Spring
2017

HANJournal

BDRN & HANJ

340B Bleeding Disorders Program

In association with:

Rutgers: Robert Wood Johnson Medical School

BDRN HANJ

Pharmacy Services In Your Hands

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.

Message from the President of HANJ

We are already off to an exciting year at HANJ and with warmer weather approaching we will continue to offer many opportunities for our community to get together. Our first membership event was our annual Testimonial Dinner where we honored an individual that has dedicated their time, effort and service to our community, Sal J. Rafanelli, RPh, CEO/Co-Founder, BiologicTX. Those recognized at the Testimonial Dinner, both past and present, work extremely hard to make sure we are all devoted to improving the lives of those with bleeding disorders. Not only is it important for us at HANJ to recognize them, it is equally important that each of you, that benefit from their efforts, to have the opportunity to recognize them as well. This is why your participation in these events is so critical. I look forward to seeing you.

Other great events where we encourage your participation will be our Gourmet Dinner, Annual HANJ meeting, Dennis Keelty Memorial Golf Tournament and our Casino Night. We understand schedules can be very tight and it may be hard to attend every one. If you cannot attend, you can still support HANJ in other ways by selling tickets and getting the word out to others that would enjoy themselves and feel rewarded by giving to a community that needs their help. Also, our Blood Brotherhood events will have a full schedule again this year and we continue to see increased participation which is great to hear. I will continue to encourage those of you that have not attended to reach out and participate at least once. The information for all of these activities can be found on our website (HANJ.org).

Although we are off to an exciting year and have many great events planned, there are also many areas of uncertainty when it comes to healthcare coverage and benefits for many individuals. We continue to monitor and discuss the changing environment within the healthcare sector and level of insurance coverage. We have on-going discussions with key government officials as well as leaders from our industry partners. Please be assured, we will always be an advocate for our members. Being an advocate requires a strong and unified voice among our community and we will, from time to time, need to call on you for help. I know that we can count on you.

We look forward to seeing old friends and making new ones in 2017. Please remember, if you would like to attend an event and need assistance, please contact the HANJ office. Thank you again and I hope you enjoy the latest HANJ journal.

Dave Lechner
President

If you would like to attend an event and need assistance, please contact the HANJ office.

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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.

Social Worker Update
By Neidy Olarte, MSW
Social Service Coordinator

Healthcare Update

On March 2017, the GOP tried to introduce a bill to repeal The Affordable Care Act (ACA) also known as Obamacare; however, it was pulled by the House Speaker Paul Ryan since it did not get the support needed to move the bill forward. The GOP reintroduced an updated bill on May 4, 2017 and it was passed by the house. The bill will now need to be voted on by the senate and depending on the outcome of that vote, there will be many changes coming in particular for individuals with a pre-existing condition. The repeal of Obamacare is one thing we can expect in the near future, however, it is uncertain how these changes will affect the bleeding disorder community and how fast a replacement will take place. The Association will continue to vigilantly monitor and inform the bleeding community on any changes in healthcare. Our Fall Symposium, which will be held on September 16, 2017, will discuss the most recent updates to the healthcare system and how those changes will affect this community. We will also discuss Medicare and information about the Marketplace. Invitations will go out to our members soon and I hope you will be available to join us for this event. In the meantime, if you have any questions regarding your current insurance plan or have any concerns or changes to your healthcare, please do not hesitate to contact us. We also continue to provide insurance assistance as well as co-pay assistance to those who qualify. For more information on the insurance grant program, contact us at the office at (732) 249-6000.

Pharmaceutical Assistance Programs

This is a reminder if you have commercial insurance and have not yet applied for the factor assistance programs offered through your product pharmaceutical company; please do so as soon as you can. You must enroll every year so even if you have applied for these programs in the past you will still have to renew your application. There have been many changes with insurance plans for employer insurance as well as plans purchased through the marketplace. Your pharmaceutical company may offer co-pay assistance to relieve some of the financial burden related to higher deductible and over all out of pocket costs. If you have received a large bill from your homecare company, do not ignore the bill. Contact the pharmaceutical company of the factor you use and your bill will most likely be paid in full. To find out if you qualify for this assistance you can contact either your pharmaceutical company directly, homecare company, hemophilia treatment center or you can contact us for more information. A complete list of Pharmaceutical Assistance Programs is included in this newsletter or you can contact us or log onto our website www.hanj.org for a full list of programs available.

Educational Symposium

HANJ's Spring Symposium was held on Saturday, March 25, 2017 at the Clarion Hotel & Conference Center in Toms River, NJ. Sonji Wilkes from the Hemophilia Federation of America (HFA) presented on Adversity, Challenge, Not a Problem; where she discussed advocacy and the many

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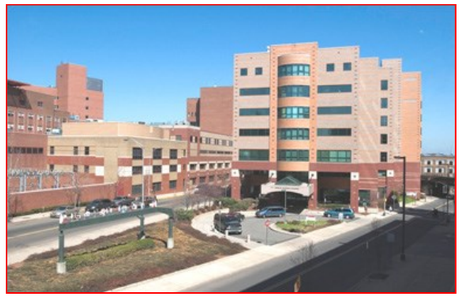
WHAT'S HAPPENING
New Jersey Hemophilia Treatment Centers

Rutgers Robert Wood Johnson Medical School Hemophilia Treatment Center



Rutgers RWJ Medical School 340B Program: In order for the hemophilia program to maintain comprehensive hemophilia 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 has become a 340B covered entity as of October 1, 2015. 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.

Educational & Programming Events: The HTC recently hosted an infusion training program. If you or your child were unable to attend this event, please do not hesitate to call the HTC to set up individual infusion training sessions (see contact information below).

School Visits: The staff at the HTC continues to provide in-service programs to school personnel about a child's hemophilia. If you are in need of an in-service program at your child's school or camp, please contact Lisa Cohen, MSW at 732-235-6533. *Please do not wait to contact Lisa, as the slots for these visits fill up very quickly during this time of year!*

Ongoing Training: The staff at the HTC continues to provide hands-on training in infusion procedures to parents and their children. A series of thirty minute sessions are held over a period of weeks/months depending on the families' 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 Beth Israel Medical Center and Children's Hospital of New Jersey

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 current programs and plans with you.

NEWS

Hemophilia 340B Program: We are excited to announce that 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 your healthcare coverage, patients have a variety of pharmacy options to choose from. Our HTC has contracted with four different home care companies; Accredo, BDRN, Bioscrip, and Option Care. Patients who are not currently using one of these four 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.

