

Summer 2021

# HANJournal

**We Celebrate 50 years!**



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## Hemophilia Association of New Jersey Upcoming 2021 Events

*HANJ has taken great care to follow the CDC guidelines to keep the bleeding disorders community safe during the Coronavirus Pandemic. Please make note of the dates below.*

### **Summer Camp Wellness Gathering**

Eagle's Landing Day Camp  
Saturday, August 28, 2021

### **HANJ Walk/5K Run**

Community Arts Center  
Sunday, September 26, 2021

### **Annual Kelly Brothers Scholarship Benefit In Memory of Bob & Dennis**

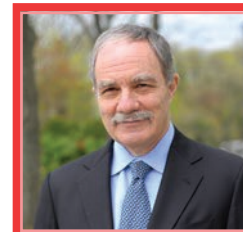
Friendly Sons of the Shillelagh  
Sunday, October 3, 2021

### **Casino Night**

Pines Manor  
Saturday, October 23, 2021

### **39th Testimonial Humanitarian Award**

Fiddler's Elbow Country Club  
Dinner Dance—Man of the Year:  
Kevin Cummings  
Chairman & Chief Executive Officer  
of Investors Bank  
Friday, November 19, 2021



### **President's Message** By Ron Grayzel, Esq.



My term as President of the Board of Trustees has come to an end. Thanks to the Board of Trustees, Officers, Volunteers and Professional Staff who have supported HANJ and made it the success that it is.

When the organization was formed, persons with hemophilia did not have access to adequate medical treatment. For the first time, medical research offers the possibility of a cure for hemophilia. HANJ is a national powerhouse of legislative accomplishments and once again hosted the PACT workshop for bleeding disorder organizations nationwide. HANJ's grassroots efforts in New Jersey have set the bar for other nonprofits in pressing their case for a seat at the table on issues concerning medical care. HANJ provides a large menu of services to its members, including assistance with medical care, camp, educational scholarships, educational programs and insurance coverage to members who cannot afford it.

We owe our founding families an enormous debt of gratitude for their dedication and hard work to establish the organization and for staying the course in the face of challenges that included public and governmental discrimination and indifference to persons with blood disorders. We will never forget the toll taken upon persons with hemophilia that were stricken with hepatitis and HIV caused by the factor concentrate product, which the pharmaceutical industry failed to manufacture safely.

The pandemic provided a challenge to the staff and trustees to maintain services and to plan for the future. Many thanks to the volunteers who have served as Trustees, Officers and on committees for their dedication to HANJ during this difficult time. The Board of Trustees is populated by past presidents who have stayed active long after their terms of office has expired. Also, a great deal of credit must be given to our Executive Director and professional staff who soldiered on, providing services to our members and planning for the future. I am pleased to report that HANJ is alive, well and ever vigilant. We have been and will remain a bastion of strength and support for persons with bleeding disorders.





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 197 Route 18 South  
 Suite 206 North  
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Phone: 732-249-6000  
 Fax: 732-249-7999  
 Editor: Genevieve Christo  
 E-mail: info@hanj.org  
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We welcome all letters and submissions for consideration.

The opinions expressed in HANJournal articles are solely those of the authors and do not necessarily reflect the philosophy of the Hemophilia Association of New Jersey. HANJ makes no recommendations for or against treatments and/or therapies.

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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**

I was pleased to announce the new 2021 scholarship award winners at our 2021 Annual Meeting. I wish you all much success. I know we will be hearing great things from each and every one of you. The 2021 Scholarship recipients are as follows:

**2021 Scholarship Award Winners**

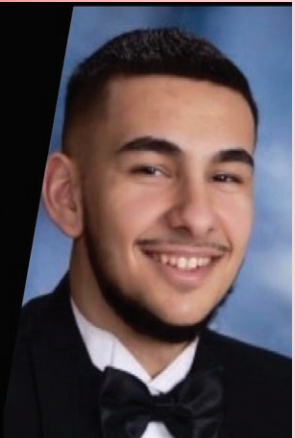
Daniel Carminio has been awarded the Hemophilia Association of New Jersey Scholarship for three years. Daniel is currently a Sophomore at Rutgers University and is pursuing a degree in Public Health. Congratulations, Daniel!




Daniel Carminio  
 Hemophilia Association of New Jersey Scholarship



Andrew DiGiovanni has been awarded the Robert and Dennis Kelly Memorial Scholarship, renewable for 4 years. Andrew will be attending Union County College in the Fall of 2021 and is pursuing a degree in Psychology. Congratulations, Andrew!



Andrew DiGiovanni  
 Robert and Dennis Kelly Memorial Scholarship



Julianna DiRocco has been awarded the Julie E. Frenkel Memorial Scholarship for one year. Julianna is currently a Senior at James Madison University in Virginia and is pursuing a Bachelor of Science degree in Health Science. Congratulations, Julianna!



Julianna DiRocco  
 Julie E. Frenkel Memorial Scholarship



KJ Kaminskas has been awarded the Robert and Dennis Kelly Memorial Scholarship, renewable for 4 years. KJ will be attending Drexel University in the Fall of 2021 and is pursuing a degree in Music Industry with a concentration in recording and music production. Congratulations, KJ!



KJ Kaminskas  
 Robert and Dennis Kelly Memorial Scholarship



**CONGRATULATIONS!**



**HANJ New Slate  
July 1, 2021 to June 30, 2022**

<b>President</b>	<b>Steve Moersdorf</b>
<b>1st Vice President</b>	<b>Jeffrey R. Lynch, MD</b>
<b>Vice President</b>	<b>Lisa Maniaci</b>
<b>Treasurer</b>	<b>Carl Piercey</b>
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<b>Imm. Past President</b>	<b>Ronald Grayzel, Esq.</b>
<b>Medical Advisor</b>	<b>Jeffrey R. Lynch, MD</b>

**TRUSTEES**

<b>Tracie DeSarno</b>	<b>Robert Lessner</b>
<b>George Keelty</b>	<b>Joe Markowitz</b>
<b>Richard Keelty</b>	<b>Rajh Odi</b>
<b>Elaine Kelly</b>	<b>Jerry Seltzer</b>
<b>David Lechner</b>	<b>Issaiah Williamson</b>

**THE HANJ ANNUAL MEETING WAS HELD ON MAY 21ST  
CONGRATULATIONS TO OUR AWARD WINNERS**

**SPECIAL AWARD**

The SPECIAL AWARD was presented to Rajh Odi. Rajh is a HANJ Trustee and serves on several committees: Development, Personnel, and Publicity and Education. HANJ is grateful for the generous contributions of Rajh's time and talents over the years. We appreciate the efforts Rajh has expended for the benefit of persons with hemophilia and related bleeding disorders in New Jersey.

