Fall
2019

HANJournal

Fall behind…
Remember to turn your clocks back one hour on November 3, 2019 at 2am.

Don't miss…Back to School: Have you Covered All the Bases? Page 12

President's Message

By Ron Grayzel, Esq.

One of the most important functions of our organization is to advocate for the concerns of the bleeding disorders community with our Governor, the Legislature and the New Jersey State Department of Health. Our legislative track record is impressive:

- 1987 HANJ obtained a grant from the Department of Health to purchase insurance policies for qualified persons in the Hemophilia Community
- 1996 Legislation opening a one year window Statute of Limitations in New Jersey for victims of tainted factor concentrate products to sue manufacturers for compensation
- 2000 Standards of Care legislation requiring medical providers in New Jersey to comply with the generally accepted Standards of Care when treating Hemophilia
- 2018 Legislation designating March of each year as "Bleeding Disorders Awareness Month" in New Jersey.

Each of these legislative accomplishments were successfully pursued against great odds only because of the dedication and commitment from community activists and HANJ Board and staff. We are also grateful to our friends, Representatives and Legislators, for working on our behalf to pass this legislation.

Each year we honor our Legislative Heroes at our Annual Meeting with the Dean Gallo award. The most recent recipients include:

- 2019 Senator Robert Menendez
- 2018 Assemblyman Daniel R. Benson
- 2016 Assemblyman Nancy Pinkin
- 2015 Marilyn Gorney-Daley, D.O., M.P.H.
- 2014 Senator Peter Barnes, III and Senator Jennifer Beck

HANJ was successful again with the recent passage of bill S3100 passed by the New Jersey Senate and Assembly and signed into law by Governor Murphy. This statute revises the definition of Hemophilia to expand the insurance grant program to include persons with acquired hemophilia, single factor deficiencies and qualitative platelet disorders. Many thanks to the sponsors of the legislation including Senators, Loretta Weinberg and Dawn Marie Addiego and Assembly Persons, Daniel R. Benson, Valerie Vainieri Huttle, Raj Mukherji, Britnee N. Timberlake, and Angela V. McKnight.

Also, congratulations to our executive staff, Stephanie Lapidow and Elena Bostick, and our Lobbyist, Board Member, Tracie DeSarno.

Still pending in the Legislature is our bill Senate 3348, requiring home health agencies and specialty pharmacies providing services related to bleeding disorders associated with hemophilia to comply with existing Standards of Care. The bill has passed the New Jersey State Senate and is awaiting action in the Assembly.

I hope to see you all at our annual fundraising event, Casino Night, on October 26, 2019 at the Pines Manor in Edison, New Jersey. Please contact the HANJ office if you would like to attend.

Best Regards,
Ron Grayzel, Esq.
President

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The Hemophilia Association of New Jersey was founded in August 1971 by 10 concerned families, and offers assistance to persons with hemophilia and their families from our office located in East Brunswick, New Jersey.
Our mission is to improve the quality of life for persons with a bleeding disorder by providing and maintaining access to highly qualified medical providers and successfully proven medical regimens.

What's in this Issue: :

Social Worker Update
By Neidy Olarte, MSW
Social Service Coordinator

Family Connections

HANJ has been bringing together families and individuals in the bleeding disorder community through our Family Connections program. Our Family Connections program encourages members to reach out to one another for support and to connect with one another. In today's world with an increase in social media and the internet, there seems to be little effort made to try and make face to face connections, leaving our community with a sense of isolation. While HANJ has increased our presence by hosting several educational and social events throughout New Jersey, we understand that it is difficult for everyone to attend some of our events. This program was started by members requesting to get in contact with other members dealing with similar circumstances. We would like to increase our list of participants in the Family Connections program. If you are interested in participating and would like more information about the Family Connections program, please contact me at (732) 249-6000 or nolarte@hanj.org for more information.

Insurance Enrollment Period

Open enrollment period for individual health insurance and insurance through the marketplace will be available from **Friday, November 1, 2019 to Sunday, December 15, 2019**. If you have individual insurance or insurance through the marketplace, this is the time period when you can make any changes to switch your plan. Changes to your insurance plan will take effect January 1, 2020. If you do not have insurance or lose coverage, this time period will be your opportunity to look at the different plans offered so you can choose one that fits your needs. If you do not enroll during this enrollment period, you will only be eligible to get insurance if you qualify for a special enrollment period. This is where there is a qualifying event that determines you are able to seek insurance outside of the enrollment period such as loss of insurance coverage.