My Life Our Future Carrier Testing: The My Life Our Future program has been providing patients with hemophilia the opportunity to determine the genotype of their hemophilia. The program has now expanded to offer genotyping to potential and known carriers of hemophilia. The carrier testing will be available, for female family members of current participants of My Life Our Future, through the end of 2017. Please contact the HTC for more information.

Hemophilia Camp: Last year, we had several children attend a hemophilia camp at either Double H Ranch or Hole in the Wall Gang Camp. Camp applications are on a first come first serve basis, so in an effort to not be waitlisted, please complete your applications in a timely manner. Those who attended had a fabulous time and many are looking forward to returning this year. Both camps also offer family programming. Children that have attended camp, and their families, would be happy to share their camp experiences with potential campers or parents. For more information about camp, or if your child is interested in attending next year, please contact our Social Worker Erica at the HTC.

Scholarships: Scholarships are now available. Please be mindful of the deadlines to submit the applications and the eligibility criteria for each scholarship. Also, please remember

to complete your FAFSA forms as early as possible to secure available funds. If you have any questions about scholarships, internships, or coordinating your care away from home please contact us.

ONGOING PROGRAMS

School Visits:
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. 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 by ATHN to improve the health of people with coagulation disorders. Patients with hemophilia can also participate in My Life Our Future to determine the genotype of their hemophilia. **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.**

Manufacturer Factor Programs:
Manufacturers of clotting factor products have programs available to help patients continue to receive factor 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.

Diagnosis Specific Programs:
Educational programs can be arranged for patients focusing on specific diagnoses such as hemophilia, von Willebrand disease, and thrombophilia for example. Sessions can cover topics such as living with the disorder, the genetics and testing of family members, nutrition, treatment options, and an overview of the disorder. Sessions can also cover other topics that are of interest to the participants. Please contact us at the HTC, if you are interested, to schedule a program.

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

St. Michael's Medical Center

School Visits:
The end of the school year is quickly approaching but we are here to help with any school related issues. For those who will be graduating this year, we can provide information on scholarships. Please feel free to call Social Worker, Joanne Rodriguez at (973)877-2967 if any questions should arise.

Camp Applications:
April 15, 2016 is the deadline for camp applications. If any of the forms need to be filled out by the doctor, please fax them to us at The Blood Research Institute at (973) 877-5466 for medical completion. Spaces get filled fairly quickly so don't miss out on this wonderful experience this summer. For more information, please feel free to call Social Worker Joanne Rodriguez, at (973) 877-2967.

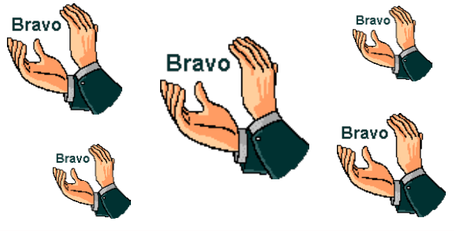
Patient Education:
We planned our Educational session in the month of April. If interested in attending future sessions, feel free to call us at The Blood Research Institute at (973)877-5340 or (973) 877-2967.

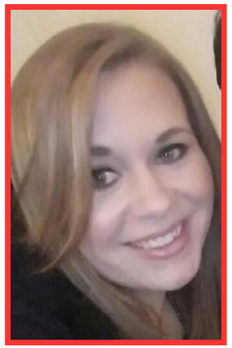
Our patients are always welcome to ask questions about New Therapies and Insurance updates. If any of you have any questions or concerns, please give us a call and we will provide you with the most up to date medical and insurance information. You may call Dominique Joseph, Nurse at (973) 877-5340 or Joanne Rodriguez, Social Worker at (973) 877-2967.

From all of us at St. Michael's Medical Center we hope you all have a wonderful spring. We will continue providing the care that we have provided to our patients for years and hope to continue providing the same care for more years to come.

Continued from page 5 ....
Educational Symposium

ways the bleeding disorder community partakes in advocacy for their families and the community as a whole. In a room not far away, Diane Horbacz, member and educator, presented FUN BLOOD, an interactive program that teaches children about plasma and exploring the components of blood as well as learning about bleeding disorders. Double H Hole in the Woods Camp had their display and answered any questions for families interested in camp. The program was attended by many families and was enjoyed by all who attended.





Meet the Staff…

Meet our Office Manager, Amy LaPorta

Amy graduated with Honors from Kean University with a Bachelor's Degree in English. She comes to HANJ with ten years of management experience. Amy enjoys taking on new challenges and feels that if you put in the time; the results are endless.

Right out of college, Amy spent a brief time working as an account manager in energy sales. From there she started her career working in early childhood education; managing a few preschool centers and holding titles such as Assistant Director and Director. With the desire to move into the healthcare industry she changed her entire focus and career path. Prior to coming to HANJ in January 2017, Amy spent the previous five years in Home Infusion healthcare.

In October of 2011, Amy began her career in home infusion at Bioscrip Infusion Services in Morris Plains, New Jersey. Although infusion therapy was a brand new arena, Amy was able to climb the ladder in a short period of time; obtaining her desired role as Hemophilia Coordinator almost instantly. As a Hemophilia Coordinator, Amy was responsible for patient benefit and insurance verifications, pharmacy claims processing, assay management, maintaining documentation to support Center of Excellence as well as arranging factor deliveries; oftentimes hand-picking patients preferred supplies. After three years in the Hemophilia Coordinator role, Amy was promoted to Supervisor for the Central Intake Department of Bioscrip. This advancement allowed her to broaden her knowledge and understanding of both chronic and acute therapies as well as participate in new company initiatives and pilot programs.

Amy feels she has always tried to be the voice of advocacy for patients and believes that her role with HANJ will allow her to express other forms of advocacy that she has only scratched the surface of. Please feel free to reach out to her at our HANJ office at any time.

Amy, who is one of nine children, truly enjoys the chaos and laughter that a large family brings to her life. She particularly cherishes every free moment she has with her husband John and four-year-old daughter Olivia. They truly are the light of her life and her greatest supporters. Amy also enjoys quality time with friends; particularly brunch dates and beach days!