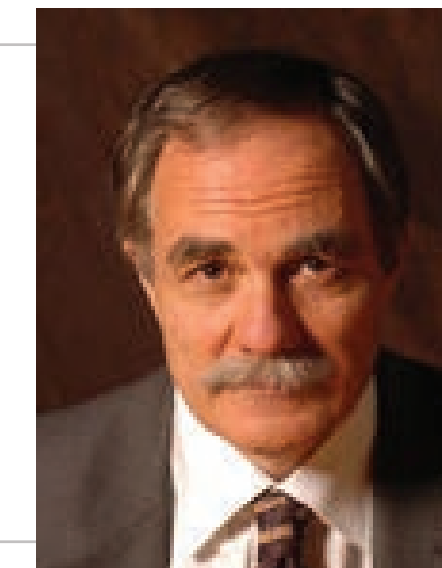


**UNsung HERO AWARD**

The UNSUNG HERO AWARD is given to individuals who make outstanding contributions to the association and receive little or no recognition for their service. This year the award was given to our professional staff: Office Manager Amy Laporta, Special Events Coordinator Mary Lou Billings, Social Services Coordinator Neidy Olarte, Program Assistant Cynthia Hansen, and Administrative Assistant Genevieve Christo. The HANJ staff worked exceptionally hard during the pandemic to keep the HANJ ship afloat to serve our community. They made innovations in the workplace to ensure that the organization performed at optimal capacity during these uncertain and difficult times. The HANJ staff didn't skip a beat these past two years and for that we are grateful.

**PAST PRESIDENT'S AWARD**

The PAST PRESIDENT'S AWARD was presented to Ronald Grayzel, Esq. There is no one more deserving of this recognition than Ron. He has been involved in our organization for over 20 years and his contributions are numerous. Ron weathered the pandemic with us and even agreed to stay on an extra year to preserve continuity through this critical time. Ron is rounding out his term as board President and we are grateful for his tireless efforts over the years, especially during the pandemic.



Thank You to our Sponsors for their support of our 1st Virtual Membership Annual Meeting.



Thank you!

**Silver Sponsors**



**Bronze Sponsors**



**Friend of HANJ**



This March marked 40 years of service for Mary Lou Billings, our Special Events Coordinator.



Mary Lou is the driving force behind our successful events and has been an instrumental part in advocating for the community.

Mary Lou has dedicated most of her adult life to HANJ and its mission. Running large scale events is no easy feat...and yet she makes it seem so seamless.



**THANK YOU FOR YOUR SERVICE MARY LOU!**

## DID YOU KNOW?

The Hemophilia Association of New Jersey is celebrating its 50th Anniversary! HANJ 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.

We remain steadfast in our mission 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.



IT'S OUR  
50th  
ANNIVERSARY!

Come celebrate with us at the

# SUMMER CAMP WELLNESS GATHERING

August 28 | 11 AM - 5 PM  
Eagle's Landing Day Camp



Learn wellness techniques at our sponsors' workshops at this family friendly event.

## CELEBRATE WITH US

HANJ will celebrate our anniversary at the Summer Camp Wellness Gathering and we invite all members of the HANJ community to join us! We are planning a day of wellness programming, food, and fun activities for all age groups including: a water park, miniature golf, and basketball, to name just a few. Best of all, it will be a time for our community to spend time together celebrating our past achievements and look forward as we chart a course for the future that is positive, prosperous, and productive.

If you would like to be part of this amazing day, you can register by scanning this code:



It's free!

## Meet the Staff...



Meet our Marketing Communications Manager, Claire Mignano

The Hemophilia Association of New Jersey is pleased to announce and welcome Claire Mignano as Marketing Communications Manager. Claire will be responsible for directing and maintaining all aspects of marketing and communications at our association. We are confident Claire will help HANJ grow and flourish by identifying marketing strategies to align with our mission and create a significant impact on our long-term goals.

An accomplished marketing professional, Claire has over 25 years' experience in working with non-profit organizations and corporations throughout New Jersey.

Claire received her bachelor's degree from Rutgers University New Brunswick. When not working, her hobbies include running, reading, and spending time "down the shore" with her husband, Anthony and two daughters, Elizabeth and Molly.

## WHAT'S HAPPENING

### New Jersey Hemophilia Treatment Centers

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

*By Lisa Cohen, MSW, LSW*



The Rutgers RWJ Hemophilia Treatment Center (HTC) recognizes the changing landscape of the global COVID health crisis and continues to focus on the provision of comprehensive care for our bleeding disorder patients. The HTC is fully operational with a hybrid operation of tele-health and in person clinical care. The clinic continues to take measures to minimize the risk to patients and staff. Please do not hesitate to contact the clinic if you have any questions.

Zoom. A Zoom educational program will be held this summer for new families. Information will be sent via email with date and time. If you anticipate the need for a school, camp or daycare visit, please contact Lisa Cohen, MSW at [cohenlr@rwjms.rutgers.edu](mailto:cohenlr@rwjms.rutgers.edu) or by phone at 732-235-6533.

Contact can be made with the Rutgers RWJMS HTC at the usual telephone numbers:

For Nurses: 732-235-6542 or  
732-235-6531

For Social Worker:  
732-235-6533

PROGRAMS & SCHOOL VISITS: Currently educational programs & school and camp visits continue to be conducted via

**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

By Phyllis Kandl



Happy Summer! The staff from the Comprehensive Hemophilia Treatment Center at Newark Beth Israel Medical Center and Children's Hospital of New Jersey would like to share some updates, current programs, and plans with you. We hope you are all doing well!