Mark Your Calendars!

Open Enrollment period for individual health insurance and insurance through the market place will be available from :

Friday, November 1, 2019
to
Sunday, December 15, 2019

For a full list of qualifying events you can log onto the market place website at **www.healthcare.gov**. On this website you can enroll into a plan, see if you qualify for any tax credits that can help reduce your monthly premium or see if you are eligible for Medicaid. If you feel you are eligible for Medicaid, you do not have to wait to apply during the enrollment period. You may log onto the healthcare website anytime or you can go onto the NJ Family Care website for more information about Medicaid at **www.njfamilycare.org**.

HANJ will also be hosting an educational program on Wednesday, September 25, 2019 at Stage Left, a steak house, in New Brunswick to discuss different insurance options and answer any insurance questions you might have. If you are interested in attending this event please contact Cindy at (732) 249-6000 or by email at chansen@hanj.org.

For more information on the insurance enrollment period or if you have any specific insurance questions please feel free to contact me at the office or contact your Hemophilia Treatment Center. You can also go on the healthcare website at **www.healthcare.gov** for further insurance assistance and to look at the current insurance plans available in your area.

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 two studies: 1) The VWD Minimize Study: Crossover Trial Comparing Recombinant von Willebrand Factor (rVWF) vs. Tranexamic Acid (TA) to Minimize Menorrhagia in Women with Type 1 von Willebrand.
2) 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 3) 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 in-service programs to school and camp personnel about a child's hemophilia. If you are in need of an in-service program at your child's school, please contact Lisa Cohen, MSW at 732-235-6533. *Please contact Lisa ASAP, as the slots for these visits fill up very quickly!*

Upcoming Training:
A family educational program is scheduled for October 14, 2019. Program information will be available shortly and mailed to HTC families. Additionally, 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.

Rutgers Robert Wood Johnson Medical School
Hemophilia Treatment Center
125 Paterson Street
5th Floor
Suite 5200
New Brunswick, NJ 08901
To make an appointment:
(732) 235-7226
Nurse Direct Line for Medical Issues:
(732) 235-6531
Social Worker:
Lisa Cohen, MSW,LSW
(732) 235-6533
cohenlr@rwjms.rutgers.edu

Newark Beth Israel Medical Center and Children's Hospital of New Jersey

As fall is just around the corner, 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.

Staff News:

New Staff:
We are happy to announce that Cassandra Amos, MA has joined our team as our Financial Coordinator. Cassandra specializes in insurance issues. Welcome Cassandra!

UPCOMING

Save the Date:
The HTC Annual Holiday Party will be held on Saturday December 14, 2019 from, 2PM to 6PM, at Newark Beth Israel Medical Center; details to follow.

NEWS

School Visits:
As the school year begins, 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.

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 patients' 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.**

ONGOING PROGRAMS

Treatment Logs:
The HTC is aiming to get all patients (who treat their bleeding disorder with medication) to track their infusions and or treatment in a treatment log. In an effort to provide the best possible care for our patients, it is extremely important that our physicians and nurses can see a patient's treatment logs, in real time, for the management of their bleeding disorder. ATHNadvoy is a web-based application that allows patients, or their caregivers, to record any and all treatment related to their bleeding disorder in a user friendly way directly through their smart phone, tablet, laptop, or computer. When a user creates an account, they choose their treatment center; linking the patient and the HTC, and allowing the HTC to have access to view a patient's treatment log. For more information, or to sign up, please contact our Social Worker, Erica.

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.

The annual evaluation is an essential component in the provision of an individual's comprehensive care.

<u>Comprehensive Evaluations</u>:
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 <u>must</u> be seen by the HTC on an annual basis.**

<u>Travel Letters</u>:
Are you going to be travelling? 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.

<u>Manufacturer Factor Programs</u>:
Manufacturers have programs available to help patients continue to receive products during a lapse of insurance coverage. They also offer co-pay assistance programs. Each program has enrollment requirements and many require yearly re-enrollment. Enrollment in these programs can be beneficial. For more information, please contact your home care company or us at the HTC.

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

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

St. Michael's Medical Center

<u>School Visits:</u>
A new school year is starting and we want to remind you that every year at the beginning of October we are available to start visiting schools for the purpose of staff education. If you are interested in scheduling a school visit, please contact, Joanne Rodriguez, Social Worker at The Blood Research Institute at (973)877-2967.