Mark Your Calendar:

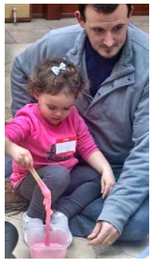
June 19, 2017
Plainfield Country Club
Dennis Keelty
Memorial Golf Classic
To Benefit

The Hemophilia Association of New Jersey
(732) 249-6000

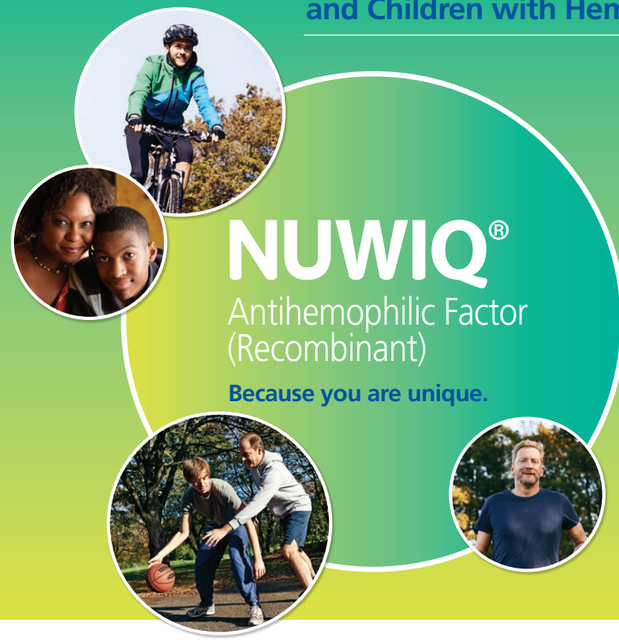
Hemophilia Association of New Jersey's Spring Educational Symposium

March 25th, 2017

Clarion Hotel & Conference Center, Toms River, NJ



For the Treatment of Adults and Children with Hemophilia A



NUWIQ®

Antihemophilic Factor (Recombinant)

Because you are unique.

The First and Only Recombinant FVIII Produced in Human Cells Without Chemical Modification or Protein Fusion[1-4]

For more information, contact your **Octapharma Representative:**

KAREN BOWE

PHONE | 717-395-5887

EMAIL | Karen.Bowe@octapharma.com

Indications and Usage

NUWIQ is a Recombinant Antihemophilic Factor [blood coagulation factor VIII (Factor VIII)] indicated in adults and children with Hemophilia A for on-demand treatment and control of bleeding episodes, perioperative management of bleeding, and for routine prophylaxis to reduce the frequency of bleeding episodes. NUWIQ is not indicated for the treatment of von Willebrand Disease.

Important Safety Information

NUWIQ is contraindicated in patients who have manifested life-threatening hypersensitivity reactions, including anaphylaxis, to the product or its components. The most frequently occurring adverse reactions (>0.5%) in clinical trials were paresthesia, headache, injection site inflammation, injection site pain, non-neutralizing anti-Factor VIII antibody formation, back pain, vertigo, and dry mouth. Development of Factor VIII neutralizing antibodies (inhibitors) may occur.

Please see adjacent page for Brief Summary of Prescribing Information.

References: 1. Sandberg H, et al. Thromb Res 2012; 130:808-817. **2.** Casademunt E, et al.. Eur J Haematol 2012; 89:165-176. **3.** Kannicht C, et al. Thromb Res 2013; 131:78-88. **4.** Valentino LA, et al. Haemophilia 2014; 20:1-9.

Date of preparation: 7/2016. NUW-016-CADr

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HIGHLIGHTS OF PRESCRIBING INFORMATION

These highlights do not include all the information needed to use NUWIQ safely and effectively. See full prescribing information for NUWIQ.

NUWIQ®, Antihemophilic Factor (Recombinant) Lyophilized Powder for Solution for Intravenous Injection
Initial U.S. Approval: 2015

INDICATIONS AND USAGE

NUWIQ is a recombinant antihemophilic factor [blood coagulation factor VIII (Factor VIII)] indicated in adults and children with Hemophilia A for:

- On-demand treatment and control of bleeding episodes
- Perioperative management of bleeding
- Routine prophylaxis to reduce the frequency of bleeding episodes

NUWIQ is not indicated for the treatment of von Willebrand Disease.

DOSAGE AND ADMINISTRATION

For intravenous use after reconstitution

- Each vial of NUWIQ is labeled with the actual amount of Factor VIII potency in international units (IU).
- Determine dose using the following formula for adolescents and adults:

  Required IU = body weight (kg) x desired Factor VIII rise (%) (IU/dL) x 0.5 (IU/kg per IU/dL)
- Dosing for routine prophylaxis:

Subjects	Dose (IU/kg)	Frequency of infusions
Adolescents [12-17 yrs] and adults	30-40	Every other day
Children [2-11 yrs]	30-50	Every other day or three times per week

- Frequency and duration of therapy depends on severity of the FVIII deficiency, location and extent of bleeding, and patient's clinical condition.

DOSAGE FORMS AND STRENGTHS

NUWIQ is available as a white sterile, non-pyrogenic, lyophilized powder for reconstitution in single-use vials containing nominally 250, 500, 1000 or 2000 IU Factor VIII potency.

CONTRAINDICATIONS

NUWIQ is contraindicated in patients who have manifested life-threatening hypersensitivity reactions, including anaphylaxis, to the product or its components.

WARNINGS AND PRECAUTIONS

- Hypersensitivity reactions, including anaphylaxis, are possible. Should symptoms occur, discontinue NUWIQ and administer appropriate treatment.
- Development of Factor VIII neutralizing antibodies (inhibitors) may occur. If expected plasma Factor VIII activity levels are not attained, or if bleeding is not controlled with an appropriate dose, perform an assay that measures Factor VIII inhibitor concentration.
- Monitor all patients for Factor VIII activity and development of Factor VIII inhibitor antibodies.

ADVERSE REACTIONS

The most frequently occurring adverse reactions (>0.5%) in clinical trials were paresthesia, headache, injection site inflammation, injection site pain, non-neutralizing anti-Factor VIII antibody formation, back pain, vertigo, and dry mouth.

USE IN SPECIFIC POPULATIONS

Pediatric Use: Lower recovery, shorter half life and faster clearance in children aged 2 - ≤12 years. Higher doses and/or a more frequent dosing schedule for prophylactic treatment should be considered in pediatric patients aged 2 to 5 years.

PATIENT COUNSELING INFORMATION

Advise patients to read the FDA-approved patient labeling (Patient Information and Instructions for Use).