### **NEWS:**

The HTC welcomes Emily Fusco, LSW as our new Hemophilia Social Worker.

### **ONGOING PROGRAMS**

#### **COVID-19:**

As the pandemic continues, the HTC staff wanted to remind you that we are here for you for your medical needs, questions, and concerns about COVID-19 as well as to connect you to resources as we recognize that the pandemic may have impacted your life. Please reach out to the HTC staff as needed.

#### **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 track 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.**

#### **School Visits:**

School may be out for the summer however it is not too early to start thinking about your child's school or educational needs for the fall. School visits are a wonderful opportunity for our HTC to provide education and outreach to your child's school or daycare about hemophilia and other bleeding disorders. Whether the visit is with the staff at your child's school, the daycare staff, or even the child study team, a school visit opens the lines of communication between the child's school or daycare and the HTC. **If you are going to want a school visit scheduled for your child's school or daycare center, or need a letter for school/forms completed, please contact Emily, our Social Worker.** Emily will make sure that we have a release on file, and will coordinate your needs with the school and schedule a visit. **If you will need any forms or letters for your child's school or daycare center, please be mindful that it may take up to two weeks for forms or letters to be completed.** For more information, please contact us at the HTC.

#### **Hemophilia 340B Program:**

Our HTC participates in the Federal 340B Program. As a comprehensive care center, we have been improving the quality of life for individuals with bleeding disorders and providing cost effective care in the long term for many years. In an effort to help HTCs sustain themselves, and provide better care for their eligible patients, Congress created the 340B Program as part of the Veteran's Health Care Act of 1992. Across the United States almost all of the HTCs participate in 340B Programs. Depending on their healthcare coverage, patients may have a variety of pharmacy options to choose from. Our HTC is contracted with three

different home care companies; Accredo, BDRN, and Option Care Health/Bioscrip. Patients who are not currently using one of these three companies may voluntarily switch if their insurance company allows. Participation in the 340B Program is voluntary. **Please contact our Program Manager, Phyllis, for further information.**

#### **Comprehensive Evaluations:**

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 traveling? 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.**



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

## St. Michael's Medical Center

By Joanne Rodriguez



### Summer and COVID-19

Summer is here!!! We know that the weather is getting better and after a year of quarantine, we all want to enjoy the beautiful weather. Please be mindful and remember that we are still dealing with a Pandemic. Wearing masks, keeping our distance and hand washing still stands, even if the weather is getting better. Even if you have been vaccinated, you still have to follow the CDC guidelines. If you are not vaccinated but are interested, please follow the link below: [covid19.nj.gov/pages/vaccine](https://covid19.nj.gov/pages/vaccine)

### Walk in COVID-19 Clinic at St. Michael's Medical Center

You may walk in on Mondays, Thursdays, and Fridays from 8:00a.m.-12:00p.m.

### Travel Letters

Summer is quickly approaching and people are starting to travel. We recommend that you call our office at least a couple of weeks before the travel date to request travel letters. Please call our center at (973)877-5342 and ask for Social Worker, Joanne Rodriguez (973)877-2967.

### Insurance

If you need to call our office to make an appointment but are not sure if your insurance is accepted in the hospital or clinic, please let us help you with any questions or concerns you may have when it comes to co-payments, deductible and coverage issues.

### Re-Evaluation

We are open and servicing our community. Give us a call and schedule your re-evaluation for the year. You can contact us at (973)877-5342, Monday through Friday.

### 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.

### Mental Health:

As we all know mental health issues are on the rise and COVID-19 hasn't made things easier. If you or anyone you know is in need of help, please know that you are not alone. There's help for you and others:

**National Suicide Prevention Lifeline**  
(800)273-8255

**Online Chat:**  
[suicidepreventionlifeline.org](https://suicidepreventionlifeline.org)

**Depression Test:**  
[screening.mhanational.org](https://screening.mhanational.org)

**Emergency:**  
911

**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.**

**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

**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](https://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>

The ability of ADVATE to treat or prevent bleeds was evaluated in a clinical study using a standard prophylaxis, pharmacokinetic driven prophylaxis, and on-demand treatment. 53 previously treated patients (PTPs) with severe to moderately severe hemophilia A were analyzed. For the first 6 months of the study, patients received on-demand treatment. For the following 12 months of the study, patients received either standard prophylaxis every 48 hours or a pharmacokinetic-driven prophylaxis every 72 hours. The primary goal of the study was to compare annual bleeding rates between those receiving prophylaxis treatment and those receiving treatment on-demand. The number of bleeds per year for the 2 prophylaxis regimens were comparable.

- Those patients experienced a median of 1 overall bleed per year on either prophylaxis treatment vs 44 overall bleeds per year with on-demand treatment!<sup>1</sup> This represented a 98% reduction in overall bleeds per year.
- Zero bleeds were reported in 42% of patients (22 out of 53 patients) during 12 months on prophylaxis

<sup>1</sup>Median is the middle number in a group of numbers arranged from lowest to highest.

### 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).





  
**ADVATE**  
**[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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Patented: see <https://www.takeda.com/en-us/patents/>

U.S. License No. 2020  
Issued: 12/2018

US-ADV-0030v1.0 02/20



### A Memorial to our dear colleague Rita Matagrano

How does one express the amazing essence and spirit of Rita – her selfless generosity, uncompromising belief in all that is good and her unwavering commitment to family and friends? Words, even the very best of words, cannot pay tribute or truly capture the sense of loss that we feel.

The loss is there, tangible and real within everyone...but Rita exemplified life, love, laughter and an irrepressible belief and faith in seeing the best in everything.

And so we honor her, by feeling and expressing our loss, but also by remembering Rita – an amazing person who has played a unique and special role in many lives.

Rita was a loyal colleague to some and a special friend to many and we honor this as we recall special moments we spent with Rita.

Amazing, unique, special...absolutely!

