Friendly Reminder: Open Enrollment to purchase 2019 health plans under the Affordable Care Act runs from November 1, 2018 — December 15, 2018. For more information visit websites: https://www.state.nj.us/dobi/getcovered/index.html or www.HealthCare.gov Or Call 1(800)318-2596.
Meet the Board…

Steven Moersdorf
HANJ Trustee

I graduated from the University of Scranton in 1993 with a BS in accounting. My first job after college was with HANJ’s accounting firm. When I left that job a few years later, Elena asked me to stop by the office and see her on my way home one night, and the rest as they say is history. I’ve now been a member of the Board of Trustees for a little over 20 years. While I am currently serving in the position of Vice President, I have been a member of the NJ Society of Certified Public Accountants since 1997. There I have previously served as a member and then the Leader of the Young CPA’s Resource Group as a member, then Treasurer and later Chairman of the Political Action Committee.

Currently, I also serve on the Board of Directors as Treasurer of the Healthcare Chaplaincy Network, an organization that “helps people faced with the distress of illness and suffering to find comfort and meaning.” I also currently serve as a member of the Environmental Commission in Chester Township, NJ, where I live.

My wife Marlena and I have been married for six years and we have a two year old daughter named Caitlin who keeps us very busy. In my “spare time” I enjoy genealogy, bicycle riding, landscaping our yard and traveling.

Best Regards,
Joe

Message from … President of HANJ
Joe Markowitz

As the warm weather winds down, and activities go from outdoor to indoor, it’s a good time to sit back and reflect on what’s important to you. And when you figure that out, are you certain you’re taking positive steps to ensure you’ll meet those important goals? Just wishing won’t get you there. Setting goals isn’t just a personal issue, it’s good for all areas of your life and your relationships with others.

As I look at the activities that HANJ performs on your behalf, I am confident that we do good work and work smartly and effectively. Working with legislators, lobbyists, manufacturers, specialty pharmacies and physicians is important to our success. It’s a core function. But working with the hemophilia families is our most important job. HANJ is here to help hemophiliacs and their families. Everything we do is in support of that mission.

So the question I’m going to ask you to think about is this: Are we doing what YOU want? Are there additional programs and activities that YOU want HANJ to get involved in?

For example, we have an active Blood Brotherhood program for adult men. But what about adult women, parents, school age boys and girls, and young adults? Should we expand into supporting these groups also? If so, will YOU be willing to volunteer to organize and run these new groups?

With YOUR involvement, we can continue to be the best at helping our membership with meaningful programs.

Best Regards,
Joe

BDRN & HANJ
340B Bleeding Disorders Program
In association with:
Rutgers: Robert Wood Johnson Medical School
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 ensuring access to care 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.
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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We welcome all letters and submissions for consideration. The opinions expressed in HANJournal articles are solely those of the authors and do not necessarily reflect the philosophy of the Hemophilia Association of New Jersey. HANJ makes no recommendations for or against treatments and/or therapies.

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Social Worker Update
By Neidy Olarte, MSW
Social Service Coordinator

Open Enrollment.
Are you covered?
For individuals that are currently in need of health insurance or have insurance through the Marketplace, please be aware that open enrollment for plans under the Health Insurance Marketplace begins November 1, 2018 and ends December 15, 2018 for plans that will become effective January 1, 2019. If you do not elect an insurance plan within this time frame, you will not be able to obtain insurance after this deadline unless you are offered insurance through an employer, qualify for Medicaid, or if you have a qualifying event that makes you eligible for a special enrollment. If you currently have insurance through the Marketplace this is your chance to switch your plan if you are not happy with the plan you currently have. If you like your current plan, you do not have to do anything and will remain on your plan as directed by your insurance carrier.

There are several ways to obtain insurance during open enrollment. The most effective way to obtain insurance is to enroll through the marketplace website at www.healthcare.gov.

