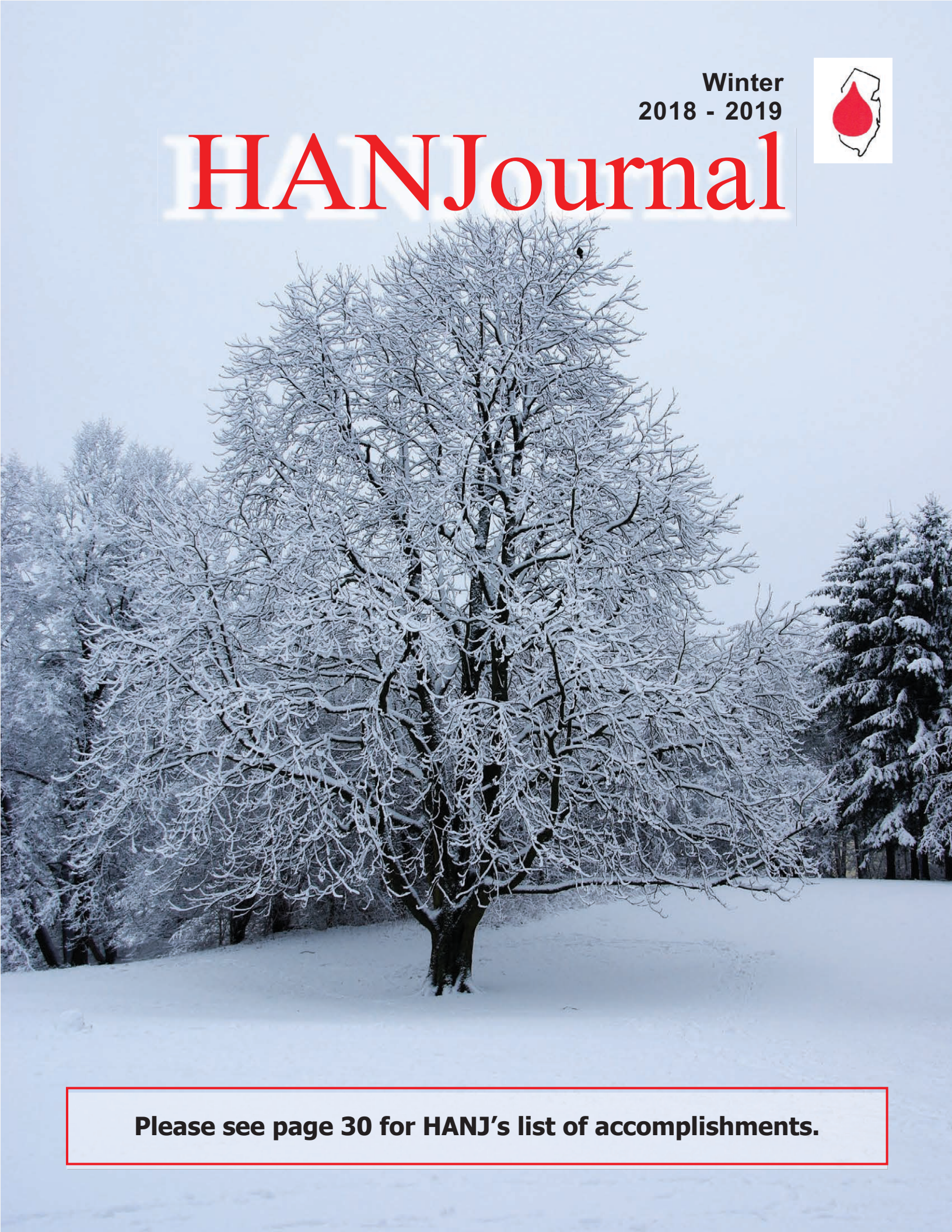
Winter
2018 - 2019

HANJournal



Please see page 30 for HANJ's list of accomplishments.

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.

Messag Presid Joe Ma

There are a lot of exciting a underway at HANJ.

Most of you probably receiv about the quality of service care/specialty pharmacy pr forts of HANJ many years a the State mandates that ho nies meet strict standards i in NJ. For instance, they mu pharmacy located in the sta we get prompt treatment w quired. However, this does insured companies, which r Jersey business. As a result HANJ is back at it! We have directed specifically to spec infusion providers. If our bil infusion provider must mee if they wish to operate in th

If we can get enough intere teen program. The teenage even without hemophilia, a our younger members will s ing a social community. Ou (more than one) to get our and functions have failed. I pursuing this, or would like this off the ground, please

As I wrote in earlier newsle munity is finally realizing th and substantial, depression members who suffer with c been recognized by the CD issues are prominent across ethnic groups, all genders i has started discussions with gist with experience in both ic medical issues to see how rience. We haven't determi ics of this program, but we portant.

As always, we need your in are working on are the thin to you. We're YOUR Hemop us know how we can make

Best Regards,
Joe

HANJournal is published by the
Hemophilia Association of NJ
197 Route18 So. Suite 206 North
East Brunswick, NJ 08816.