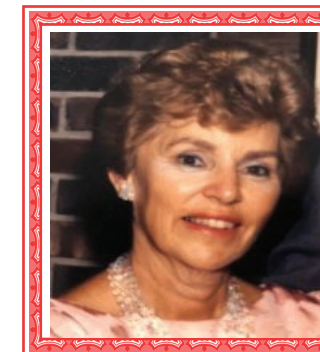
All who knew Rita will remember her with our memories from all the days gone before that we were privileged to share with you...

...today we'll grieve for you, and cry for you and even smile because of you...

And in all the tomorrows we'll feel you – gone in some ways, but your presence ever near.

### A Memorial to one of our Past President's and founders Dorothy Child

It is with great sadness we inform you of the passing of HANJ past President, and one of our founders, Dorothy Child. Dorothy Varni Child passed away last month surrounded by family at her daughter's home in Georgia.



In 1967, after she and her husband Tom settled their growing family in Basking Ridge, Dorothy welcomed her seventh and youngest child, Kevin Michael Child. In his first year of life, Kevin was diagnosed with hemophilia. As Dorothy later wrote reflecting on the diagnosis, "My first reaction was to feel very sorry for myself. But my husband and I decided to find out everything we could about hemophilia and its treatment." And they did.

Dorothy dedicated her time to improving the quality of life for people living with hemophilia in New Jersey, even while running back and forth to the hospital to treat Kevin's bleeding episodes. She worked tirelessly for Kevin to have a normal life. When she could not find the support she needed in her home state, Dorothy formed the Hemophilia Association of New Jersey in 1973. She served as Chapter President and became Regional Director of the National Hemophilia Foundation. After years of volunteering as a blood donor recruiter, Dorothy became a part-time employee of the North Jersey Blood Center. Dorothy believed no organization was too big to take on in the service of others. She spent endless hours lobbying on the state and national level, pushing for New Jersey to become the first U.S. state to pass a hemophilia bill and opening the first Hemophilia Treatment Center. In recognition for her outstanding contributions and deep compassion, Dorothy received several awards, including the Hemophilia Association of New Jersey President's Award (1975), the L. Michael Kuhn Award (1981), the National Hemophilia Association Special Award (1985), and the National Hemophilia Foundation Lifetime Achievement Award (2001). The Hemophilia Association of New Jersey is grateful for Dorothy's efforts on behalf our community. She was a valued member of the community and will be missed.

# 42nd Annual Dennis Keelty Memorial Golf Classic Plainfield Country Club June 21, 2021

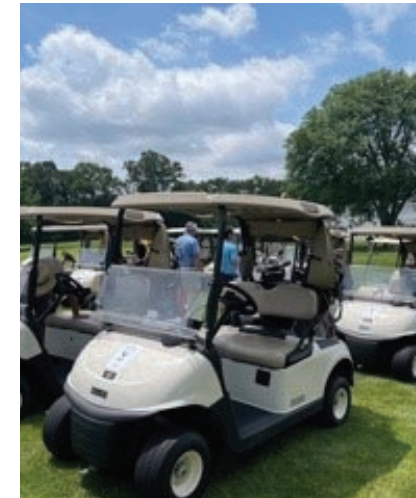
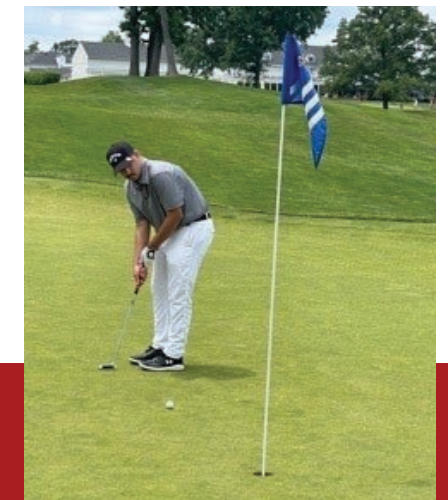


# Thank you to our sponsors

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For more golf  
photos, scan  
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# What to Expect after Getting a COVID-19 Vaccine

The COVID-19 shot may cause side effects in some people. Side effects should go away in a few days.

## COMMON SIDE EFFECTS

### On the arm where you got the shot:

- Pain
- Redness
- Swelling

### In the rest of your body:

- Fever
- Chills
- Tiredness
- Headache
- Muscle pain
- Nausea



### Ask the facility healthcare provider (or facility staff) for help if:

- The redness or pain where you got the shot gets worse after 24 hours
- Your side effects are worrying you
- Your side effects do not seem to be going away after a few days

## HELPFUL TIPS

If you have pain, headache, or fever, ask a healthcare provider (or facility staff) if you can have medicine.

### If you are sore where you got the shot:

- Apply a clean, cool, wet washcloth over the area
- Use or move your arm gently

### If you have a fever:

- Drink a lot of water
- Get plenty of rest
- Dress lightly

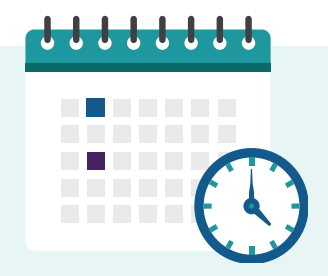


## REMEMBER

Side effects may make you feel a little sick or even make it hard to do daily activities, but they should go away in a few days.

Some COVID-19 vaccines need 2 shots to work. You should get the second shot even if you have side effects after the first shot, unless a doctor tells you not to.

COVID-19 vaccines may not fully protect you until a week or two after your final shot. It takes time for your body to build protection after any vaccination.



Even after your COVID-19 vaccination, when you are in a correctional facility, it's important to continue wearing your mask, try to stay at least 6 feet away from others as much as possible, and wash your hands often.



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

CS324160A

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

It has seemed like an eternity since the first Covid-19 case was reported in New Jersey on March 2, 2020 in Bergen County. On March 9th the Governor issued the first emergency declaration and on March 10th the first in state death occurred. Since then we have lived in a state of total or partial lockdown with all its attendant miseries.