When you log onto the marketplace website, you can review the different plans that are offered as well as compare rates. You will also have a chance to see if you qualify for any subsidies which can lower your monthly premium rate depending on your family income. On the website there is also a directory of local Navigators that can assist you with your application process should you need any assistance. You may also contact the health insurance plan directly if you do not want to apply through the marketplace website. Please note that by bypassing enrollment through the Marketplace website, you will not be eligible for any subsidies to lower your monthly premium. Those subsidies can only be obtained by submitting your application through the marketplace website.

If you feel like you cannot afford your portion of the premium cost or you feel like your income is too low to purchase a policy through the marketplace, you can contact NJ Family Care at www.njfamilycare.org to see if you qualify for a Medicaid plan.
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 is a 340B covered entity. Participation in the federal 340B program makes it possible for our HTC to continue to serve the hemophilia community with the high level of services and quality of care it expects. If you have questions about this program, please do not hesitate to contact the HTC directly at 732-235-6533.

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

School & Camp Visits:
The staff at the HTC continues to provide 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 schedules. Please call Frances Maceren, RN at 732-235-6542, if you are interested in arranging infusion training.

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 schedules. 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

As we transition into fall, the staff from the Comprehensive Hemophilia Treatment Center at Newark Beth Israel Medical Center and Children’s Hospital of New Jersey would like to share some updates, current programs, and plans with you.

News
Hemophilia Camp:
This year, like last year, we had several children attend hemophilia camp at either Double H Ranch or Hole in the Wall Gang Camp. Camp can be an integral part of a patient’s journey towards independence. Both camps offer family camps as well. For more information about camp, or if your child or family is interested in attending camp in the future, please contact Erica, our Social Worker, at the HTC.

Upcoming
Back to School:
As the school year continues, we know that you might need forms completed, letters for school, or school visits scheduled. School visits are a wonderful opportunity for our HTC to provide education and outreach to your child’s school or daycare about hemophilia and other bleeding disorders. Whether the visit is with the staff at your child’s school, the daycare staff, or even the child study team, a school visit opens the lines of communication between the child’s school or daycare and the HTC. If you are going to want a school visit scheduled for your child’s school or daycare center, or need a letter for school/forms completed, please contact Erica, our Social Worker. Erica will make sure that we have a release on file, and will coordinate your needs with the school and schedule a visit. If you will need any forms or letters for your child’s school or daycare center, please be mindful that it may take up to two weeks for forms or letters to be completed. For more information, please contact us at the HTC.

Save the Date:
The HTC Annual Holiday Party will be held on Saturday December 15, 2018 from 2PM to 6PM at Newark Beth Israel Medical Center; more details to follow.

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

Travel Letters:
Are you going to be traveling? Are you going to need a travel letter? If you answered yes to either of
those questions, this information is for you. Please remember to let the HTC staff know if you are going to need a travel letter at least two weeks prior to your scheduled trip so you can rest assured that your letter is in your hand as you embark on your journey.

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

**Manufacturer Programs:**
Manufacturers have programs available to help patients continue to receive products during a lapse of insurance coverage. They also offer copay 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 the HTC.

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

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**St. Michael’s Medical Center**

**School Visits:**
School is certainly back in session and we want to remind you that we are available for school visits. Our main goal is to educate school staff about the different types of bleeding disorders and new treatments. You may call The Blood Research Institute at (973) 877-5342 for more information.

**Scholarships:**
Feel free to call us at (973) 877—5342 for information on scholarships. We know a lot of our patients are now entering college and might be in need of financial assistance. Please do not hesitate to call and ask for information, help, and assistance.

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

**End of Year Celebration:**
Our Psychosocial gathering will be taking place at St. Michael’s Medical Center on December 22, 2018 from 12:30pm to 2:30pm. Please call our center at (973) 877-5342 to RSVP and be on Santa’s List. We are looking forward to having a day of fun.

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.

From all of us at St. Michael’s Medical Center we wish you all a beautiful and healthy Fall Season!!!
My Hemophilia Journey…
By Andrew Michael DiGiovanni

My name is Andrew Michael DiGiovanni. I am 15 years old and in the 10th grade. I love staying active and hanging out with my friends.