Every year at the beginning of October we are available to start visiting schools for the purpose of staff education.

<u>Patient Education:</u>
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.

Our Staff is available for individual educational sessions on topics such as infusion techniques and factor products.

<u>Individualized Sessions:</u>
Our Staff is available for individual educational sessions on topics such as infusion techniques and factor products. If you need assistance please contact Dominique Joseph, RN at (973) 877-5340. Our staff is also available for counseling sessions. If you need assistance please contact Joanne Rodriguez, Social Worker at (973) 877-2967.

<u>Psychosocial Yearly Evaluations:</u>
It is very important to visit your HTC yearly to follow up on treatments and with any issues or concerns that may arise during the year. Please call The Blood Research Institute at (973)877-5340 to schedule your next visit.

<u>Insurance:</u>
Please feel free to get in contact with us if any questions, issues or concerns arise in reference to changes with insurance plans. Our staff will be able to educate you as well as help you.

Here at St. Michael's Medical Center we hope you all had a great and safe summer. We hope this new school year finds everyone ready to have another successful year.

St. Michael's Medical Center
Hemophilia Treatment Center
111 Central Ave., Bldg. M2
Newark, NJ 07102
Patient's call: (973) 877-5340 or
(973) 877-5341 or
(973) 877-5342
Social Worker:
Joanne Rodriguez, CSW
(973) 877-2967
JRodriguez27@primehealthcare.com
Fax (973) 877-5466

Meet the Board...
Peter Marcano
HANJ Trustee

My name is Peter Marcano and I've been on the HANJ Board of Trustees for approximately eight years. I'm also one of the Co-Chairs of our Blood Brotherhood program. But most importantly, I'm a severe Hemophiliac. Diagnosed at eight months old. My life has been a series of ups and downs that I wouldn't trade for the world. Being a Hemophiliac has given me an extended family that had I not been one, I'm not sure what my life would be like. All important facets of my life, from meeting my best friend, my excursions around the country and my volunteer efforts, have all come from being a part of the world of Hemophilia.

I can't express how much joy I feel when I see younger Hemophiliacs start volunteering their time with local and national organizations. I think it's important to have the younger hemophiliacs continue to carry the torch our former blood brothers have started as we embark on significant change in treatment, funding and senior leadership with our national organizations.

It's never too late to get involved, I would be more than happy to share my experiences and suggest volunteer opportunities during our Blood Brotherhood events. I look forward to seeing you there!

HANJ Pharmaceutical Educational Programs

Thank you to all our members who came out for dinner and a presentation at Gourmet Italian Cuisine in Galloway, NJ, on Wednesday, July 17, 2019. It was great to see everyone. The presentation titled "Empowered: Tools for Self-Advocacy" by Annie Sukhnandan from Pfizer was very informative and the dinner at Gourmet was delicious. We all enjoyed an evening of education and community!

Members enjoyed a fabulous brunch at The Essex House and an educational program in partnership with Bayer. Margarita Rogers presented "Living with Hemophilia Ages 6 - 18". After the program, attendees met HANJ staff at the Turtle Back Zoo to enjoy an afternoon with their family. Thank you all for attending!

Upcoming Program:

Saturday, October 12, 2019
HANJ partnering with Shire
"Self-Advocacy: Sharing Your Story"

Presented in both English and Spanish

During the year, HANJ hosts several educational programs in partnership with various pharmaceutical companies once a month throughout New Jersey. These educational programs are a time for our members and their families to enjoy time together as well as be educated on updates and new information on Hemophilia. It also offers the opportunity to meet members of the community you have never met before and make some new friends. Please contact the HANJ office for additional information or to RSVP for any program you would like to attend. There is no limit on the programs you can attend.

Back to School: Have You Covered All the Bases?

Paul Clement

Sending your child with a bleeding disorder off to school for the first time can cause a mixed bag of feelings. You may feel relief: you're no longer on duty 24/7 and may even have some "me-time." But your anxiety may skyrocket: you're no longer your child's guardian angel, monitoring her every move and protecting her from harm. You must now rely on teachers and other school staff to protect your young student. And you must rely on your child's ability to communicate if he's experiencing a bleed or injury.