On May 28th, good news broke through with the Governor lifting mask mandates and capacity limits on public gathering places. Public health measures and in particular, the vaccines, have given us the potential for a normal summer. The vaccines are widely available with walk in appointments at a large number of pharmacies. Even with our new freedoms the virus is still out there and everyone should operate from their own risk tolerance.

The biggest factor in assessing individual risk is vaccination status. All three vaccines convey over 90% protection from severe disease and almost complete protection from mild disease along with making transmission to another individual highly unlikely. While adverse reactions are featured on the news they are usually individual cases against a backdrop of 130 million people vaccinated so far. Sorting through the data, compared to masks, hand washing and social distancing the vaccines are by far the best protection against the virus.

The potential need for a booster has also been widely discussed. Current studies confirm the antibodies from the vaccines last at least a year. The data is limited by

the fact that few people are one year out from receiving the vaccine but so far there does not appear to be a significant drop off in antibodies. In addition, the vaccines produce memory B cells in the bone marrow which can mount an immune response to Covid and may exist for a lifetime.

Also on the good news front, there are now three monoclonal antibody treatments approved for use in Covid 19. Because of supply issues these have been given under strict protocols but with a third drug now available they should come into routine use. These are administered intravenously and are highly effective in the severity of infection. In addition, there are several oral tamiflu type medications under development. It is possible that in the near future there will be a pill to take at the onset of symptoms to ensure a mild case.

So optimistically it is possible that our next problem will be what to talk about after Covid. Meanwhile from myself and HANJ we wish all members a healthy and free summer.

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

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

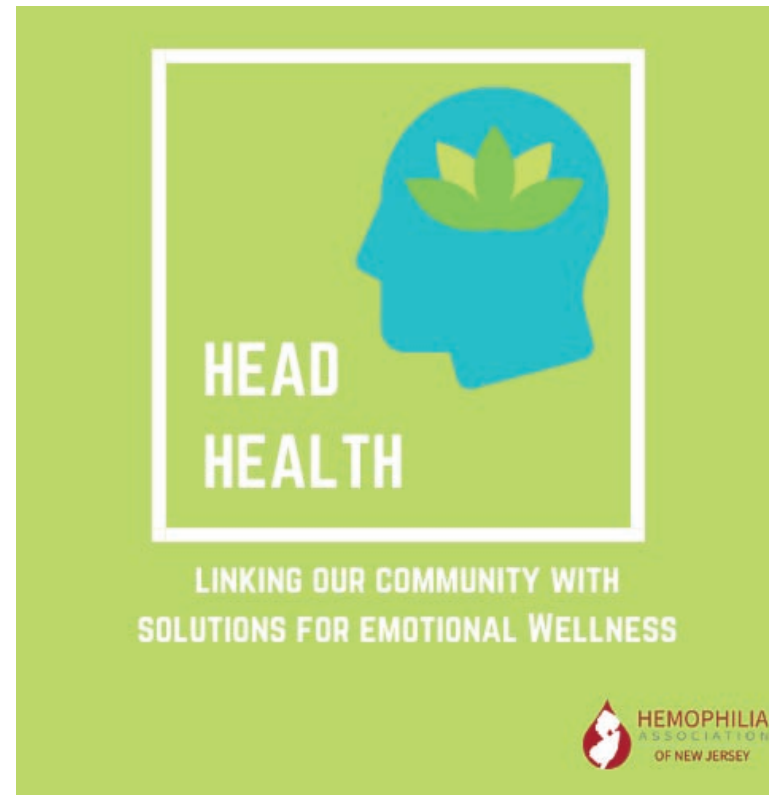


## We are here to help you ...

Do you need assistance with your health insurance premium, co-pays and deductibles? HANJ offers assistance to eligible individuals, through our Medical Insurance Grant.

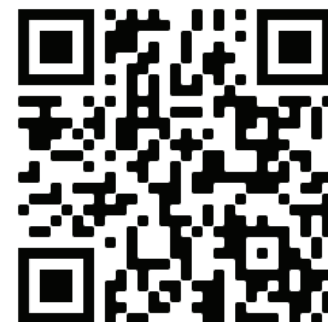
Please contact Neidy Olarte, **HANJ Social Worker**, via email at [nolarte@hanj.org](mailto:nolarte@hanj.org) or call **(732) 249-6000** for information about the requirements and how to apply for assistance.

The HANJ is very proud of our new mental health and wellness initiative!



*"It is our mission to empower individuals and families with bleeding disorders in New Jersey on their journey toward mental wellness and recovery by providing resources and facilitating access to comprehensive mental health care services in our community."*

To learn more about  
Head Health  
go to our website:



**Join one of our bleeding disorder support groups:**

**The Common Factor** – Virtual community group. The goal of The Common Factor is to connect the bleeding disorder community, allowing for a safe space, to be a support system for all. The meetings are open to all individuals in the bleeding disorder community, including family and friends that would like to support the mission of the group.

**NJ Blood Brotherhood** - The purpose of the Blood Brotherhood program is to provide an opportunity for adult hemophiliacs to connect with their peers in a fun, relaxed setting.

The NJ Blood Brotherhood program holds free events for men with bleeding disorders. This group is open to anyone 21 years and older 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.

**Please see more information about these programs on our website, or call the HANJ office with questions. We look forward to hearing from you.**

**The Crisis Text Line**

Text "**Home**" to **741741** when you are feeling depressed or suicidal. A crisis worker will text you back immediately and continue to text with you. Many people don't like talking on the phone and would be more comfortable texting.

It's a **FREE** and confidential service to ANYONE—teens, adults, etc...who live in the U.S. and it is available 24/7

**2-1-1**

2-1-1 is a **special abbreviated telephone number** reserved in Canada and the United States as an easy-to-remember three-digit telephone number meant to provide information and referrals to health, human, and social service organizations.