Because hypersensitivity reactions are possible with NUWIQ , inform patients of the early signs of hypersensitivity reactions, including hives, generalized urticaria, tightness of the chest, wheezing, hypotension, and anaphylaxis. Advise patients to stop the injection if any of these symptoms arise and contact their physician, and seek prompt emergency treatment.

Advise patients to contact their physician or treatment center for further treatment and/or assessment if they experience a lack of clinical response to Factor VIII replacement therapy, as this may be a manifestation of an inhibitor.

Advise patients to consult with their healthcare provider prior to traveling. While traveling, patients should be advised to bring an adequate supply of NUWIQ based on their current treatment regimen.

To report SUSPECTED ADVERSE REACTIONS, contact Octapharma USA Inc. at 1-866-766-4860 or FDA at 1-800-FDA-1088 or www.fda.gov/medwatch.

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New Federal Rules Will Require Home Health Agencies To Do Much More For Patients

By **Judith Graham** February 9, 2017, Kaiser Health News, (KHN) is a nonprofit national health policy news service.

Home health agencies will be required to become more responsive to patients and their caregivers under the first major overhaul of rules governing these organizations in almost 30 years.

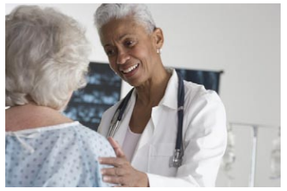
The federal regulations, published last month, specify the conditions under which 12,600 home health agencies can participate in Medicare and Medicaid, serving more than 5 million seniors and younger adults with disabilities through these government programs.

They strengthen patients' rights considerably and call for caregivers to be informed and engaged in plans for patients' care. These are "real improvements," said Rhonda Richards, a senior legislative representative at AARP.

Home health agencies also will be expected to coordinate all the services that patients receive and ensure that treatment regimens are explained clearly and in a timely fashion.

The new rules are set to go into effect in July, but they may be delayed as President Donald Trump's administration reviews regulations that have been drafted or finalized but not yet implemented. The estimated cost of implementation, which home health agencies will shoulder: $293 million the first year and $234 million a year thereafter.

While industry lobbying could derail the regulations or send them back to the drawing board, that isn't expected to happen, given substantial consensus with regard to their contents. More likely is a delay in the implementation date,



which several industry groups plan to request.

"There are a lot of good things in these regulations, but if it takes agencies another six or 12 months to prepare let's do that, because we all want to get this right," said William Dombi, vice president for law at the National Association for Home Care & Hospice (NAHC).

Home health services under Medicare are available to seniors or younger adults with disabilities who are confined to home and have a need, certified by a physician, for intermittent skilled nursing services or therapy, often after a hip replacement, heart attack or a stroke.

Patients qualify when they have a need to improve functioning (such as regaining the strength to walk across a room) or maintain abilities (such as retaining the capacity to get up from a chair), even when improvement isn't possible. These services are not for patients who need full-time care because they're seriously ill or people who are dying.

Several changes laid forth in the new regulations have significant implications for older adults and their caregivers:

Patient-Centered Care

In the past, patients have been recipients of whatever services home health agencies deemed necessary, based on their staffs' evaluations and input from physicians. It was a prescriptive "this is what you need and what we'll give you" approach.

Now, patients will be asked what they feel comfortable doing and what they want to achieve, and care plans will be devised by agencies with their individual circumstances in mind.

"It's much more of a 'help me help you' mentality," said Diana Kornetti, an industry consultant and president of the home health section of the American Physical Therapy Association.

While some agencies have already adopted this approach, it's going to be a "sea change" for many organizations, said Mary Carr, NAHC's vice president for regulatory affairs.

Patient Rights

For the first time, home health agencies will be obligated to inform patients of their rights — both verbally and in writing. And the explanations must be communicated clearly, in language that patients can understand.

Several new rights are included in the regulations. Notably, patients now have a right to receive all the services deemed necessary in their plans of care. These plans are devised by agencies to address specific needs approved by a doctor, such as speech therapy or occupational therapy, and usually delivered over the course of a few months, though sometimes they last much longer. Also, patients must be informed about the agency's initial comprehensive assessment of the patient's needs and goals, as well as all subsequent assessments.

A patient's rights to lodge complaints about treatment and be free from abuse, which had already been in place, are described in more detail in the new regulations. The government surveys home health agencies every three years to make sure that its rules are being followed.

NAHC officials said they planned to develop a "notice of rights" for home health care agencies, bringing greater standardization to what has sometimes been an ad hoc notification process.

Caregiver Involvement

For the first time, agencies will be required to assess family caregivers' willingness and ability to provide assistance to patients when developing a plan of care. Also, caregivers' other obligations — for instance, their work schedules — will need to be taken into account.

Previously, agencies had to work with patients' legal representatives, but not "personal representatives" such as family caregivers.

"These new regulations stress throughout that it's important for agencies to look at caregivers as potential partners in optimizing positive outcomes," said Peter Notarstefano, director of home and community-based services for LeadingAge, a trade group for home health agencies, hospices and other organizations.

Plans Of Care

Now, any time significant changes are made to a patient's plan of care, an agency must inform the patient, the caregiver and the physician directing the patient's care.

"A lot of patients tell us 'I've never seen my plan of care; I don't know what's going on; the agency talks to my doctor but

not to me,'" said Kathleen Holt, an attorney and associate director of the Center for Medicare Advocacy. The new rules give "patients and the family a lot more opportunity to have input," she added.

In another notable change, efforts must be made to coordinate all the services provided by therapists, nurses and physicians involved with the patient's care, replacing a "siloed" approach to care that has been common until now, Notarstefano said.

Discharge Protections

Allowable reasons for discharging a patient are laid out clearly in the new rules and new safeguards are instituted. For instance, an agency can't discontinue services merely because it doesn't have enough staff.

The government's position is that agencies "have the responsibility to staff adequately," Carr of NAHC said. In the event a patient worsens and needs a higher level of services, an agency is responsible for arranging a safe and appropriate transfer. "Agencies in the past have had the ability to just throw up their hands and say 'We can't care for you or we think we've done all we can for you and we need to discharge you,'" Holt said. Now a physician has to agree to any plan to discharge or transfer a patient, and "that will offer another layer of protection."

richard's review

Richard J. Atwood

(This article is a reprint from PEN February 2017 Volume 27 Issue 1)

Treatment by Transfusion

The first reported successful blood transfusion in an attempt to treat bleeding due to hemophilia is truly a landmark historic event.