When I was a baby, my mom noticed that I was getting lots of bruises. She took me to the doctors who asked if anyone was hurting me or if she knew of anyone that would abuse me. The doctor even said that if I were to go to the hospital that they would call child protective services. My mom was very worried and took me back to the doctors for the 3rd time and insisted that I get blood work done. That’s when I was diagnosed with Hemophilia B Severe. I was nine months old.

Hemophilia is a life threatening bleeding disorder in which I have no clotting factor, which means I can bleed spontaneously internally or externally. There is no cure for Hemophilia, but I am protected with the protein of Factor IX which I infuse intravenously directly into my veins. YES, I can inject myself. IX which I infuse intravenously protects me. There is no cure for Hemophilia, but I am protected with the protein of Factor IX which I infuse intravenously directly into my veins. YES, I can inject myself. IX which I infuse intravenously protects me.

They helped me overcome many obstacles. I believe in myself and have more confidence. I’m not afraid anymore because I know I will always have my Hemophilia Family. All my troubles go away when I’m with my Hemophilia Family. I’m a new Me Now! I’m better, I’m stronger! I’m more caring and more understanding to others feelings. I’m a kinder person because of the bond this Community has. I learned so much. I can do anything I really want to do because I believe in myself, my dreams, my future. I’m going out to the big world out there and be all I can be! I’m going to be me, Andrew Michael DiGiovanni. My Hemophilia Journey…

Thank you all for your support. You changed my life. You brought me hope. You helped me through my troubles. I couldn’t do this on my own before, but I have this strong Community by my side with me now and forever!!

Thank you all for your support. You changed my life forever.

For people with hemophilia, Factor treatment temporarily replaces what’s missing. With a long track record of proven results, Factor treatment works with your body’s natural blood clotting process to form a proper clot.

Brought to you by Shire, dedicated to pursuing advancements in hemophilia for more than 70 years.

Stay empowered by the possibilities.

In hemophilia B
TAKE CONTROL TO A HIGH LEVEL WITH REBINYN®

Now available:
Rebinyn elevates factor levels above normal levels†
+94% Factor IX (FIX) levels achieved immediately after an infusion
17% FIX levels sustained after 7 days‡

With a single dose of Rebinyn® 40 IU/kg in adults with ≥2% FIX levels

How should I use Rebinyn®?
• Rebinyn® is given as an infusion into the vein.
• Call your healthcare provider right away if your bleeding does not stop after taking Rebinyn®.
• Do not stop using Rebinyn® without consulting your healthcare provider.

What are the possible side effects of Rebinyn®?
• Common side effects include swelling, pain, rash or redness at the location of infusion, and itching.
• Call your healthcare provider right away or get emergency treatment right away if you get any of the following signs of an allergic reaction: hives, chest tightness, wheezing, difficulty breathing, and/or swelling of the face.
• Tell your healthcare provider about any side effect that bothers you or that does not go away.

Who should not use Rebinyn®?
• Are allergic to Factor IX or any of the other ingredients of Rebinyn®.
• Are allergic to hamster proteins.
• Have had any medical conditions.
• Take any medicines, including non-prescription medicines and dietary supplements.
• Are nursing, pregnant, or plan to become pregnant.
• Have been told you have inhibitors to Factor IX.

Please see Brief Summary of Prescribing Information on the following page.

Rebinyn® is a prescription medication. 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.

Learn more at rebinyn.com

In hemophilia B
TAKE CONTROL TO A HIGH LEVEL WITH REBINYN®
Ask the Expert
Kim Stenberg
Vice President, Policy and Advocacy,
Hemophilia Federation of America (HFA)

If you are experiencing a problem with Accu- mulator Adjuster Programs (AAPs), please contact the HANJ Office for assistance.