**Please take the time for yourself to use one of these resources if you feel depressed or need someone to talk to.**

**You are not alone...  
Mental Health Services**

**Suicide Prevention Line**  
**1 (800) 273-8255**  
[www.suicidepreventionlifeline.org](http://www.suicidepreventionlifeline.org)

**National Alliance on Mental Illness (NAMI)** **1 (800) 950-6264**  
[www.nami.org](http://www.nami.org) or [info@nami.org](mailto:info@nami.org)

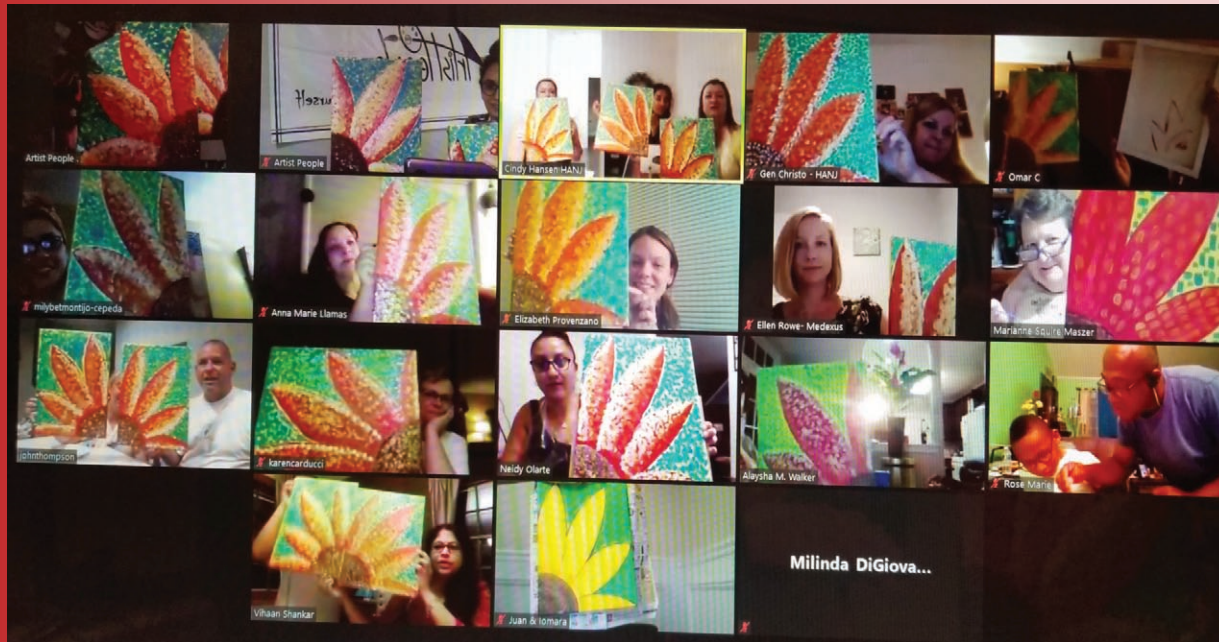
**Division of Mental Health & Addiction Services (Adults)**  
**1 (800) 382-6717**

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

**NJ Connect for Recovery**  
**1 (855) 652-3737**  
[www.njconnectforrecovery.org](http://www.njconnectforrecovery.org)

**NJMentalHealthCares**  
**1(866) 202-Help (4357)**  
**7 days a week, 8am to 8pm**

**Paint Night Program  
June 9, 2021 Sponsored by Medexus**



**On June 9, 2021 HANJ hosted a Paint Night, sponsored by Medexus. Everyone had a great time! Please look for more educational programs with a little side of fun, when we join one of our Pharmaceutical companies to bring you another great program you won't want to miss.**

**Check our website: [www.hanj.org](http://www.hanj.org)  
Keep an eye out in your email for notifications.**



**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](mailto:chansen@hanj.org).**



**HANJ Leads the Way  
with the Annual  
PACT WORKSHOP**

By Stephanie Lapidow  
Executive Director

HANJ was proud to host the Partnership for Advocacy and Communications Training (PACT) Workshop this June. This workshop was established by the Hemophilia Association of New Jersey in partnership with Takeda (at the time Baxter) in the early 2000's. Historically, this workshop has been an in-person, one-and-a-half-day advocacy program providing organizational development, education and enhanced advocacy skills to state hemophilia chapters and organizations. The workshop is geared towards training, thought-provoking discussion, and guidance. This year it looked a little different and the workshop was presented virtually via Zoom to state hemophilia chapters and organizations in 42 states.

Each year we tackle huge issues while collaborating with our fellow advocacy peers around the country. This training allows our Association the opportunity to gain more knowledge and skills as well as collaborate with peers to tackle head-on issues within the bleeding disorders community, so that we are stronger in our legislative efforts each year. This year we dove into crucial conversations regarding; The American Rescue Plan Act as well as the Co-pay Accumulator/Maximizer.

Both days of the PACT WORKSHOP were recorded. If you would like to view the recordings, scan this qr code:



We received great tips and gained extensive knowledge from all our speakers this year. With our newfound knowledge we will continue to improve our messages and communications to community members and legislators.

Thank you to our speakers:

- Miriam Goldstein  
**HFA**
- Kollet Koulianos  
**NHF**
- Kate O'Brien
- Joe Simonetta  
**Public Strategies Impact**
- Bill Murray  
**MWW**

Thank you to our sponsors:

- **Platinum**  
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HFA

HANJ is proud of the leadership role we have played in educating and promoting advocacy efforts on behalf of the bleeding disorder community, not only in NJ, but nationwide.

## Impact of the Covid-19 Pandemic on Rare Disease Patients and Caregivers

FEBRUARY 26, 2021 MAROI SANTOS  
Reprinted with permission from Rare Patient Voice, LLC  
[www.rarepatientvoice.com](http://www.rarepatientvoice.com)

The COVID-19 pandemic has negatively affected people from different backgrounds and all walks of life. The struggle of one particular group has gone largely unnoticed – people diagnosed with rare diseases.

In the U.S., according to the Orphan Act of 1983, a rare disease is defined as a condition that affects fewer than 200,000 Americans. There are 7,000 kinds of rare diseases in the country. And although each disease affects fewer than 200,000 people, every one in ten people is likely impacted by one of these diseases.

