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

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

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Social Worker Update
By Neidy Olarte, MSW
Social Service Coordinator

**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 Medicaid 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 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 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

Continued on page 9
WHAT'S HAPPENING
New Jersey Hemophilia Treatment Centers

Rutgers RWJ 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 or school visits, counseling, insurance issues, education and schedule. Please call Frances Maceren, RN at 732-235-6542, if you are interested in arranging infusion training.

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.

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, BD RN, 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 the 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.
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

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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.

Refer for more information:

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.

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 - 17 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.

To report SUSPECTED ADVERSE REACTIONS, contact Octapharma USA Inc. at 1-866-765-4880 or FDA at 1-800-FDA-1088 or www.fda.gov/medwatch.
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.

By that time, 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 obliged 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 Natarstefano, director of home and community-based services for LeadingAge, a trade group for home health agencies, hospices and other organizations.

Plants 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..."
George Firmin's father brought his son to London, and had just met a hemophilic patient. George Firmin's father brought his son to 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 per- formed the surgery unaware of George's bleeding condition.

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 reme- dies were applied; pressure and propping the patient's arm up allowed 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 dy- ing 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 sur- geon Henry Ancell (1802–1863) and in the presence of several observers. At the time, blood transfusion was a risky proce- dure: some patients died from infection and reactions due to being infused with an incompatible blood type. (Blood typing be- fore an infusion would not be developed until 1910.)

Lane was prepared. He had already con- sulted the obstetrician and physiologist James Blundell (1790–1878) about blood transfusions. Lane obtained a commercial- ly available tin-lined brass syringe, along with a funnel designed by Blundell to col- lect 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 anes- thesia—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 in- serting 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 im- mediately. 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 appe- tite 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 hemo- philia, and that the lifesaving procedure by transfusion was more significant for partially restoring blood volume and oxy- gen 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 in- hibitors, though it's unclear what the doc- tors 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 con- sidered a "specialist," though he main- tained his lucrative practice of bladder stone surgery. 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 progres- sively learn about the true cause of hemo- philia.

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-trans- fusion 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.

Bioverativ is committed to making a meaningful impact in the lives of people with hemophilia and other rare blood disorders by:

- Striving for progress when and where people need it most
- Advancing innovative programs to address serious unmet needs
- Challenging the status quo at every step with focus, urgency, and integrity
- Carrying on Biogen’s hemophilia treatments with a continued focus on quality, safety, manufacturing, and product accessibility

Visit Bioverativ.com to find out more

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 bother him about the topic. Repeatedly.

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

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.
**SENATE RESOLUTION No. 108**  
**STATE OF NEW JERSEY**  
**217th LEGISLATURE**  
INTRODUCED FEBRUARY 27, 2017

**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 had—n’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 Capitol Hill.

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

AFSTYLA does not contain any animal products. It is highly purified and contains no human proteins.

**AFSTYLA** is manufactured by CSL Behring GmbH and distributed by CSL Behring LLC. AFSTYLA® is a registered trademark of CSL Behring LLC.

**Important Safety Information**

AFSTYLA® is a medicine 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 have had a life-threatening allergic reaction to it in the past.

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 observed. Low incidence adverse effects in clinical trials included back pain, dizziness, and allergic reactions.

**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.

**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, difficulty breathing, tightness of the chest or throat, difficulty breathing, tightness of the chest or throat, difficulty breathing, tightness of the chest or throat, difficulty breathing, tightness of the chest or throat.
- **Your body forms 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.

**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.

**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.**

Please see full prescribing information, including full FDA-approved patient labeling, for more information, visit www.AFSTYLA.com.
<table>
<thead>
<tr>
<th>Manufacturer</th>
<th>Program Name &amp; Contact Information</th>
<th>Details</th>
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<tbody>
<tr>
<td>Bayer</td>
<td><a href="http://www.kogenatefs.com">www.kogenatefs.com</a></td>
<td>Access Solutions: Gives patients support with co-pays, understanding insurance, live Helpline Support, Free Trial (6 free doses), GAP coverage, and Patient Assistance Program.</td>
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<td></td>
<td>1-800-288-8374</td>
<td>• No income eligibility</td>
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<td></td>
<td>• Eligible patients can receive up to $12,000 in assistance per year</td>
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<td>• The program is only available to patients with private insurance</td>
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<td>• Assistance is awarded per patient. Multiple members of a household are eligible for assistance if they meet the required criteria</td>
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<td>1-855-BAX-8379</td>
<td>• 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.</td>
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<tr>
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<td>• Freedom of Choice – Eligible patients can receive free sample dose of eligible Baxalta's hemophilia products along with educational resources. 1-(855)332-6282</td>
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<td>• 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</td>
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<tr>
<td>Bayer</td>
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<td>BAEP Co-Pay Shire Hemophilia Support Website</td>
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<tr>
<td>Aptuvo Therapeutics</td>
<td><a href="http://ixinity.com/save-on-IXINITY">http://ixinity.com/save-on-IXINITY</a></td>
<td>IXINITY Savings Program</td>
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<td></td>
<td>1-855-494-6489</td>
<td>• Must have valid prescription for IXINITY</td>
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<td>• Must have commercial insurance</td>
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<tr>
<td></td>
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<td>• No monthly limits unless limit total is reached.</td>
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<td>• No income requirements</td>
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<td>• Co-pay program can be used retroactively for up to 12 months</td>
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<td>• Limit Total $12,000</td>
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**Bioverativ**

- 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


- 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 Eloxate 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**

- 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
<table>
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<tr>
<th>Manufacturer</th>
<th>Program Name &amp; Contact Information</th>
<th>Details</th>
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| 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. |
- 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 |
- 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/ |
| 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

<table>
<thead>
<tr>
<th>Organization</th>
<th>Program Name &amp; Contact Information</th>
<th>Details</th>
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</table>
| Patient Services Inc.                | www.patientservicesinc.org          | - 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  
| 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                 | Factor XIII deficiency program                                         |

** 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

**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 tender and salmon flakes easily with a fork.
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.*
Looking for a new, fresh perspective on living with hemophilia?

Introducing your all NEW guide to Living With Hemophilia

Discover the new online destination for learning about hemophilia, living a healthy life and even leading in the hemophilia community. It’s all at the new LivingWithHemophilia.com. Our site has been totally redesigned to give you more of the information you want and less of the stuff you don’t want.

See What’s New at
www.LivingWithHemophilia.com

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.