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

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.

See what's in this Issue: :

Social Worker Upda
By Neidy Olarte, MS
Social Service Coor

Happy New Year! this new year, I w everyone of the p available through sociation of New would like more i programs below, our website at ww reach out to us d

Medical Insuranc

The Hemophilia Ass offers insurance as in the bleeding disc are diagnosed with philia B or von Will who have no insura surance, or cannot current health insu surance Grant Prog assistance as well a pays and deductibl ance through your cannot afford your will be able to assis the guidelines of th note that this progr **last resort** and if y ance through other caid or other qualif grams, this may di ing covered throug Program. Individua bleeding disorders tance through our gram. If you have ing the Medical Ins or the Patient Serv feel that you or you for any of these pr us at the office.

Patient Services

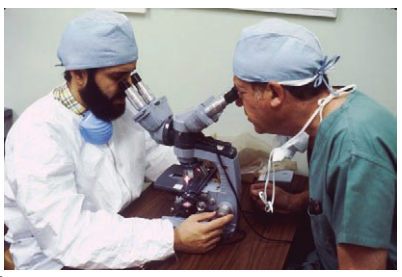
The Patient Service assistance to those hardship and are in assistance. In orde tance to this progra hausted all other re closely with your S Hemophilia Treatm

WHAT'S HAPPENING

New Jersey Hemophilia Treatment Centers

Rutgers Robert Wood Johnson Medical School Hemophilia Treatment Center

Rutgers RWJ Medical School 340B Program:
In order for the hemophilia program to maintain comprehensive hemo- philia care in an era of increasing health care costs amidst dwindling levels of federal and state funding of hemophilia programs, the Rutgers Robert Wood Johnson Medical School Hemophilia Treatment Center is a 340B covered entity. Participation in the federal 340B program makes it possible for our HTC to continue to serve the hemophilia community with the high level of services and quality of care it expects. If you have questions about this program, please do not hesitate to contact the HTC directly at 732-235-6533.



Studies:
Currently, the HTC is participating in 2 studies: 1) TAURUS: A Multinational Phase IV Study Evaluating "Real World" Treatment Pattern in Previously Treated Hemophilia A Patients Receiving KOVALTRY (Octocog alfa) for Routine Prophylaxis and 2) A Multicenter Phase 2 Open-Label, Single-Arm, Prospective, Interventional Study of Plasma-Derived Factor VIII/VWF (Alphanate®) in Immune Tolerance Induction Therapy in Subjects with Congenital Hemophilia A. A third study for women with Type 1 Von Willebrands disease is upcoming. If you are interested in or have questions regarding these studies, please call the HTC.

School & Camp Visits:
The staff at the HTC continues to provide in-service programs to school and camp personnel about a child's hemophilia. If you are in need of an in-service program at your child's school, please contact Lisa Cohen, MSW at 732-235-6533. *Please contact Lisa ASAP, as the slots for these visits fill up very quickly!*

Ongoing Training :
The staff at the HTC continues to provide hands-on training on infu- sion procedures to parents and their children. A series of thirty minute sessions are held over a period of weeks/months depending on the family's needs, abilities and schedule. Please call Frances Maceren, RN at 732-235-6542, if you are interested in arranging infusion training.

General Information:
For information regarding women with bleeding disorders and/or a family history of hemophilia, clinical trials, genetic counseling, insurance issues, educational sessions or school visits, please call the **Hemophilia Treatment Center at 732-235-6531.**

Newark Be Medical Ce Children's H New Je

Happy Winter from t prehensive Hemophil at Newark Beth Isr and Children's Hospit We are happy to sha est news from our tre

Staff News:
We wanted to form Dr. Kamalakar, who Director of the HTC a el Medical Center s 1999, has retired, been promoted to HTC.

NEWS
Holiday Party:
Our HTC's Annual Ho on Saturday Decemb to 200 patients and were in attendance. gave families an op each other and to sp with great food, a D painting and a visit fr had staff from both Gang Camp an HANJ in attendance.

UPCOMING
Hemophilia Camp:
Camp applications wi Last year, we had tend a hemophilia ca H Ranch or Hole in th Camp can be an int tient's journey tow Camp applications a first serve basis, so i waitlisted, please co tions in a timely m

also offer family prog information about ca

is interested in atten our Social Worker, Er

Scholarships:
Keep an eye out for ships which will soon be

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 Erica, our Social Worker.** Erica will make sure that we have a release on file, and will coordinate your needs with the school and schedule a visit. **If you will need any forms or letters for your child's school or daycare center, please be mindful that it may take up to two weeks for forms or letters to be completed.** For more information, please contact us at the HTC.

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 us at the HTC.