Q: I’m hearing more and more about accumulator adjuster programs (AAPs). As we move into open enrollment this fall, how do I find out if my health insurance plan has an AAP?
A: Accumulator adjuster programs are part of a strategy to drive patients to a generic drug in order to contain costs that pharmacy benefit managers (PBMs) are implementing around the country. AAPs are part of the benefit design that PBMs apply to health insurance plans, and apply to patients who use drug co-pay cards and other forms of manufacturer copay assistance. AAPs are still applied to patients who are prescribed specialty products such as clotting factor even though there are no generics available. Under an AAP, a PBM accepts the manufacturer copay assistance for out-of-pocket costs associated with a prescribed drug, but then doesn’t credit that amount toward the patient’s overall deductible. This means that patients with chronic and expensive disorders will still be required to personally pay deductibles, copays, and other out-of-pocket expenses up to the yearly out-of-pocket maximum, even as the health plan draws down the full amount of the copay card. This creates a huge financial burden for patients and their families.

So how do you find out if your health insurance plan has an AAP? Many employers provide a choice of health insurance plans during open enrollment. Prior to enrolling in your 2019 health insurance plan, review the policies for each plan offered and all plan documents. Make sure you have copies of the summary of benefits and coverage, drug formularies, and provider network. Most of this information is available online. Fully understand your options. Ask your HR department or call the insurance plan directly if you think you need more guidance or can’t find information on AAPs in your plan options—and keep pressing for clear answers. Note that there is no industry standard name for AAPs, and some plans use euphemistic titles such as “Out of Pocket Protection Program.” This can make it hard to detect an AAP in your plan. Finally, don’t wait until the last minute to enroll. Start researching as early as you can.

Throughout your plan year, closely watch your Explanation of Benefits (EOB) notifications. You should be able to track whether the copay assistance payment is being applied to your deductible and/or out-of-pocket maximum. If your plan has an AAP, this means you’ll be billed for your copay after your copay assistance is depleted. You may need to budget for that unanticipated out-of-pocket cost or seek additional financial assistance.

Q: My health insurance plan is provided by my employer, so how can I find resources to help with the financial hardship an AAP creates?
A: Before enrolling in your employer’s health insurance plan, explore your options. For example, compare your employer’s plan to your spouse’s plan. Or find out if your state has a chronic disease assistance program that provides assistance with out-of-pocket costs.

AAPs can leave people who live with expensive chronic conditions, like bleeding disorders, with unexpected barriers to treatment when an individual or a family can’t pay the out-of-pocket cost. If this happens to you, check out the options in HFA’s Resource Library: Navigating Patient Assistance Programs. Or contact HFA directly at advocacy@hemophiliafed.org. You may also want to see if your specialty pharmacy provider can suggest any sources of assistance. A new patient assistance fund may be able to help with expenses if you’re faced with an AAP.

HFA and National Hemophilia Foundation (NHF) are working to educate health plans and PBMs about the dangers posed by AAPs. If you have received a letter from your employer or benefits manager stating that your copay cards will no longer be applied to your deductible, HFA needs to hear from you. Please share your story with Project CALLS5 Collecting data about these issues is the only way to fight them.

Seasonal Affective Disorder

Overview
Seasonal Affective Disorder (SAD) is a type of depression that comes and goes with the seasons, typically starting in the late fall and early winter and going away during the spring and summer. Depressive episodes linked to the summer can occur, but are much less common than winter episodes of SAD.

Signs and Symptoms
Seasonal Affective Disorder (SAD) is not considered as a separate disorder. It is a type of depression displaying a recurring seasonal pattern. To be diagnosed with SAD, people must meet full criteria for major depression coinciding with specific seasons (appearing in the winter or summer months) for at least 2 years. Seasonal depressions must be much more frequent than any non-seasonal depressions.

Symptoms of Major Depression
• Feeling depressed most of the day, nearly every day
• Feeling hopeless or worthless
• Having low energy
• Losing interest in activities you once enjoyed
• Having problems with sleep
• Experiencing changes in your appetite or weight
• Feeling sluggish or agitated
• Having difficulty concentrating
• Having frequent thoughts of death or suicide.