Samuel Armstrong Lane (1802–1892) submitted a long letter to the journal *Lancet* on September 28, 1840. The letter described hemorrhagic diathesis, now called hemophilia. Lane was a lecturer on anatomy and surgery at St. George's School in London, and had just met a hemophilic patient.

Probably in August 1840, 11-year-old George Firmin's father brought his son to the hospital to undergo surgery to relieve the "deformity of squinting." Lane performed the surgery unaware of George's bleeding condition—and no surgeon wants to be surprised by that news.

George bled more than usual and became faint during the minor surgical operation, but nothing else was noted. When bleeding subsided, George walked home at noon. Bleeding from his eye began 15 minutes later and continued for six or seven hours. That evening, after 30 minutes of effort, Lane successfully halted the blood flow for a brief remission. He then learned of George's bleeding history.

Twice in 1836, George had been admitted to St. George's Hospital with hemorrhages lasting 4 to 14 days after tooth loss. He also lost a lot of blood from a finger cut that was treated with pressure. In 1839 George had what Lane called an "affection" of the knee joint, which was treated with leeches at the hospital. Such treatment was common medical practice at that time, even for hemophilic patients. The leech wounds on George's skin would not easily heal, and were treated with needles, according to Lane, and ligatures (the tying off of arteries).

Back at home after his 1840 surgery, George continued to bleed from his eye—an alarming location for a bleed—with occasional intermissions for the next six days. The usual general and local remedies were applied; pressure and propping the patient in an upright position slowed the bleeding. By the sixth postoperative day, George's skin was pale and cold, and Dr. Lane could not feel George's pulse at the wrist.

Lane determined that his patient was dying of hemorrhage because his blood was "less disposed to coagulate." That evening at the Firmin home, Lane decided to transfuse blood with the assistance of surgeon Henry Ancell (1802–1863) and in the presence of several observers. At the time, blood transfusion was a risky procedure: some patients died from infection and reactions due to being infused with an incompatible blood type. (Blood typing before an infusion would not be developed until 1910.)

Lane was prepared. He had already consulted the obstetrician and physiologist James Blundell (1790–1878) about blood transfusions. Lane obtained a commercially available tin-lined brass syringe, along with a funnel designed by Blundell to collect the blood and a pipe to insert into the patient's vein. A healthy young woman provided the blood from her arm vein.

For the actual transfusion—with no anesthesia—Lane made a one-inch incision parallel to George's vein at the bend of his elbow. He raised the exposed vein and opened it with a lancet (a sharp-pointed, usually two-edged instrument) before inserting the syringe pipe. The donated blood kept coagulating, so Lane washed the syringe four times. Still, only about half an ounce of blood could be pushed into the boy at each attempt. The young woman donated about 10 to 12 ounces (280–340 ml) of blood, of which George received about 5 ounces (150 ml), until the flow slowed from her arm.

Lane observed his patient for physical signs of distress. George's pulse returned immediately. After an hour, George sat up and drank a glass of wine and water. There was no more bleeding from his eye. The wound in his elbow healed in 10 days. George recovered his appetite and appetite and strength. He visited the country after three weeks, returning in a few days perfectly well, with his eye restored to the "straight position," according to Lane.

The blood transfusion was successful: the patient survived, even if the procedure was crude by today's standards. Yet some physicians have questioned the results. In 1981 Dr. A. D. Farr speculated that George Firmin did not have severe hemophilia, and that the lifesaving procedure by transfusion was more significant for partially restoring blood volume and oxygen carrying capacity than for stopping the prolonged bleeding. Then in 1988, doctors D. J. Perry and A. MacWhannel proposed that the partial coagulation of the transfused whole blood generated an "activated clotting-factor complex" (possibly stimulating the clotting cascade, similar to using a bypassing agent for inhibitors, though it's unclear what the doctors meant), rather than a rise in factor VIII.

After George's case, Lane never published another article on hemophilia or on blood transfusions. He did not want to be considered a "specialist," though he maintained his lucrative practice of bladder stone surgery. And he later focused on medical education at St. Mary's Hospital of London.

The next report of a blood transfusion to treat hemophilia appeared in 1905, after a gap of 65 years. Part of the delay was in overcoming obstacles such as improving the equipment and understanding blood groups for compatibility. And part of the wait was because doctors had to progressively learn about the true cause of hemophilia.

Given the high risk of death, Samuel Armstrong Lane most likely attempted blood transfusion in 1840 as a lifesaving measure for his patient with hemorrhagic brave effort—which today seems almost legendary—as the first whole-blood transfusion attempt to treat hemophilia.

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. Additionally, transportation assistance (gas cards or pre-paid Visa cards) may be available for each event, depending on our budget.

A former senator explains how regular people can effectively lobby Congress

Byron Dorgan spent 30 years representing North Dakota in Congress — 18 years in the Senate and 12 in the House. And there's one constituent he thinks of when people ask how ordinary people can effectively lobby their representatives. She was a determined woman whose fight to help her son eventually changed how American health insurance works.

Dorgan told me this story a few weeks ago, when I was working on a piece about the Affordable Care Act's ban on lifetime limits in health insurance. Next week, as legislators return to their districts for recess and town halls, his advice might prove especially relevant. As David Leonhardt writes for the New York Times, those meetings will be "a chance for people to make clear the actual stakes in the health care debate."

I initially reached out to the former North Dakota senator because I had heard from a former Senate staffer, John McDonough, that Dorgan was the driving force behind the push to ban lifetime limits. Before the Affordable Care Act, many health insurance plans capped medical benefits at $1 million or $2 million. I wanted to understand how Dorgan became so passionate about ending those caps.

The answer was surprisingly simple: A constituent bothered him about the topic. Repeatedly.

"I used to use her as an example of how to be effective at lobbying Congress," Dorgan, now a senior policy adviser at law firm Arent Fox, says. "She caught my attention, I cared about it, and it became personal."

The woman was named Brenda Neubauer. Her son Jack has hemophilia, a blood disease that requires regular injections of an expensive blood clotting agent. The medication cost $30,000 each month.

Jack was in elementary school when he capped out of his dad's (Neubauer's ex-husband's) health plan, which had a $1 million limit. He switched to his mom's plan, which had a $2 million ceiling. By age 12, he was already halfway through that second policy. Neubauer estimated her son would run out of benefits by time he turned 16.

She started to write letters to the editor in the mid- 2000s and attended Dorgan's events, where she would ask about the issue.