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

St. Michael's Medical Center

Medic Alert Bracelets:
It is very important that our patients carry medical information with them at all times. We advise our patients not only to have emergency cards with their medical information but medical bracelets, necklaces and or dog tags, are also very important in case of an emergency. If you are in need of one

or are interested in re
information, please ca
Research Institute at
5340 for more inform

Patient Education:
Our patients are alwa
questions about New
Insurance updates. If
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us a call and we will p
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call Dominique Josep
877-5340 or Joanne
Worker at (973) 877-

Education:
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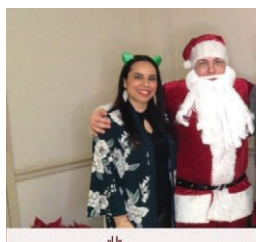

time gripping a golf club. My hands were very tiny. It felt weird. He taught me and others the fundamentals of a good grip or hold. I also learned from him golf etiquette and rules. I know there are more terms but I am still learning the sport. And I am having fun! I did my research and discovered that golf is one of the safest sports to participate in. Despite my hemophilia, being involved in sports has really helped me with my self-esteem and self-confidence. Playing golf is safe and to be honest really calms down my mother, who can be very over protective at times. I also learned teamwork and how to win and lose. It was an honor to see Mr. Parker again in Phoenix last month. Thank you HANJ for nominating me for this opportunity."

Being involved in sports helps develop strong muscles, and protects Omar's joints and less chances of having bleeds. Golf provides Omar with the valuable life skills, such as perseverance, patience, respect, and great memories.

It was a proud moment for me to see him interact with other participants and learn the importance of staying active, staying in shape and being diligent with their treatments.

My He

As a woman, can you
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mophilia? Yes, that's

Whenever I talked
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same time. Again, I sim

Up until my diagno
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mom, I never thoug
thing or anyone els
had to take care of m
take care of Omar.

My son's diagnosis was confirmed at birth. I was diagnosed at age 39 when I lived in Miami Florida. I guess I didn't focus on myself and focused on spending all my energy and time and pretty much understanding and managing my son's condition and not mine. The thought that I might be more than just a carrier never entered my mind. Some of the signs are easy bruising, frequent nosebleeds, heavy menstrual periods, and prolonged bleeding at the end of any surgery.

There are women in our community that may suffer from an overlooked bleeding disorder themselves. It is so crucial that we help raise awareness and educate these families on the importance of receiving an accurate diagnosis. It is important for women to be resilient and realize that they are not alone. I learned to find my silver lining. No doubt, having a bleeding disorder has a major impact in my life and for those who are part of my life.

While managing a bleeding disorder may seem overwhelming at times, I look at the opportunities that continue to be available to the bleeding disorders community. This has helped me build confidence, foster relationships, and strengthen my family in very special and meaningful ways. I listen to many stories of some of the challenges others face in the community and have found this diagnosis does not define who they are and how they relate to others.

In essence, more education is needed because women are still being misdiagnosed. And, there are women out there who are having a poor quality of life and bad bleeds. I think it's crucial that you visit your HTC, your primary, or physical therapist, it is up to you, however seek help as soon as possible… please.

I might not have been tested, and I might not have been diagnosed. There's a lot of power in talking—so ladies, don't be embarrassed to talk about any symptoms you're experiencing. We spend a lot of time advocating for our children and our families, but we also need to take some time to advocate for ourselves. Know your rights, know yourselves, advocate for yourselves, and get tested! We now know that many carriers do experience symptoms of hemophilia. As our knowledge about the disorder has increased, so has our understanding of why and how women can be affected.

As a tribute to my father (severe hemophilia-passed in 1992), my son Omar, and misdiagnosed or undiagnosed women everywhere, it is my mission to raise awareness for hemophilia and other bleeding disorders. My goal is to inform as many people as possible about this condition. My quality of life is good because I manage my hemophilia and I maintain an active lifestyle without serious problems. I travel quite frequently for work and for leisure with my family. I realize that this chronic health condition does not define me, but rather has made me stronger.

Ladies, some of the things that I've done to manage my hemophilia, as well as my son's, is education. Learn as much as you can about this specific condition. Also, avoid any prescription and over-the-counter medications, such as aspirin. If you need help with medical care, talk to your physician, talk to your hematologist. Ask questions. Take care of yourself with exercise and a healthy diet. And, wear your Medic Alert bracelet!

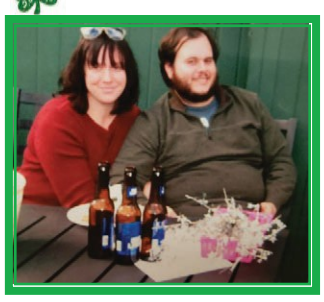
Thank you!
To everyone who supported
26th Annual
Kelly Brother's Scholarship Benefit
In Memory of Bob and Dennis
October 13, 2018













Casino Night
October 27, 2018
at the
Pines Manor
Edison NJ

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The Access to Marketplace Insurance Act: Allowing Charities Be Charitable