Symptoms of the Winter Pattern of SAD include:
• Having low energy
• Hypersomnia
• Overeating
• Weight gain
• Craving for carbohydrates
• Social withdrawal (feel like “hibernating”)

Symptoms of the less frequently occurring summer seasonal affective disorder include:
• Poor appetite with associated weight loss
• Insomnia
• Agitation
• Restlessness
• Anxiety
• Episodes of violent behavior

Risk Factors
Attributes that may increase your risk of SAD include:
• Being female. SAD is diagnosed four to five times more often in women than men.
• Living far from the equator. SAD is more frequent in people who live far north or south of the equator. For example, 1 percent of those who live in Florida and 9 percent of those who live in New England or Alaska suffer from SAD.
• Family history. People with a family history of other types of depression are more likely to develop SAD than people who do not have a family history of depression.
• Having depression or bipolar disorder. The symptoms of depression may worsen with seasons if you have one of these conditions (but SAD is diagnosed only if seasonal depressions are the most common).
Younger Age. Younger adults have a higher risk of SAD than older adults. SAD has been reported even in children and teens.

The causes of SAD are unknown, but research has found some biological clues:

- People with SAD may have trouble regulating one of the key neurotransmitters involved in mood, serotonin. One study found that people with SAD have 5 percent more serotonin transporter protein in winter months than summer months. Higher serotonin transporter protein leaves less serotonin available at the synapse because the function of the transporter is to recycle neurotransmitter back into the pre-synaptic neuron.
- People with SAD may overproduce the hormone melatonin. Darkness increases production of melatonin, which regulates sleep. As winter days become shorter, melatonin production increases, leaving people with SAD to feel sleepier and more lethargic, often with delayed circadian rhythms.
- People with SAD also may produce less Vitamin D. Vitamin D is believed to play a role in serotonin activity. Vitamin D insufficiency may be associated with clinically significant depression symptoms.

Treatments and Therapies

There are four major types of treatment for SAD:

- Medication
- Light therapy
- Psychotherapy
- Vitamin D

These may be used alone or in combination.

Medication

Selective Serotonin Reuptake Inhibitors (SSRIs) are used to treat SAD. The FDA has also approved the use of bupropion, another type of antidepressant, for treating SAD.

As with other medications, there are side effects to SSRIs. Talk to your doctor about the possible risks of using this medication for your condition. You may need to try several different antidepressant medications before finding the one that improves your symptoms without causing problematic side effects. For basic information about SSRIs and other mental health medications, visit NIMH's Medications webpage. Check the FDA's website for the latest information on warnings, patient medication guides, or newly approved medications.

Light Therapy

Light therapy has been a mainstay of treatment for SAD since the 1980s. The idea behind light therapy is to replace the diminished sunshine of the fall and winter months using daily exposure to bright, artificial light. Symptoms of SAD may be relieved by sitting in front of a light box first thing in the morning, on a daily basis from the early fall until spring. Most typically, light boxes filter out the ultraviolet rays and require 20-60 minutes of exposure to 10,000 lux of cool-white fluorescent light, an amount that is about 20 times greater than ordinary indoor lighting.

Psychotherapy

Cognitive behavioral therapy (CBT) is a type of psychotherapy that is effective for SAD. Traditional cognitive behavioral therapy has been adapted for use with SAD (CBT-SAD). CBT-SAD relies on basic techniques of CBT such as identifying negative thoughts and replacing them with more positive thoughts along with a technique called behavioral activation. Behavioral activation seeks to help the person identify activities that are engaging and pleasurable, whether indoors or outdoors, to improve coping with winter.

Vitamin D

At present, vitamin D supplementation by itself is not regarded as an effective SAD treatment. The reason behind its use is that low blood levels of vitamin D were found in people with SAD. The low levels are usually due to insufficient dietary intake or insufficient exposure to sunshine. However, the evidence for its use has been mixed. While some studies suggest vitamin D supplementation may be as effective as light therapy, others found vitamin D had no effect.