"We formed a relationship," Neubauer says of Dorgan. "When he would come to Bismarck, he started stopping by my law office. Then I started going to Capital

Continued on 21 page...

SENATE RESOLUTION No. 108
STATE OF NEW JERSEY
217th LEGISLATURE

INTRODUCED FEBRUARY 27, 2017

Sponsored by:
Senator LORETTA WEINBERG
District 37 (Bergen)

SYNOPSIS

Designates March 2017 as "Bleeding Disorders Awareness Month."

CURRENT VERSION OF TEXT

As introduced.

A SENATE RESOLUTION designating March 2017 as "Bleeding Disorders Awareness Month" in New Jersey.

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

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

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

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

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

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

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

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

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

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

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

BE IT RESOLVED *by the Senate of the State of New Jersey:*

1. The month of March 2017 is designated as "Bleeding Disorders Awareness Month" in New Jersey in order to increase public awareness about bleeding disorders, generate a greater understanding of all inheritable bleeding disorders, and foster a greater sense of community and shared purpose among individuals with inheritable bleeding disorders and the general public.

2. The Governor is respectfully requested to issue a proclamation designating March 2017 as "Bleeding Disorders Awareness Month" in New Jersey, and calling upon public officials and the citizens of this Senate to observe the month with appropriate activities and programs.

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

STATEMENT

This resolution designates March 2017 as "Bleeding Disorders Awareness Month" in New Jersey in order to increase public awareness about bleeding disorders, generate a greater understanding of all inheritable bleeding disorders, and foster a greater sense of community and shared purpose among individuals with inheritable bleeding disorders and the general public.

.....A former senator explains how regular people can effectively lobby Congress

Hill, and I would bring books and books full of pictures of my son, and we would just meet with anybody we could."

What made Neubauer effective, Dorgan says, was two things: She was persistent, and she made the issue personal. She would bring along her medical bills, photographs of Jack, and sometimes Jack himself. She was trying to make it clear that there was a tangible problem— one that was affecting her son at that very moment—and that Congress could solve it.

"She stood up at several meetings, and then she came back to DC with her son, who was a high school student, " he says, "She brought sample invoices of the bills they had to pay."

All of Neubauer's work made the issue very real to Dorgan. Before that, he hadn't even known that a lot of insurance plans capped benefits. "I thought if you were insured, you were insured," he says. Afterward, he became an advocate.

Dorgan's story is a potent reminder: Citizen input does matter, and it can shape the issues senators choose to prioritize on Capital Hill.

Originally Published Feb. 17, 2017 in www.vox.com

Biotherapies for Life® **CSL Behring**

For adults and children with hemophilia A

REACH HIGHER

With the Long-lasting Protection of AFSTYLA

2x WEEKLY AVAILABLE

FDA-approved for dosing 2 or 3 times a week

ZERO BLEEDS (median AsBR*)

In clinical trials, whether dosed 2 or 3 times a week

COMPARABLE TO **NATURAL FACTOR VIII**

Identical to natural Factor VIII once activated

Zero inhibitors observed—Low incidence of side effects in clinical trials

In clinical trials, dizziness and allergic reactions were the most common side effects.

Visit AFSTYLA.com to sign up for the latest news

*Annualized spontaneous bleeding rate in clinical trials (interquartile range [IQR]=0–2.4 for patients ≥12 years; 0–2.2 for patients <12 years).

Important Safety Information

AFSTYLA is used to treat and control bleeding episodes in people with hemophilia A. Used regularly (prophylaxis), AFSTYLA can reduce the number of bleeding episodes and the risk of joint damage due to bleeding. Your doctor might also give you AFSTYLA before surgical procedures.

AFSTYLA is administered by intravenous injection into the bloodstream, and can be self-administered or administered by a caregiver. Your healthcare provider or hemophilia treatment center will instruct you on how to do an infusion. Carefully follow prescriber instructions regarding dose and infusion schedule, which are based on your weight and the severity of your condition.

Do not use AFSTYLA if you know you are allergic to any of its ingredients, or to hamster proteins. Tell your healthcare provider if you previously had an allergic reaction to any product containing Factor VIII (FVIII), or have been told you have inhibitors to FVIII, as AFSTYLA might not work for you. Inform your healthcare provider of all medical conditions and problems you have, as well as all medications you are taking.

Immediately stop treatment and contact your healthcare provider if you see signs of an allergic reaction, including a rash or hives, itching, tightness of chest or throat, difficulty breathing, lightheadedness, dizziness, nausea, or a decrease in blood pressure.

Your body can make antibodies, called inhibitors, against FVIII, which could stop AFSTYLA from working properly. You might need to be tested for inhibitors from time to time. Contact your healthcare provider if bleeding does not stop after taking AFSTYLA.

In clinical trials, dizziness and allergic reactions were the most common side effects. However, these are not the only side effects possible. Tell your healthcare provider about any side effect that bothers you or does 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.

Please see the following brief summary of full prescribing information on the adjacent page, and the full prescribing information, including patient product information, at AFSTYLA.com.

AFSTYLA® Antihemophilic Factor (Recombinant), Single Chain

AFSTYLA®, Antihemophilic Factor (Recombinant), Single Chain
For Intravenous Injection, Powder and Solvent for Injection
Initial U.S. Approval: 2016

BRIEF SUMMARY OF PRESCRIBING INFORMATION
These highlights do not include all the information needed to use AFSTYLA safely and effectively. Please see full prescribing information for AFSTYLA, which has a section with information directed specifically to patients.

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

- Your healthcare provider or hemophilia treatment center will instruct you on how to do an infusion on your own.
- Carefully follow your healthcare provider's instructions regarding the dose and schedule for infusing this medicine.

What is AFSTYLA?

- AFSTYLA is a medicine used to replace clotting Factor VIII that is missing in patients with hemophilia A.
- Hemophilia A is an inherited bleeding disorder that prevents blood from clotting normally.
- Does not contain human plasma derived proteins or albumin.
- Your healthcare provider may give you this medicine when you have surgery.
- Is used to treat and control bleeding in all patients with hemophilia A.
- Can reduce the number of bleeding episodes when used regularly (prophylaxis) and reduce the risk of joint damage due to bleeding.
- Is not used to treat von Willebrand disease.

Who should not use AFSTYLA?

You should not use AFSTYLA if you:

- Have had a life-threatening allergic reaction to it in the past.
- Are allergic to its ingredients or to hamster proteins.