By PSI, Mandy Herbert & Jim Romano

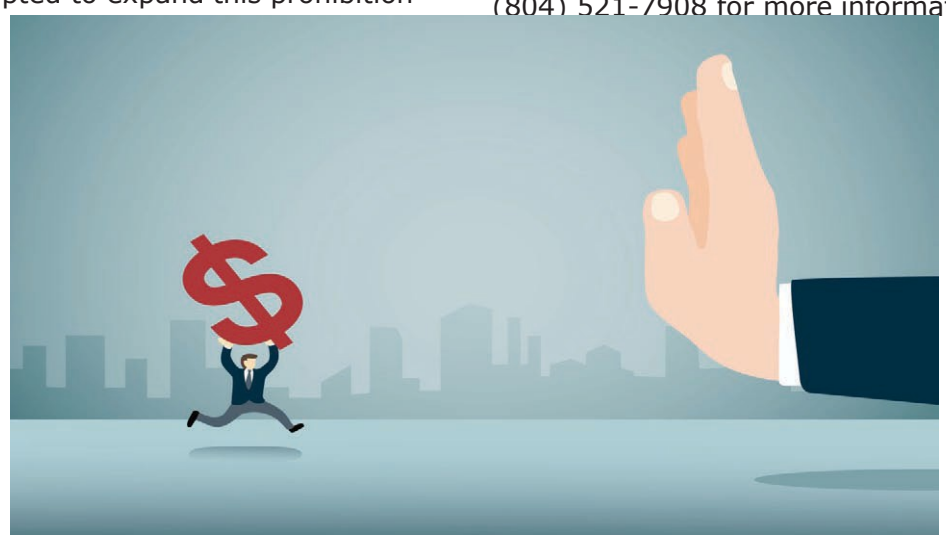
Reprinted with permission from Comprehensive Health Education Services (CHES) www.ches.education

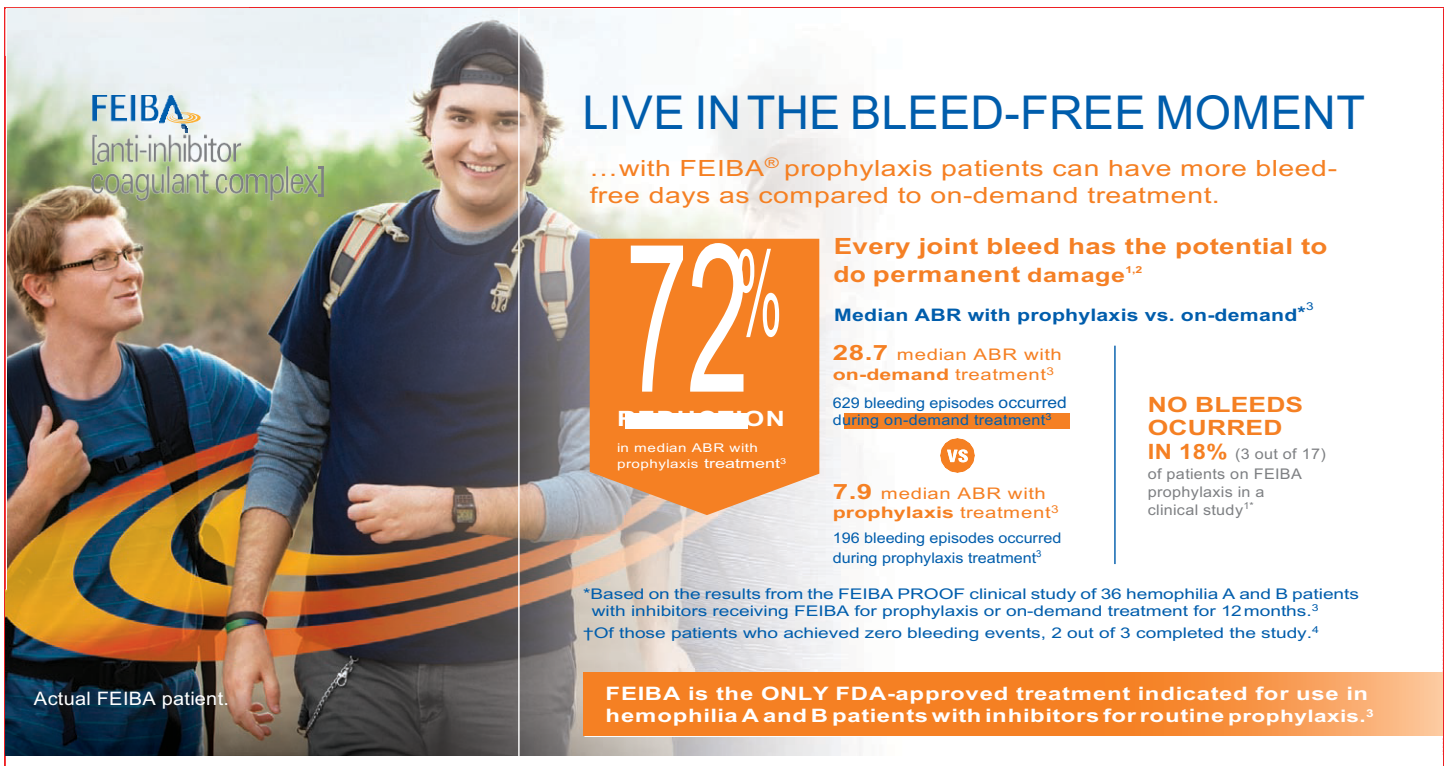
Patient Services Incorporated (PSI) is leading the effort to pass H.R. 3976, The Access to Marketplace Insurance Act, and protect the valued safety net of patient assistance. This legislation is in response to a regulation issued in 2014, during the implementation of the Affordable Care Act (ACA), that **allowed Marketplace insurance companies to deny charitable third-party premium and cost-sharing assistance.** The rule essentially provided a permission slip to health insurance providers to prohibit assistance by charities looking to help patients in need in order to shift sicker patients off their plans.