To learn more, visit www.jivi.com.
Our Association held its Fall Educational Symposium on September 13, 2018 at The Madison Hotel in Morristown, NJ. We encourage our members to attend our Educational Symposiums to learn more about important topics affecting their life with a bleeding disorder and to meet and network with others in the community.

Miriam Goldstein, Association Director of Policy for the Hemophilia Federation of America (HFA), presented “Can I get a Witness? Legal Rights for Bleeding Disorders” and Clarissa Robles, Senior Community Specialist for WellCare Health Plans of New Jersey presented “Everything you need to know about New Jersey Family Care”. Both presentations were a hit!

We encourage members to submit topics of interest you would be interested in learning about. Please feel free to contact us with your suggestions.
Planning for Health Care Costs

Discussing worst-case scenarios with family is never easy. These tips from Merrill Lynch Wealth Management outline four conversations every family should have right now.

“When my mom and dad started having health problems about a decade ago, my wife, Maddy, and I said, ‘Do we want to have a discussion about our own long-term care?’” recalls Dr. Ken Dychtwald. “And we both realized we did not want to talk about it, because it is a horrible discussion to have. You know—what happens if you have a stroke, or you can no longer walk?”

Not even experts in the field of aging, like Dychtwald and his wife, Maddy, co-founders of Age Wave, an organization that studies the challenges of aging, want to think about frightening health-related “what-ifs” when it comes to their personal lives.

“My generation—the boomers—prefer to think of ourselves as indestructible,” Dychtwald says. “But, you know what? We said to ourselves, ‘It is not fair to either of us or our kids not to have this discussion.’” So the Dychtwalds did their homework. “We made some important decisions. For one, we decided to buy long-term-care insurance.”

Talking about how you will pay for your future health needs is just one of several critical conversations related to health and wealth that family members should be having. “For many, it is the missing piece of the retirement puzzle,” says Dychtwald. Yet as important as these conversations are, the vast majority of people are not having them. Seven out of 10 couples age 50 and older have not discussed how much they will need to save for health care in retirement; and only one in five people age 50+ has talked about long-term-care plans with their adult children, according to a 2015 Merrill Lynch study conducted in partnership with Age Wave.

Here are four questions that can help you start having these important family conversations. Sit down with your spouse, your children, your parents and your siblings. Talk about your expectations. Make plans together. Then, should one of you become ill, you can all concentrate on one another instead of worrying about the finances and whether you are doing the right thing for everyone concerned.

1. Where will the money come from?
   It is never too early to talk about the potential costs and other consequences of medical care for yourself, your children or your parents. The considerations should include possible outlays for such expenses as home health care or changes to your house to accommodate a disability.

   "Once Maddy and I had our talk, we felt better," Dychtwald says. "We may not be able to wave a magic wand and make ourselves perfectly healthy for the rest of our lives, but at least we know that we are covered should one of these things happen to either of us."

   Though long-term-care insurance was an appropriate choice for the Dychtwalds, it is not right for everyone. There are a number of other financial choices you can consider, from hybrid forms of life insurance and Health Savings Accounts to simply saving and investing more for eventual medical costs.

   A logical next step, after you discuss these issues with your family, is to re-examine your choices with a financial advisor to help ensure that your retirement and any legacy you hope to pass on will not be threatened.

2. Will our parents have the care they need as they grow older?
   In addition to considering their own future, many people struggle with aging parents’ unwillingness to face their limitations. The best response is to ask specific questions: At what point would it make sense for you to stop driving, or to have a caretaker come in to help with meals?

   Cynthia Hutchins, director of Financial Gerontology at Bank of America Merrill Lynch, advises bringing these issues up long before safety concerns arise, and then positioning yourself as your loved ones’ ally.

   “Often when you first broach the topic, you will be rebuffed,” says Kate Wilber, professor of gerontology at the University of Southern California Davis School of Gerontology. “That is normal. It does not mean the door is closed. This will likely take more than one conversation.”

3. Who will provide the caregiving, if it is needed?
   Taking care of aging parents—or paying for their care—can be a large responsibility, and yet it is a responsibility that often falls unevenly in families.