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

What should I tell my healthcare provider before using AFSTYLA?

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 hamster proteins.
- Have been told you have inhibitors to Factor VIII (because this medicine may not work for you).

How should I use AFSTYLA?

- Administer directly into the bloodstream.
- Use as ordered by your healthcare provider.
- You should be trained on how to do intravenous injections by your healthcare provider or hemophilia treatment center. Once trained, many patients with hemophilia A are able to inject this medicine by themselves or with the help of a family member.
- Your healthcare provider will tell you how much to use based on your weight, the severity of your hemophilia A, and where you are bleeding.
- You may need to have blood tests done after getting 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 this medicine.

What are the possible side effects of AFSTYLA?

- Allergic reactions may occur. Immediately stop treatment and call your healthcare provider right away if you get a rash or hives, itching, tightness of the chest or throat, difficulty breathing, light-headedness, dizziness, nausea, or decrease in blood pressure.
- Your body may form inhibitors to Factor VIII. An inhibitor is a part of the body's defense system. If you form inhibitors, it may stop this medicine from working properly. Your healthcare provider may need to test your blood for inhibitors from time to time.
- Common side effects are dizziness and allergic reactions.
- These are not the only side effects possible. Tell your healthcare provider about any side effect that bothers you or does not go away.

What else should I know about AFSTYLA?

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

Please see full prescribing information, including full FDA-approved patient labeling. For more information, visit www. AFSTYLA.com

Manufactured by:
CSL Behring GmbH
35041 Marburg, Germany

for:
CSL Behring Recombinant Facility AG
Bern 22, Switzerland 3000
US License No. 2009

Distributed by:
CSL Behring LLC
Kankakee, IL 60901 USA

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

Manufacturer	Program Name & Contact Information	Details
Aptevo Therapeutics	IXINITY Savings Program http://ixinity.com/save-on-IXINITY 1-855-494-6489	• Must have valid prescription for IXINITY • Must have commercial insurance • No monthly limits unless limit total is reached. • No income requirements • Co-pay program can be used retroactively for up to 12 months • Limit Total $12,000
Baxalta/Shire	www.hematologysupport.com 1-855-BAX-8379 Co-Pay Shire Hemophilia Support Website	• Baxalta's CoPay Assistance Program –Non-Financial Needs Based Program http://www.hematologysupport.com/copay-assistance/ • Financial Needs Based Assistance Program (Free Product) 1-888-BAX-8379 Available to patients with no insurance or a gap in insurance. Must have current prescription for a Baxalta hemophilia product. • Freedom of Choice – Eligible patients can receive free sample dose of eligible Baxalta's hemophilia products along with educational resources. 1-(855)322-6282 • Smart Start – Enrolled patients may be eligible to receive up to 12 months of medication while they pursue commercial insurance coverage. Healthcare providers call 1-(855)-229-7377
Bayer	www.kogenatefs.com 1-800-288-8374	Access Solutions: Gives patients support with co-pays, understanding insurance, live Helpline Support, Free Trial (6 free doses), GAP coverage, and Patient Assistance Program. • No income eligibility • Eligible patients can receive up to $12,000 in assistance per year • The program is only available to patients with private insurance • Assistance is awarded per patient. Multiple members of a household are eligible for assistance if they meet the required criteria

Manufacturer	Program Name & Contact Information	Details
Bioverativ	http://www.alprolix.com/resources-and-support/available-financial-support.html 1-855-692-5776	• Free Trial Plus Program – Patients who have never used Alprolix before may be eligible for a free 30 day trial of medicine. Download application at http://www.alprolix.com/pdfs/Free_Trial_Plus_Program_Form_Electronic_Form.pdf • MyAprolix Factor Access Program – Uninsured patients may be eligible for up to a year of free Alprolix . Download application at http://www.alprolix.com/pdfs/MyALPROLIX_Enrollment_Form.pdf • MyAlprolix Co-Pay Assistance Program – Provides $12,000 co-pay/deductible assistance for patients who use Alprolix. Download application at: http://www.alprolix.com/pdfs/MyALPROLIX_Enrollment_Form.pdf • My Eloctate 1-855-MyELOCTATE (1-855-693-5628) * Free Trial Plus Program * Co-pay Program: offers up to $12,000 per year on out-of-pocket costs * Factor Access Program
CSL Behring	www.cslbehringassurance.com 1-866-415-2164 CSL Behring Care Coordination Center CSL Behring Assurance Program c/o Sonexus Health PO Box 368 Lewisville, TX 75067 Email: info @cslbehringassurance.com	• CSL Behring *Assurance*: Contact a *CSL Behring Assurance Program* Care Coordinator at 1-800-415-2164 • Patient Assistance Program – A 3 month supply will be donated for those using CSL product who do not have insurance and unable to afford their factor. • MyAccess Cost Share Assistance Program – Program to assist with deductibles/co-pays associated with Helixate and Humate-P, Idelvion and Afstyla up to $12,000 annually. No income limits. 800-676-4266

Manufacturer	Program Name & Contact Information	Details
Grifols	FACTORS FOR HEALTH www.grifolspatientcare.com 1-844-MY-FACTOR (693-2286)	• The $0 Copay Program, wherein eligible patients or caregivers may pay as little as $0 for prescriptions. • The Free Trial Program for eligible patients who are new to treatments from Grifols. • Benefits investigation and support services to help you coordinate with your insurer. • The Patient Assistance Program for patients with no coverage or lapsed coverage. • Care Coordination to help you access and stay on treatment.
Kedrion	www.koate-dvi.com 1-855-353-7466	No assistance programs are offered.
Novo Nordisk	http://NovoeightPro.com www.MyNovoSecure.com Novo Nordisk NovoSecure Hotline 1-844-NOVOSEC (1-844-668-6732) www.novonordisk-us.com	• Novo Nordisk Co-pay Assistance Program – Save up to $12,000 annually on co-pay, deductible, and coinsurance costs, regardless of income. • Product Assistance Program – http://www.mynovosecure.com/support/continue_your_treatment.html • Product Assistance Program (PAP)/Trial Program – Download the application at www.mynovosecure.com/support.continue_your_treatment.html
Octapharma	www.wilateusa.com	• Bridge Program – Free trial program for Wilate (5,000 units/30 day supply). Application form at: http://www.wilateusa.com/images/PDF_Files/wilateBridgeProgramEnrollment-Form_102512.pdf • **NUWIQ® Co-Pay Assistance Program** Offers eligible patients a savings up to $12,000 per year on the out-of-pocket costs associated with treatment http://www.nuwiqusa.com/factor-viii-patient-assistance-program/