Since 2014, the impact of this regulation has been considerable, with approximately 90 insurance plans in 43 states having implemented the prohibition. This rule allows insurers to evade the reforms of the ACA removing the pre-existing condition exclusions and provides an open route to discriminate against patients with higher healthcare costs simply because they receive assistance. Taking these discriminatory practices, a step further, health insurance providers have also attempted to expand this prohibition into other markets including the Medicare Supplemental Insurance Market.

In response to this misguided policy, PSI created the Marketplace Access Program (MAP) coalition to bring together leading patient advocacy groups and patient assistance organizations dedicated to protecting charitable assistance for individuals suffering from chronic and life-threatening illnesses. The focal point for our coalition's work is **H.R. 3976, federal legislation that would require insurers to accept assistance from non-profits,** places of worship, and local civic organizations. PSI has worked closely with H.R. 3976's sponsor, Congressman Kevin Cramer (R-ND), to develop this legislation and stop this harmful policy from continuing.

We have made great progress on the bill, garnering over 130 cosponsors since introduction in October. **However, if we have any chance of passing this needed legislation, we need patients and other stakeholders who care about patient assistance to make their voices heard.** PSI would welcome any assistance from readers who would like to get involved. If interested, please contact PSI at jromano@uneedpsi.org or (804) 521-7908 for more information.





FEIBA [Anti-Inhibitor Coagulant Complex]

Indications and Detailed Important Risk Information for Patients

Indications for FEIBA

FEIBA is an Anti-Inhibitor Coagulant Complex approved for use in hemophilia A and B patients with inhibitors for:

- Control and prevention of bleeding episodes
- Use around the time of surgery
- Routine prophylaxis to prevent or reduce the frequency of bleeding episodes.

FEIBA is NOT for use in the treatment of bleeding episodes resulting from coagulation factor deficiencies without inhibitors to factor VIII or factor IX

Detailed Important Risk Information for FEIBA

WARNING: EVENTS INVOLVING CLOTS THAT BLOCK BLOOD VESSELS

Blood clots that block blood vessels and their effects have been reported during post-marketing surveillance following infusion of FEIBA, particularly following administration of high doses (above 200 units per kg per day) and/or in patients at risk for forming blood clots.

If you experience any of these side effects, call your doctor right away.

Who should not use FEIBA?

You should not use FEIBA if

- You had a previous severe allergic reaction to the product
- You have Disseminated Intravascular Coagulation (DIC), or signs of small blood vessel clots throughout the body
- You have sudden blood vessel clots or blocked blood vessels, (such as, heart attack or stroke)

What other important information should I know about FEIBA?

Events involving blood clots blocking blood vessels (such as blood clot in vein, blood clot in the lung, heart attack, and stroke) can occur with FEIBA, particularly after receiving high doses (above 200 units per kg per day) and/or in patients with risk factors for clotting.

Events of thrombotic microangiopathy (TMA), a condition where blood clots and damage occur in small blood vessels, were reported in an emicizumab (Hemlibra®) clinical trial where patients received FEIBA with emicizumab as part of a treatment plan for breakthrough bleeding. The safety and efficacy of FEIBA for breakthrough bleeding in patients receiving emicizumab has not been established. If you take, or anticipate taking, FEIBA with emicizumab, tell your doctor, since they will need to closely monitor you.

At first sign or symptom of a sudden blood vessel clot or blocked blood vessel (such as chest pain or pressure, shortness of breath, fever, altered consciousness, vision, or speech, limb or abdomen swelling and/or pain), stop FEIBA administration right away and seek immediate emergency medical treatment.

nfusion of FEIBA should not exceed a single dose of 100 units per kg body weight and daily doses of 200 units per kg of body weight. Maximum injection or infusion rate must not exceed 2 units per kg of body weight per minute.

Allergic reactions, including severe, sometimes fatal allergic reactions that can involve the whole body, can occur following the infusion of FEIBA. Stop using FEIBA promptly and call your doctor or get emergency treatment right away if you get a rash, hives or welts, experience itching, tightness of the throat, vomiting, abdominal pain, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.

Because FEIBA is made from human plasma it may carry a risk of transmitting infectious agents, such as viruses, variant Creutzfeldt-Jakob disease (vCJD) and, theoretically, the Creutzfeldt-Jakob disease (CJD).