Although you may feel reassured after meeting with the school nurse and your child's teachers, be careful. How much of the information you provided really sank in? How will you ensure that school personnel know what to do in an emergency? You can make sure that staff are properly trained by requesting an Individualized Healthcare Plan (IHP) and an Emergency Care Plan (ECP). If you haven't heard of an IHP or ECP, or an IEP or 504 Plan, read on: your child's healthcare and academic success may depend on it.

What's an Individualized Healthcare Plan?

An IHP is a variation of a Nursing Care Plan.[1] It's written by the school nurse, based on information and approval from your child's physician, and in collaboration with the student, parent/guardian, healthcare providers (for example, hemophilia treatment center [HTC] physician, nurse, or social worker), and designated school staff (for example, vice principal or special education teacher). All these people normally sign off on the plan.

An IHP is designed to ensure that a child's medical requirements are properly met during a school day. It contains all pertinent information about your child's healthcare needs, including information about medications and where they'll be stored at school, as well as emergency contact information. The IHP lists the names of school staff who are responsible for monitoring your child's special healthcare needs: during transportation to and from school; while at school; during field trips; and in afterschool care or activities, such as sports or clubs. The IHP also includes a plan for how and when these staff will be trained. IHPs are reviewed at least annually, updated as needed, and revised when significant changes occur in the student's health.

Does My Child Need an IHP?

If your child has a bleeding disorder, the answer is yes. An IHP is the only way to make sure your child's healthcare needs are met at school.

How Do I Get an IHP?

The process for starting to develop an IHP can vary from state to state, and from school district to school district. Here are some general guidelines:

- Contact your child's hematologist and explain that you're requesting an IHP from your child's school. Ask if the doctor has an IHP template for your child's condition. Having a bleeding disorder IHP template will help the school nurse and jump-start the process.
- Contact the school principal or school nurse, preferably in writing, and request a meeting to develop an IHP. If your child is starting at a new school in the fall, begin this process three to six months in advance, so the IHP will be in place when school starts. If you already have an IHP in place, it must be renewed every year.
- After these first steps, the school should contact you to schedule a meeting with the nurse to discuss your child's needs. If your child is old enough, including him or her can be helpful and reassuring for everyone involved. If you're not confident that you can adequately discuss your child's needs, contact your HTC and ask if a nurse or social worker can accompany you to the meeting. Some specialty pharmacies with contracted nursing services may also provide this service.
- Give the nurse as much information as possible about your child's condition and healthcare needs, to help in developing the IHP. Some schools require a physician's letter detailing your child's medical condition and any special care and medications needed at school—ask if this is a requirement before meeting with the nurse.
- Provide emergency contact information for your child's hematologist, as well as emergency contacts for parents/ guardians.
- Before you meet with the nurse, sign a HIPAA (Health Information Portability and Accountability Act) Waiver of Authorization with your HTC hematologist. The HIPPA Privacy Rule (1996) is a federal law that established privacy standards related to sharing health information. The waiver is a legal document that allows your physician to share protected health information (PHI) about your child's health condition with the school nurse, who may call the physician to request health information.[2] As a part of the IHP team, you should participate in deciding which staff requires PHI for your child's safety. Staff who are trusted with PHI should be trained on their responsibility to safeguard that information.
- Ask the school to give you the quickest contact information to reach the right people, including the nurse and your child's teacher: direct phone numbers (bypassing switchboard or secretary) and perhaps cell phone numbers.
- Request copies of the IHP and ECP when they are completed.
- Document all communications: save emails, and record date, time, person spoken to, and summary of conversations with the school in case there is a dispute.

Don't assume that your child will automatically receive a factor infusion at school in an emergency. Because of budget constraints, many school districts no longer staff each school with a nurse. Instead, schools may have a nurse's aide, with one or two nurses rotating from school to school in the district. *Only a trained and licensed school nurse (RN) can give an IV infusion*. Even if the school has a full-time nurse, don't assume the nurse can, or will, infuse your child. Regulations on IV infusions by school nurses vary by state. Some states allow infusion of IV meds only through a central line and only after specialized training. In other states, infusion of IV meds by the school nurse isn't even an option.

Field Trips

Federal law prohibits schools from excluding students with special healthcare needs from attending school-sponsored field trips. If your child needs factor infusions and can't infuse himself, volunteer to accompany him on the field trip (check beforehand if fingerprinting is necessary). If you or a guardian with infusion skills can't attend the field trip, the school can't require you to attend (unless all parents are required to attend), and your child can't be excluded from the field trip. It's the school nurse's responsibility to make sure your child's healthcare needs are met.