It is therefore essential that the struggles of rare disease patients and their caregivers during the pandemic are given adequate attention.

### Effects of Covid-19 on the Rare Disease Community

Thus far, the pandemic has caused a variety of issues including limited access to healthcare and added stress and anxiety.

A survey conducted by the National Institutes of Health confirmed that access to medicine and medical treatment was one of the most common initial concerns of rare disease patients and their families when the pandemic hit.

According to the Rare Genomics Institute, half of the individuals with rare diseases are children. This has introduced another challenge when it comes to facing the threat of the pandemic.

The survey also mentioned that the families affected were concerned about the status and continuity of clinical trials. This is because these diseases pose a certain level of difficulty when it comes to research because of how rare patients are. This means many of these conditions have limited treatment options even before COVID-19.

This is one of the issues being addressed by patient advocacy organization partnerships, including Rare Patient Voice.



We have been empowering rare disease research studies by offering study volunteer opportunities, making sure that there is continuity in the development of treatments and improvements in medical access.

### Measures Taken

According to another survey by the National Organization for Rare Disorders, telehealth has been particularly helpful according to rare disease patients and their caregivers. Because of the rarity and difficulty of some of these diseases, before the pandemic and the subsequent rise of telehealth, 39 percent of patients travel more than 60 miles just to access the appropriate medical care.

The survey also mentioned that the development of this technology is also having positive impacts on other facets of life of these patients and their families. One example is how some patients can now actively participate in work and schooling without having to worry about missing medical appointments.

This increased coverage of telehealth was also facilitated, in part, by the federal government. When the pandemic struck in early March of 2020, the government started taking steps to expand the reach of telehealth services that were previously intended primarily for patients in rural areas.

The government impetus opened doors for out-of-state medical practitioners to offer their services across state lines. Many private insurers also followed suit to include telehealth services in their coverages.



## EXPERIENCE MATTERS

BeneFix is FDA approved for once-weekly prophylaxis and on-demand use to fit your dosing needs— from the only recombinant factor IX supporting individuals with hemophilia B for more than 20 years.\*

Not actual patients.



**More than 20 years\* of experience**—the first recombinant treatment for individuals with hemophilia B



**Dosing options to meet your needs**—for once-weekly prophylaxis and on-demand use



Designed with viral safety in mind. More than 150 quality control tests are done on each batch of BeneFix



The convenience of the BeneFix Rapid Reconstitution (R2) Kit with a range of vial sizes



### What is BeneFix?

BeneFix, Coagulation Factor IX (Recombinant), is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia B. Your doctor might also give you BeneFix before surgical procedures.

BeneFix is **NOT** used to treat hemophilia A.

### Important Safety Information

- BeneFix is contraindicated in patients who have manifested life-threatening, immediate hypersensitivity reactions, including anaphylaxis, to the product or its components, including hamster protein.
- Call your health care provider right away if your bleeding is not controlled after using BeneFix.
- Allergic reactions may occur with BeneFix. Call your health care provider or get emergency treatment right away if you have any of the following symptoms: wheezing, difficulty breathing, chest tightness, your lips and gums turning blue, fast heartbeat, facial swelling, faintness, rash, or hives.
- Your body can make antibodies, called "inhibitors," which may stop BeneFix from working properly.
- If you have risk factors for developing blood clots, such as a venous catheter through which BeneFix is given by continuous infusion, BeneFix may increase the risk of abnormal blood clots. The safety and efficacy of BeneFix administration by continuous infusion have not been established.
- Some common side effects of BeneFix are fever, cough, nausea, injection site reaction, injection site pain, headache, dizziness, and rash.

Please see the Brief Summary for BeneFix on the next page.



**BeneFix**  
Coagulation Factor IX (Recombinant)  
Room Temperature Storage  
\*BeneFix was approved February 11, 1997.



Rx only

### Brief Summary

See package insert for full Prescribing Information. This product's label may have been updated. For further product information and current package insert, please visit [www.Pfizer.com](http://www.Pfizer.com) or call our medical communications department toll-free at 1-800-438-1985.

Please read this Patient Information carefully before using BeneFix and each time you get a refill. There may be new information. This brief summary does not take the place of talking with your doctor about your medical problems or your treatment.

### What is BeneFix?

BeneFix is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia B. Hemophilia B is also called congenital factor IX deficiency or Christmas disease. Your doctor might also give you BeneFix before surgical procedures.

BeneFix is **NOT** used to treat hemophilia A.

### What should I tell my doctor before using BeneFix?

Tell your doctor and pharmacist about all of the medicines you take, including all prescription and non-prescription medicines, such as over-the-counter medicines, supplements, or herbal medicines.

Tell your doctor about all of your medical conditions, including if you:

- have any allergies, including allergies to hamsters.
- are pregnant or planning to become pregnant. It is not known if BeneFix may harm your unborn baby.
- are breastfeeding. It is not known if BeneFix passes into the milk and if it can harm your baby.

### How should I infuse BeneFix?

The initial administrations of BeneFix should be administered under proper medical supervision, where proper medical care for severe allergic reactions could be provided.

### See the step-by-step instructions for infusing in the complete patient labeling.

You should always follow the specific instructions given by your doctor. If you are unsure of the procedures, please call your doctor or pharmacist before using.

### Call your doctor right away if bleeding is not controlled after using BeneFix.

Your doctor will prescribe the dose that you should take. Your doctor may need to test your blood from time to time. BeneFix should not be administered by continuous infusion.

### What if I take too much BeneFix?

Call your doctor if you take too much BeneFix.

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

Allergic reactions may occur with BeneFix. Call your doctor or get emergency treatment right away if you have any of the following symptoms:

wheezing	fast heartbeat
difficulty breathing	swelling of the face
chest tightness	faintness
turning blue (look at lips and gums)	rash
	hives

Your body can also make antibodies, called "inhibitors," against BeneFix, which may stop BeneFix from working properly.

Some common side effects of BeneFix are fever, cough, nausea, injection site reaction, injection site pain, headache, dizziness and rash.