What are the possible side effects of FEIBA?

The most common side effects observed during the prophylaxis clinical study were low number of red blood cells, diarrhea, bleeding into a joint, positive test for hepatitis B surface antibodies, nausea, and vomiting.

The serious side effects seen with FEIBA are allergic reactions and clotting events nvolving blockage of blood vessels, which include stroke, blockage of the main blood vessel to the lung, and deep vein blood clots.

Call your doctor right away about any side effects that bother you during or after you stop taking FEIBA.

What other medications might interact with FEIBA?

Talk with your doctor about the possibility of formation of blood clots when taking drugs that may prevent clot breakdown such as tranexamic acid, and aminocaproic acid. There have not been adequate studies of the use of FEIBA and rFVIIa (NovoSeven®), or emicizumab together, or one after the other. Use of drugs that may prevent clot breakdown within approximately 6 to 12 hours after the administration of FEIBA is not ecommended

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.

Please see next page for Important Facts about FEIBA.

Please see accompanying FEIBA full Prescribing Information, including BOXED WARNING on blood clots, and discuss with your doctor.

References: 1. Pergantou H, Matsinos G, Papadopoulos A, Platokouki H, Aronis S. Comparative study of validity of clinical, X-ray and magnetic resonance imaging scores in evaluation and management of haemophilic arthropathy in children. Haemophilia. May 2006;12(3):241-247. **2** Gringeri A, Ewenstein B, Reininger A. The burden of bleeding in haemophilia: is one bleed too many? Haemophilia. Jul 2014;20(4):459-463. **3** FEIBA Prescribing Information. **4.** Antunes SV, Tangada S, Stasyshyn O, et al. Randomized comparison of prophylaxis and on-demand regimens with FEIBA NF in the treatment of haemophilia A and B with inhibitors. Haemophilia. 2014;20(1):65-72.

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Important Facts about FEIBA®

What is FEIBA used for?

FEIBA (Anti-Inhibitor Coagular
episodes, around surgery, or rou
without inhibitors to Factor VI

When should I not take F

You should not take FEIBA if you
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What Warnings should I

**FEIBA can cause blood clots, in
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Allergic reactions, including se
of FEIBA. Stop using FEIBA pro
experience itching, tightness of t
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Because FEIBA is made from hu
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What should I tell my hea

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What are the side effects

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What other medications

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Warnings Should I Know abo

**You are encouraged to report
www.fda.gov/medwatch,**

**The risk information provide
pharmacist. The FDA-app**

http://www.feiba.com/us/

S39632 07/18

It's Easy! How We Can Report an Adverse Event

by Jane Cotter Forbes
Reprinted with permission from Comprehensive Health Education Services (CHES)
www.ches.education

There are many medications for people with bleeding disorders in the marketplace today and our pipelines are bursting with new therapies and medications.

Some medications have been available for many years while others are newly FDA approved. If you or your loved ones experience a serious adverse event (AE) while using a bleeding disorders medication, it is always a good idea to voluntarily report an AE to the Food and Drug Administration (FDA) MedWatch consumer voluntary reporting program.

AE's should be reported as soon as possible to MedWatch using Form FDA 3500B by those who are consumers and medical personnel for the following situations: death, life-threatening medical events (e.g., anaphylactic reactions), AEs that require hospitalization (short or long term), disability or permanent damage, congenital anomaly and/or birth defect, and any required medical intervention to prevent permanent impairment (e.g., hemorrhage). If you are not sure if the AE is related to the medications you are using, it still is a good idea to voluntarily submit a report to MedWatch just in case. Mandatory reporting is required by law by user-facilities, importers, distributors, and manufacturers. AE's for these organizations need to be reported to MedWatch within 24–48 hours.

In considering the filing of a voluntary report for an AE to the FDA, here are some points for guidance!

IT IS EASY. First you go directly to the FDA MedWatch website [https://www.accessdata.fda.gov/scripts/medwatch/index.cfm?action=reporting.home] and click on form 3500B. Then you start filling in the blanks. When you are done, you hit send. In particular, the website asks for a lot number, an NDC number, the strength, the units, and the quantity (how many doses or vials of the medication were used). Most of this information can be found from the container of the medication and/or on the prescription label. The website asks for a detailed description of the AE or serious problem as well as any and all medical reports (if available). You will need to include a list of all other medications in use. This website also suggests not throwing the medication away because the FDA may request what remains for further inspection.

In addition, medication that comes with faulty equipment or devices such as needle breaking or ineffective transfer device to be reported. If you are not able to use the website addressed herein, you are free to call the FDA at 1-800-FDA-1088 in order to file a report. "The FDA encourages patients to report AEs as soon as possible. If the AE team gets a cluster of reports about the same drug in a short period of time, it will be able to respond more quickly." **IT TAKES ONLY A FEW MINUTES.** Depending on the details of what you submit and the explanation of the AE, it will mostly likely take only 10 to 15 minutes to complete.