   Hutchins recommends that siblings talk first among themselves about how they will share the caregiving role. “You want to be sure that both your parents’ and your own needs are considered,” she says. “Sometimes it makes sense to cobble together a combination of in-home and outside care.” That way, siblings can at least share the costs, if not the hands-on responsibilities.

4. What about end-of-life issues?
   Having this conversation can help ensure that a loved one’s (or your own) wishes will be honored. Among the things to consider: Which medical treatments do you want to be used or avoided at the end of your life? Whom do you want to be your health-care proxy if you are unable to communicate your wishes? You can use a health-care power of attorney and a living will to document your choices.

   Once you have discussed these tough subjects with your family, it is important to keep talking as years go by and circumstances change. “No one can predict their health future,” Dychtwald says. “But you can put plans in place to help prepare yourself for what might come.”

   Having these important conversations is the first step to getting there.

For more information, contact your Merrill Lynch Financial Advisor Cono T. Spinelli of the Paramus, N.J. office at 201.967.2730 or cono_spinelli@ml.com.

Long-term care insurance coverage contains benefits, exclusions, limitations, eligibility requirements and specific terms and conditions under which the insurance coverage may be continued in force or discontinued. Not all insurance policies and types of coverage may be available in your state.
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**Hemophilia Association of New Jersey**

**2018 Fall Educational Symposium Exhibitors**

Bayer Healthcare Pharmaceuticals  
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Pfizer Inc.  
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We would like to Thank all the Exhibitors at our Fall Educational Symposium this year. We appreciate your support!

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**JOIN US FOR**

**GATEWAYS TO EDUCATION; EXPLORING OPPORTUNITIES THAT MAY BE RIGHT FOR YOU**

Educational opportunities are everywhere - you just need to know where to look

In this CoRe Conversation, we will explore a wide variety of programs that can help you achieve your educational goals. Whether you’re considering a 4-year university, are a non-traditional student heading back to school, or are interested in pursuing a technical skill, this event is designed to help you find the path to learning what is right for you.

**Wednesday - December 5th, 2018 6:30pm**

Seasons 52: 217 Lafayette Ave, Edison, NJ  
Hemophilia Association of New Jersey  
RSVP: chansen561@comcast.net or 732-249-6000

**CONNECT WITH US ON FACEBOOK @BIOVERATIVCORES**
The NJ Blood Brotherhood program holds free events for men with bleeding disorders. This group is open to anyone over the age of 21 who has a bleeding disorder. Each of our events incorporates a bit of education, socializing and a physical activity, but we typically use the time to get to know other guys in the community. The events are completely free and there is no commitment to attend every event.

If you’d like to join the Blood Brotherhood group and attend one of our events, please reach out to Joe Markowitz (Joe.Markowitz@gmail.com, 201-650-0335) or Peter Marcano (petermarcano@gmail.com, 201-401-7080) or HANJ directly.

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

DONATE! DONATE! DONATE!
Please show your support by donating to The Hemophilia Association of New Jersey. Every single dollar counts!
Your donations go towards providing crucial programs to support persons with hemophilia in New Jersey.

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

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

WHAT IS HEMLIBRA?
HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children with hemophilia A with factor VIII inhibitors.

WHAT IS THE MOST IMPORTANT INFORMATION I SHOULD KNOW ABOUT HEMLIBRA?
HEMLIBRA increases the potential for your blood to clot. Discontinue prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis. Carefully follow your healthcare provider’s instructions regarding when to use an on-demand bypassing agent, and the dose and schedule you should use.

HEMLIBRA may cause the following serious side effects when used with aPCC (FEIBA®), including:

- **Thrombotic microangiopathy (TMA).** This is a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs. Get medical help right away if you have any of the signs and symptoms of TMA during or after treatment with HEMLIBRA.

- **Blood clots (thrombotic events).** Blood clots may form in blood vessels in your arm, leg, lung or head. Get medical help right away if you have any of the signs or symptoms of blood clots during or after treatment with HEMLIBRA.