Nursing responsibilities for infusing IV meds can't be delegated to nurse's aides or other unlicensed faculty or staff. This means the nurse must accompany your child on the field trip if other arrangements can't be made for emergency factor infusion. The school nurse must arrange for staffing the school health office during the field trip, and the costs of providing nursing or EMS services are the responsibility of the school district. Although a district may ask, parents can't be required to pay for nursing or EMS services for their child on a field trip, and the child can't be excluded from the field trip because of cost.

And you can't rely on emergency medical services (EMS) personnel, such as paramedics, to infuse your child. In all states but Missouri, EMS personnel are not permitted to infuse someone with his or her own medication (with some exceptions, such as insulin, Narcan®, and EpiPen®). To further complicate this, some hospitals also prohibit infusing meds brought in by the patient or parent/guardian—even if the hospital doesn't have the medication on hand. Ask the school nurse about the policy on infusing IV meds, and contact your local hospital to ensure that they will infuse your child with his own medication in an emergency (document all communication). Finally, if your child can self-infuse, make sure the IHP includes authorizations from your medical provider and the school nurse allowing him to infuse himself at school.

What Is an Emergency Care Plan?

An ECP differs from an IHP. An ECP is a one- or two-page set of guidelines providing concise, specific directions on what to do in a particular emergency.[3] Unlike an IHP, an ECP is a tool for

1. An Individualized Health Plan may also be called an Individualized School Health Plan or Individualized Healthcare Plan.
2. Your physician does not need the waiver to share medical information with the school nurse, because HIPPA allows this under an exception called "treatment purposes." But medical offices often aren't aware of this exception and may reject a PHI inquiry, so be prepared with a waiver. Once PHI is entered into a school's educational record, it's no longer subject to HIPPA privacy rules. The confidentiality of student education records is weakly protected by another federal law, the Family Educational Rights and Privacy Act (FERPA). Unlike HIPPA, FERPA doesn't generally protect the confidentiality of information; beyond the school nurse, most school staff don't know about FERPA guidelines. Nurses also may not completely understand FERPA, and may violate FERPA regulations by publishing schoolwide lists of student names and health conditions. You have a right to see what's in your child's record: FERPA requires every school district to annually notify parents and eligible students (over age 18) of their right to inspect and review their children's or their own education records.
3. An Emergency Care Plan may also be called an Emergency Action Plan or Action Plan.

nonmedical personnel, like teachers, to follow in an emergency until medical assistance arrives. An ECP may also have a field trip plan. An ECP is a stand-alone document, included in the IHP.

Does My Child Need an ECP?
Any child with a bleeding disorder should have an ECP in addition to an IHP. The ECP is written for nonmedical personnel, often in a "If this happens, then do this" format. It contains as few words as possible, so someone can do a fast visual scan and quickly learn what to do in an emergency. So, although an ECP may include some of the same medical information found in the IHP, it is only an action plan—it focuses on what to do in an emergency and little else. The ECP is distributed to your child's teachers and to other school staff, such as bus drivers or school aides, who your child may see during the day. Teachers should also include a copy of the ECP in their substitute folder (containing lesson plans and instructions for a substitute teacher, in case the teacher is absent).

ECPs for children with bleeding disorders must stress the importance of early treatment, and of contacting the parent/guardian immediately if the child is injured or reports having a bleed. Also, staff should be told that most bleeds are internal, often with no outward signs; so they must always accept the word of the student.

Education Acronyms
ECP: Emergency Care Plan
FAPE: Free and Appropriate Education
FERPA: Family Educational Rights and Privacy Act
HIPAA: Health Information Portability and Accountability Act
IDEA: Individuals with Disabilities Education Act
IEP: Individualized Education Plan
IHP: Individualized Healthcare Plan

Academic Help
IHPs and ECPs help protect your child's health at school. But what if your child's bleeding disorder is affecting—or might affect—her academic performance?

All US children are guaranteed the right to a free and appropriate public education, or FAPE. This right is guaranteed by two federal laws: Section 504 of the Rehabilitation Act of 1973 (Public Law 93-112) and the Individuals with Disabilities Education Act, or IDEA (Public Law 101-476). The two laws approach FAPE in very different ways.