BeneFix may increase the risk of thromboembolism (abnormal blood clots) in your body if you have risk factors for developing blood clots, including an indwelling venous catheter through which BeneFix is given by continuous infusion. There have been reports of severe blood clotting events, including life-threatening blood clots in critically ill neonates, while receiving continuous-infusion BeneFix through a central venous catheter. The safety and efficacy of BeneFix administration by continuous infusion have not been established.

These are not all the possible side effects of BeneFix.

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

### How should I store BeneFix?

DO NOT FREEZE the BeneFix kit. The BeneFix kit can be stored at room temperature (below 86°F) or under refrigeration. Throw away any unused BeneFix and diluent after the expiration date indicated on the label.

Freezing should be avoided to prevent damage to the pre-filled diluent syringe.

BeneFix does not contain a preservative. After reconstituting BeneFix, you can store it at room temperature for up to 3 hours. If you have not used it in 3 hours, throw it away.

Do not use BeneFix if the reconstituted solution is not clear and colorless.

### What else should I know about BeneFix?

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

If you would like more information, talk with your doctor. You can ask your doctor or pharmacist for information about BeneFix that was written for healthcare professionals.

This brief summary is based on BeneFix® [Coagulation Factor IX (Recombinant)] Prescribing Information LAB-0464-12.0, revised June 2020.



## How Caregivers Can Care for Themselves

### Caregivers devote themselves to the well-being of others, but to be their best they need to practice self-care

Author: Michael Hickey  
Fitness & Nutrition

Being a caregiver for an adult with a chronic condition is hard, and can be emotionally exhausting. It can result in a range of feelings, from loneliness, sadness and fear to anger, worry and guilt. Plus, such high levels of stress can lead to anxiety and depression, weaken the immune system, and increase your risk of serious chronic illnesses such as heart disease and arthritis.

This is why caregivers need to remind themselves that they need care, too, and should give themselves the opportunity to rest and rejuvenate. Here are four self-care tips that can prevent caregiver burnout and fatigue, even during the age of social distancing.

### Reach Out for Help

Caregivers put a lot of responsibility on their shoulders, but that doesn't mean they need to carry the emotional burden themselves. Be willing to accept assistance and reach out to a psychologist or mental health professional to help deal with your stress and anxiety. With the pandemic, you may be hesitant to set up an in-person appointment, but there are still opportunities for virtual visits, and a wealth of mental health resources available online for free. Studies have shown that talking through your feelings with another person can have a significant positive impact on your mental health.

If you feel more comfortable talking to someone you know, don't be afraid to speak with a family member or close friend whom you trust to talk about your struggles.

### Take Advantage of Respite Care

It might be hard to leave loved ones in the care of others even for a brief period, but respite care can give you a much-needed break. Respite care is when primary caregivers share the responsibility of caregiving—and get support for themselves—by leaving loved ones in the hands of professionals for a short period

of time. Caregivers can do this by enlisting paid carers to watch a loved one in their home or by leaving a loved one in an out-of-home care facility, such as a nursing home or adult day care center. While their loved ones receive care from professionals, primary caregivers can rest, relax, see other family, take care of other responsibilities, or simply take a day to do something they enjoy. The National Respite Network can help you find providers, programs and resources in your community.

Some services even offer in-home care, which could put you and your loved one at ease knowing they're in a familiar place.

### Manage Your Basic Needs

When you're completely devoted to caring for another person, it can be easy to neglect your own health. But without a healthy diet, proper sleep and enough exercise, you won't be at your best, which means you may not have the capacity to effectively care for others. So don't ignore your body when your stomach growls; grab a quick snack instead. Feel weak or shaky? Give yourself a few minutes to sit down and regroup. When you listen to your body, you and the person you care for will benefit.

### Practice Relaxation Techniques

Practicing relaxation techniques such as deep breathing exercises, guided meditation, guided imagery, yoga and progressive muscle relaxation takes only minutes out of your day but can greatly reduce stress and improve your mood. And with smartphone apps such as Calm and free yoga classes online, you don't even have to leave your bedroom to get started.

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2021 Spring



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

PEOPLE LIKE YOU. STORIES LIKE YOURS.  
Explore more at [HEMLIBRAjourney.com](https://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. People who use activated prothrombin complex concentrate (aPCC; Feiba®) to treat breakthrough bleeds while taking HEMLIBRA may be at risk of serious side effects related to blood clots.**

These serious side effects include:

- **Thrombotic microangiopathy (TMA)**, a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs
- **Blood clots (thrombotic events)**, which may form in blood vessels in your arm, leg, lung, or head

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



#### Medication Guide HEMLIBRA® (hem-lee-bruh) (emicizumab-kxwh) injection, for subcutaneous use

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

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

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

- **Thrombotic microangiopathy (TMA).** This is a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs. Get medical help right away if you have any of the following signs or symptoms during or after treatment with HEMLIBRA:
  - confusion
  - weakness
  - swelling of arms and legs
  - yellowing of skin and eyes
  - stomach (abdomen) or back pain
  - nausea or vomiting
  - feeling sick
  - decreased urination
- **Blood clots (thrombotic events).** Blood clots may form in blood vessels in your arm, leg, lung, or head. Get medical help right away if you have any of these signs or symptoms of blood clots during or after treatment with HEMLIBRA:
  - swelling in arms or legs
  - pain or redness in your arms or legs
  - shortness of breath
  - chest pain or tightness
  - fast heart rate
  - cough up blood
  - feel faint
  - headache
  - numbness in your face
  - eye pain or swelling
  - trouble seeing

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

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](https://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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**Save the date**  
**Sunday**  
**September 26, 2021**

**Hemophilia**  
**1 Mile Walk**  
**5 K Run**



COMMUNITY IS IN OUR BLOOD

Grab your friends and register as a team.  
Huge post race party with food, music and  
bounce house for kids!

Prizes awarded to top fundraising  
teams and individuals!

T-shirts for all registrants.

Medals for all finishers.

To register for the  
Hemophilia  
1 Mile Walk/5K Run  
scan this QR code:

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