If aPCC (FEIBA®) is needed, talk to your healthcare provider in case you feel you need more than 100 U/kg of aPCC (FEIBA®) total.
Hemophilia A is a bleeding condition people can be born with where what is the most important information I should know about HEMLIBRA?

HEMLIBRA increases the potential for your blood to clot. Discontinue prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis. Carefully follow your healthcare provider’s instructions regarding when to use an on-demand bypassing agent, and the dose and schedule you should use. HEMLIBRA may cause the following serious side effects when used with aPCC (FEIBA®), including:

- Thrombotic microangiopathy (TMA). This is a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs. Get medical help right away if you have any of the following signs or symptoms during or after treatment with HEMLIBRA:
  - coughing up blood
  - gas or vomiting
  - feeling sick
  - decreased urine

- Blood clots (thrombotic events). Blood clots may form in blood vessels in your arm, leg, lung, or head. Get medical help right away if you have any of these signs or symptoms of blood clots during or after treatment with HEMLIBRA:
  - swelling in arms or legs
  - pain or redness in your arms or legs
  - shortness of breath
  - chest pain or tightness
  - fast heart rate

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

See “What are the possible side effects of HEMLIBRA?” for more information about side effects.

WHAT IS HEMLIBRA?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children with hemophilia A with factor VIII inhibitors. HEMLIBRA is a therapeutic antibody that bridges clotting factors to help your blood clot.

BEFORE USING HEMLIBRA, TELL YOUR HEALTHCARE PROVIDER ABOUT ALL OF YOUR MEDICAL CONDITIONS, INCLUDING IF YOU:

- are pregnant or plan to become pregnant. It is not known if HEMLIBRA may harm your unborn baby. Female who are able to become pregnant should use birth control (contraception) during treatment with HEMLIBRA.
- are breastfeeding or plan to breastfeed. It is not known if HEMLIBRA passes into your breast milk.

Tell your healthcare provider about all the medicines you take, including prescription medicines, over-the-counter medicines, vitamins, or herbal supplements. Keep a list of them to show your healthcare provider and pharmacist when you get a new medicine.

HOW SHOULD I USE HEMLIBRA?

See the detailed “Instructions for Use” that comes with your HEMLIBRA for information on how to prepare and inject a dose of HEMLIBRA, and how to properly throw away (dispose of) used needles and syringes. You may report side effects to the FDA at (800) FDA-1088 or www.fda.gov/medwatch. You may also report side effects in your blood is clotting and may cause a false reading. Talk to your healthcare provider about how this may affect your care.

WHAT ARE THE POSSIBLE SIDE EFFECTS OF HEMLIBRA?

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

The most common side effects of HEMLIBRA include:

- redness, tenderness, warmth, or itching at the site of injection
- headache
- joint pain
- joint swelling
- These are not all of the possible side effects of HEMLIBRA.

Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088 or 1-888-835-2555.

HOW SHOULD I STORE HEMLIBRA?

Store HEMLIBRA in the refrigerator at 36°F to 46°F (2°C to 8°C). Do not freeze.

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

If needed, unopened vials of HEMLIBRA can be stored out of the refrigerator and then returned to the refrigerator. HEMLIBRA should not be stored out of the refrigerator for more than 7 days at 86°F (30°C) or below.

After HEMLIBRA is transferred from the vial to the syringe, HEMLIBRA should be used right away.

Throw away (dispose of) any unused HEMLIBRA left in the vial.

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

GENERAL INFORMATION ABOUT THE SAFE AND EFFECTIVE USE OF HEMLIBRA.

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use HEMLIBRA for a condition for which it was not prescribed. Do not give HEMLIBRA to other people, even if they have the same symptoms that you have. It may harm them. You can ask your pharmacist or healthcare provider for information about HEMLIBRA that is written for health professionals.

WHAT ARE THE INGREDIENTS IN HEMLIBRA?

Active ingredient:emicizumab

Inactive ingredients: L-arginine, L-histidine, poloxamer 188, and L-ascorbic acid.

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