Manufacturer	Program Name & Contact Information	Details
Octapharma continued …		• **NUWIQ® Free Trial Program** Eligible patients can receive treatment with NUWIQ at no cost. (Not to exceed 6 doses, or approximately 20,000 IUs) http://www.nuwiqusa.com/factor-8-free-trial/#Free-Trial-Program • Find us online at: www.NUWIQUSA.com • **Octapharma Reimbursement Hotline** usreimbursement@octapharma.comTel: 800-554-4440 | Fax: 800-554-6744 • Wilate Co-Pay Assistance Program -- Savings of up to $6,000 per year on the out-of-pocket costs associated with your therapy. For more information or to enroll, contact the Octapharma Support Center at 1-800-554-4440.
Pfizer	www.hemophiliavillage.com	• Trial Prescription Program- Allows patients to get a one-time, 1-month supply up to 20,000 IU of Pfizer factor product delivered at no cost to him or her. Call 1-844-989-4366 for more information or visit the website http://www.HemophiliaVillage.com/hemophilia-resources-support • Pfizer Factor Savings Card – Up to $12,000 annual support for co-pay, deductible and co-insurance costs for Benefix and Xyntha regardless of income. Call 1-844-989-4366 for more information or visit the website: http://www.HemophiliaVillage.com/hemophilia-resources-support • Pfizer RxPathways – A comprehensive assistance program that provides eligible patients (insured, uninsured, and underinsured) with a range of support services. Call 844-989-4366 for more information or visit the website PfizerRxPathways.com

Non-Pharmaceutical Assistance Programs

Organization	Program Name & Contact Information	Details
Patient Services Inc.	www.patientservicesinc.org P.O. Box 5930 Midlothian, VA 23112 Email: uneedpsi@uneedpsi.org 1-(800) 366-7741 Fax 1-(804) 744-9388	• Premium Assistance (PSI – Patient Services, Inc.) Administered by PSI, eligible patients receive financial assistance for health insurance premiums. Call 1-800-366-7741 https://www.patientservicesinc.org • A.C.C.E.S.S. Hemophilia Legal Hotline (PSI – Patient Services, Inc.) 1-(800)700-7010 Support patients with Social Security benefits and disability benefits via legal counseling. www.patientservicesinc.org
Hope for Hemophilia	PO Box 77728 Baton Rouge, LA 70879 (888) 529-8023 Fax (888) 835-1449 info@hopeforhemophilia.com	Patient Resource Program and Direct Financial Assistance Program
Colburn Keenan Foundation	www.colkeen.org	Provides funding to assist with socio-economic and insurance needs.
211	www.211.org	Links to additional resources in your local area for specific needs.
Caring Voice Coalition (CVC)	www.caringvoice.org Caring Voice Coalition, Inc. 8249 Meadowbridge Road Mechanicsville, VA 23116 (804) 427-6468 Patient Line (888) 267-1440	Factor XIII deficiency program

Organization	Program Name & Contact Information	Details
HFA Helping Hands	www.hemophiliafed.org/programs/helping-hands Hemophilia Federation of America (HFA) 820 First Street NE, Suite 720 Washington, DC 20002 (202) 675-6984 (800) 230-9797 Fax: (202) 675-6983 Email: info@hemophiliafed.org	Emergency assistance, items reimbursement and inhibitor support.

**** Please note that all co-pay/deductible assistance programs are for patients with *private insurance*. Patients with Medicaid or Medicare are not eligible **Updated April 12, 2017**

One-Pan Maple Mustard Salmon with Sweet Potatoes and Arugula

Serves: 4 Active Time: 5 minutes Total Time: 40 minutes

Ingredients:

- 1 package store-cut diced sweet potatoes
- Grapeseed oil spray
- 4- 6 ounce salmon filets
- 2 tablespoons maple syrup
- 3 tablespoons whole-grain mustard
- 1 5-ounce package baby arugula
- 1 lemon, cut into 4 wedges
- Salt and pepper, to taste

This kid-friendly salmon dish makes clean-up a snap thanks to its use of pre-cut veggies and only one pan!

Directions:

1. Preheat the oven to 425°F. Line a rimmed baking sheet with parchment paper.
2. Place sweet potatoes on baking sheet and spray with a thin layer of grapeseed oil spray. Season with salt and pepper and toss to coat. Bake for 10 minutes, or until sweet potatoes are almost tender.
3. Meanwhile, in a medium bowl, whisk together maple syrup and mustard. Place the salmon filets in the mixture, one at a time, and toss to coat. Using a spatula, gently move the sweet potatoes to the outer edge of the baking sheet and place the salmon filets in the center. Season with salt and pepper and return pan to the oven. Continue to bake for another 15-20 minutes, or until sweet potatoes are tender and salmon flakes easily with a fork.
4. To serve, place a small handful of arugula on each plate and season with the juice of one lemon wedge and a pinch of salt and pepper. Finish each plate with a salmon filet and divide the sweet potatoes evenly amongst the four plates.

Recipe provided by Monica Hansen, Registered Dietitian at the ShopRite of Greater Morristown.

Hemophilia Association of New Jersey

Upcoming Events

HANJ Annual Meeting
Pines Manor
Edison NJ
Thursday, May 25, 2017 at 6PM

Dennis Keelty Memorial Golf Classic
Plainfield Country Club
South Plainfield, NJ
Monday, June 19, 2017

HANJ Fall Educational Symposium
Saturday, September 16, 2017
More Details will be available soon.

Kelly Brothers Annual
Scholarship Benefit
Saturday, September 23, 2017

Casino Night
Pines Manor
Edison, NJ
Saturday, October 14, 2017

PACT Workshop
December 2017

Gourmet Dinner
Il Tulipano
Cedar Grove, NJ
Monday, September 18, 2017

You are Invited
To Attend
The Annual Meeting & Educational Forum
of

The Hemophilia Association
Of
New Jersey

Thursday, May 25th, 2017
At
The Pines Manor
2085 Lincoln Highway
Edison, NJ 08817

Reservations Required*

***R.S.V.P.**

You must call The Hemophilia Association of New Jersey office at (732) 249-6000 on or before May 19, 2017 to make your reservations.