IT IS IMPORTANT. It is the fundamental way by which American people can alert the FDA of any and all AEs after having taken a pharmaceutical medication. This information is gathered, reviewed, analyzed, and a determination is readily made if further action is needed. All AE reports are kept in the FDA database.

IT IS APPRECIATED. The FDA truly welcomes this information, for it provides ready and immediate feedback

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SO WHAT HAPPENS
PORT IS FILED?
The FDA reviews all
MedWatch reports fo
similar adverse even
particular drug. Som

- A new serious AE
  in the drug's pac

Examples of AEs:

- confusion
- debilitating migrain
- TMA (Thrombotic
- Microangiopathy)
- stroke
- syncope
- seizures
- swelling in extremit
- chest pain

What is HEMLIBRA?

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

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

HEMLIBRA increases the potential for your blood to clot. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent or factor VIII, and the dose and schedule to use for breakthrough bleed treatment. HEMLIBRA may cause serious side effects when used with activated prothrombin complex concentrate (aPCC; FEIBA®), including thrombotic microangiopathy (TMA), and blood clots (thrombotic events). If aPCC (FEIBA®) is needed, talk to your healthcare provider in case you feel you need more than 100 U/kg of aPCC (FEIBA®) total.

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

HEMLIBRA
emicizumab-kxwh
injection for subcutaneous use | 150 mg/mL

Medication Gu
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kx
injection, for

What is the most important information I

HEMLIBRA increases the potential for y
healthcare provider's instructions regard
bypassing agent or factor VIII (FVIII) and t
use for breakthrough bleed treatment.

HEMLIBRA may cause the following seric
prothrombin complex concentrate (aPC

- **Thrombotic microangiopathy (TMA)**
  and injury to small blood vessels tha
  and other organs. Get medical help ri
  signs or symptoms during or after tr
  – confusion
  – weakne
  – swelling of arms and l
  – yellowing of skin and e

- **Blood clots (thrombotic events).** Bloo
  arm, leg, lung, or head. Get medical h
  signs or symptoms of blood clots duri
  – swelling in arms or leg
  – pain or rednessin your
  arms or legs
  – shortnes
  – chest pain or tightness
  – fast hear

If aPCC (FEIBA®) is needed, talk to your hea
more than 100 U/kg of aPCC (FEIBA®) tota

See "**What are the possible side effects o**
information about side effects.

What is HEMLIBRA?

HEMLIBRA is a prescription medicine used
reduce the frequency of bleeding episod
and older, with hemophilia A with or with

Hemophilia A is a bleeding condition pe
or faulty blood clotting factor (factor VIII
normally.

HEMLIBRA is a therapeutic antibody that
blood clot.

Before using HEMLIBRA, tell your health
conditions, including if you:

- are pregnant or plan to become pregn
  harm your unborn baby. Females who
  birth control (contraception) during tr
- are breastfeeding or plan to breastfee
  into your breast milk.

Tell your healthcare provider about all
prescription medicines, over-the-counte
supplements. Keep a list of them to show
pharmacist when you get a new medicin

How should I use HEMLIBRA?

See the detailed "Instructions for Use"
information on how to prepare and inj
properly throw away (dispose of) used n

- Use HEMLIBRA exactly as prescribed
- **Stop (discontinue) prophylactic use o**
  starting HEMLIBRA prophylaxis.
- **HEMLIBRA prophylaxis.**
- HEMLIBRA is given as an injection und
  injection) by you or a caregiver.
- Your healthcare provider should show
  prepare, measure, and inject your dos
  yourself for the first time.

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 Joe Markowitz (Joe.Markowitz@gmail.com, 201-650-0335) or Peter Marcano (petermarcano@gmail.com, 201-401-7080) or HANJ directly.

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

DONATE! DONATE! DONATE!

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

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

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

Name:_____

Address:_____

City:_____ **State:**_____ **Zip:** _____

Phone: Cell/Home : _____

Amount of Donation: _____

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

HANJ Pha
We partner wit

**On January 2
HANJ partner
Pfizer to pres
"Planning Ah
and Hemophi
program was
ano's in Rahw**

*ADYNOVATE allows you to infuse on the same 2 days every week. Work with your doctor to determine an infusion schedule that is appropriate for you.

The pediatric study of children <12 years of age (N=66) evaluated the immunogenicity, efficacy, PK (as compared to ADVATE® [Antihemophilic Factor (Recombinant)]), and safety of ADYNOVATE twice-weekly prophylaxis (40-60 IU/kg) and determined hemostatic efficacy in the treatment of bleeding episodes for 6 months.[1,2]

The pivotal trial of children and adults ≥12 years (N=137) evaluated the efficacy, PK, and safety of ADYNOVATE twice-weekly prophylaxis (40-50 IU/kg) vs on-demand (10-60 IU/kg) treatment, and determined hemostatic efficacy in the treatment of bleeding episodes for 6 months.[1]

+Children (<12 years) experienced a median overall ABR of 2.0 (IQR: 3.9) and a median ABR of zero for both joint (IQR: 1.9) and spontaneous (IQR: 1.9) bleeds[1,3]

+38% (n=25) of children (<12 years) experienced zero total bleeds; 73% (n=48) experienced zero joint bleeds; and 67% (n=44) experienced zero spontaneous bleeds[1]

Talk to your doctor to see if ADYNOVATE treatment may be right for you and visit **ADYNOVATE.com**

ADYNOVATE [Antihemophilic Factor (Recombinant), PEGylated] Important Information

What is ADYNOVATE?

