – World Federation of Hemophilia</td>
<td>(514) 875-7944 <a href="http://www.wfh.org">www.wfh.org</a></td>
<td></td>
</tr>
<tr>
<td>Email: <a href="mailto:contactus@aidsinfo.nih.gov">contactus@aidsinfo.nih.gov</a></td>
<td></td>
<td></td>
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<tr>
<td>Email: <a href="mailto:info@hemophiliafed.org">info@hemophiliafed.org</a></td>
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<tr>
<td>Email: <a href="mailto:wfh@wfh.org">wfh@wfh.org</a></td>
<td></td>
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</tbody>
</table>
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)
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
41st 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 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, 201-401-7085) 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.
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 enjoy the event. 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.

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Medication Guide
HEMLIBRA® (hemlibra-brucho) (emricizumab-kwvh)
Injection for subcutaneous use

What is the most important information I should know about HEMilibra?

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 shown how to do it and have learned to do it correctly.

Your healthcare provider will prescrible your dose based on your weight. If your weight changes, tell your healthcare provider.

You will receive HEMilibra 1 time a week for the first 4 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 this schedule to make up for a missed dose.

HEMilibra may interfere with laboratory tests that measure how well your blood is clotting and may make a false reading. Talk to your healthcare provider about how this may affect your care.

What are the possible side effects of HEMilibra?

See “What is the most important information I should know about HEMilibra?”

The most common side effects of HEMilibra include:

- redness, tenderness, warmth, or itching at the site of injection (hypothesis)
- joint pain

There are not all of the possible side effects of HEMilibra.

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

Have you stored HEMilibra?

Store HEMilibra in the refrigerator at 36°F to 46°F (2°C to 8°C).

Do not freeze.

Store HEMilibra in the original carton to protect the vials from light.

Do not shake HEMilibra.

If needed, unopened vials of HEMilibra can be stored out of the refrigerator and then returned to the refrigerator. HEMilibra 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 HEMilibra is transferred from the sun to the syrup, HEMilibra should be used right away.

Throw away any unused HEMilibra left in the vial.

Keep HEMilibra and all medicines out of the reach of children.

General information about the safe and effective use of HEMilibra:

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use HEMilibra for a condition for which it was not prescribed. Do not give HEMilibra to people other than those you have been told to give it to.

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 and show it to your healthcare provider and pharmacist when you get a new medicine.

How should I use HEMilibra?

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

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

What should I do if I miss a dose of HEMilibra?

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**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

**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**

<table>
<thead>
<tr>
<th>Earlybird Special*</th>
<th>After Nov. 2nd</th>
<th>Day of Run</th>
</tr>
</thead>
<tbody>
<tr>
<td>5K Participants:</td>
<td>5K Participants 5 &amp; under:</td>
<td>1 Mile Walkers:</td>
</tr>
<tr>
<td>$25</td>
<td>FREE!</td>
<td>Only $15</td>
</tr>
</tbody>
</table>

**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.**

**New Location!**

**Rescheduled Date!**

**Nov. 8, 2020**

**Schedule:**

<table>
<thead>
<tr>
<th>Event</th>
<th>Time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Registration</td>
<td>8:30 AM</td>
</tr>
<tr>
<td>5K Start</td>
<td>9:30 AM</td>
</tr>
<tr>
<td>1 Mile Walk Start</td>
<td>9:45 AM</td>
</tr>
<tr>
<td>Event Ends</td>
<td>12:00 PM</td>
</tr>
</tbody>
</table>

**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!

“**To make a donation**” or for other events, please visit www.hanj.org

Call 732.249.6000 for a Registration Packet.