- ADYNOVATE is an injectable medicine that is used to help treat and control bleeding in children and adults with hemophilia A (congenital Factor VIII deficiency).
- Your healthcare provider (HCP) may give you ADYNOVATE when you have surgery.
- ADYNOVATE can reduce the number of bleeding episodes when used regularly (prophylaxis).

ADYNOVATE is not used to treat von Willebrand disease

DETAILED IMPORTANT RISK INFORMATION

Who should not use ADYNOVATE?

Do not use ADYNOVATE if you:

- Are allergic to mice or hamster protein
- Are allergic to any ingredients in ADYNOVATE or ADVATE [Antihemophilic Factor (Recombinant)]

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

What should I tell my HCP before using ADYNOVATE?

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 ADYNOVATE passes into your milk and if it can harm your baby.
- Are or become pregnant. It is not known if ADYNOVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADYNOVATE may not work for you).

What important information do I need to know about ADYNOVATE?

- You can have an allergic reaction to ADYNOVATE. 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.
- Do not attempt to infuse yourself with ADYNOVATE unless you have been taught by your HCP or hemophilia center.

What else should I know about ADYNOVATE 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 ADYNOVATE 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 ADYNOVATE?

- The common side effects of ADYNOVATE are headache and nausea. These are not all the possible side effects with ADYNOVATE. Tell your HCP about any side effects that bother you or do not go away.

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

For additional safety information, please see Important Facts about ADYNOVATE on the following page and discuss with your HCP.

For full Prescribing Information, visit www.ADYNOVATE.com.

References: 1 ADYNOVATE Prescribing Information. **2** Mullins ES, Stasyshyn O, Alvarez-Román MT, et al. Extended half-life pegylated, full-length recombinant factor VIII for prophylaxis in children with severe haemophilia A. *Haemophilia*. 2017;23(2):238-246. **3** Data on file

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Patient Important

ADYNOVATE [Antihemophili

This leaflet summarizes imp
ADYNOVATE. Please read
medicine. This information c
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the important information abo
questions after reading this,

What is the most important i about ADYNOVATE?

Do not attempt to do an infusio
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You must carefully follow yo
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What is ADYNOVATE?

ADYNOVATE is an injectable
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Who should not use ADYNOV

You should not use ADYNOV

- Are allergic to mice or han
- Are allergic to any ingredien [Antihemophilic Factor (R

Tell your healthcare provider
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How should I use ADYNOVA

ADYNOVATE is given directl

You may infuse ADYNOVATE
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THE HEMOPHILIA ASSOCIATION OF NEW JERSEY

Much has been learned in the nearly 46 years since the incorporation of the Hemophilia Association of New Jersey. One recurring theme has been that some of the best opportunities surface when times are seemingly at their most uncertain. This was true in the seventies with the creation of the first State Hemophilia Program in the nation; in the eighties with the passage of Hemophilia Insurance Legislation which eliminated lifetime limits; and again in the nineties with the enactment of Hemophilia Standards of Care. Persons with Hemophilia who reside in New Jersey know that in HANJ they have an organization that can respond. Individuals with hemophilia nationwide have come to understand that as well.

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

The value of HANJ is built upon the commitment of its people, and the relationships developed, over time, with leaders in all fields pertinent to hemophilia. This has included medical professionals, insurance industry representatives, pharmaceutical manufacturers, legislators, regulators, and, of course, consumers. We have created a pool of experts from different disciplines to draw upon when comprehensive solutions are needed. Our challenge has been to preserve policies that work, try to make them work better, and be relentless about anything viewed as detrimental to the health and well-being of persons with hemophilia. In order to be effective, consumers, and their representatives must be informed, present, and engaged. We seek to impart the lessons we have learned to others representing the hemophilia community. The whole can only be as strong as the sum of its parts.
A brief synopsis of our history follows:

Meeting the challenges since 1971

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

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

1976 Federal funding for NJ treatment centers obtained.

1981 HANJ legislative effort leads to major medical open enrollment.

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

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

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

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

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

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

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

2000 HANJ Standards of C
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2003 HANJ pursues an Ex
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HANJ VIRTUAL
TURKEY TROT

Celebrating!

DENNIS KEELTY

40TH ANNIVERSARY
2019

Dennis Keelty

MEMORIAL CLASSIC GOLF TOURNAMENT

To Benefit
The Hemophilia Association of New Jersey
Monday June 17, 2019
Plainfield Country Club