Section 504
Section 504 of the Rehabilitation Act is a civil rights law that protects anyone with a disability who attends a federally funded program, activity, or institution. Section 504 states that "no otherwise qualified individual with a disability in the United States…shall, solely by reason of his or her disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance."[4] The main goal of Section 504 is to ensure that the educational needs of disabled students are met as adequately as those of the nondisabled. This applies to all public schools, charter schools, and magnet schools; to any class level, including magnet, gifted, advanced placement, and honors; and to private and religious schools that accept any federal funds, such as federal school voucher funds.[5]

To qualify for support under Section 504, a student must have a physical or mental impairment that "substantially limits any major life activities at any time." The Americans with Disabilities Act (ADA), Amendments of 2009, expanded this definition to include "anyone who has a record of such an impairment" and "anyone who is regarded as having such an impairment."

Section 504's definition of "major life activities" is very broad, and includes caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating, working…and much more. When your child with a bleeding disorder suffers from a bleed or other complication, he could be greatly limited in several of these activities, and this would qualify him for support under Section 504. Your child doesn't have to be substantially limited in any life activities when you apply for Section 504 support. An impairment that is *episodic* (like a bleed) or is in remission or controlled by medications (like prophylactic factor infusions) is still considered a disability if it would limit participation in a major life activity when an episode is taking place.

If you would like a Section 504 evaluation meeting, email your request to the 504 coordinator in your school district, and copy the school principal. The school will then notify you in writing of its intent to conduct an evaluation, why the evaluation is being conducted, and how it will be

4. www2.ed.gov/about/offices/list/ocr/504faq.html 5. Private schools often deny that they are subject to federal laws. However, pursuing a complaint against a private school has become more challenging, as the current US secretary of education has refused to commit to enforcing federal laws in private schools.

conducted. And although not required by law, parental/guardian consent for an evaluation is usually requested before convening the 504 team. Section 504 defines "evaluation" as the gathering of data or information from a variety of sources to assist the evaluation committee in its work. Common sources of evaluation data for 504 eligibility are the student's grades, disciplinary referrals, health information (including an IHP), language surveys, information from parents or guardians, standardized test scores, and teacher comments.

Don't walk into a 504 meeting unprepared! Before the meeting, look at sample 504 plans and know your state and school policies. Read the US Department of Education resource guide for parents and educators seeking a 504.[6] Make a list of the accommodations you want for your child. Bring your child's IHP and ECP, as well as specific instructions for everyday and emergency management of your child's bleeding disorder. Who should attend the 504 meeting with you? A friend or advocate (who knows the law and represents your interests) to take notes, the school nurse and classroom teacher(s), and the 504 coordinator, at a minimum. The school principal, a counselor, lunch or recess aide, or special education coordinator may also be present. See if your HTC can offer support.

What Are Accommodations and Modifications?
If your child is eligible for Section 504 support, then a 504 *accommodation* plan (504 Plan) is created. Remember that 504 Plans provide for accommodations, and, less commonly, for *modifications*. There are no changes in the curriculum itself for 504 eligible students.

Accommodations are changes in *how* a student accesses information and demonstrates learning. They do not alter the instructional level or content, and they do not lower standards or achievements. 504 Plan accommodations are offered in the "least restrictive environment," meaning the student's regular general education classroom, not in a special education classroom.

Modifications are changes in *what* a student is expected to learn. Modifications may include changes in instructional level, content or curriculum, performance criteria, and assignments. Modifications are the backbone of Individualized Education Plans (IEPs) for special education, but are not common in 504 Plans.

6. Department of Education Parent and Educator Resource Guide to Section 504 in Public Elementary and Secondary Schools: www.ed.gov.

No additional funding is supplied to the school for implementing accommodations or modifications as part of a 504 Plan (though private schools may sometimes charge extra tuition for providing services). Unlike 504 Plans, schools receive additional funding for implementing accommodations and modifications as part of an IEP.

When Your 504 or IEP Request is Denied
What if your school refuses to give your child the accommodations needed to succeed?
Section 504 offers parents options for resolving disagreements with the school:
- Mediation
- Alternative dispute resolution
- Impartial hearing
- Complaint to the Office of Civil Rights (OCR)
- Lawsuit (remember that Section 504 provides fewer safeguards and rights than IDEA)

IDEA offers parents specific ways to resolve disputes:
- Mediation
- Due process complaint
- Resolution session
- Civil lawsuit
- State complaint

504 Accommodations for a Bleeding Disorder
There are dozens of possible accommodations for a child with a bleeding disorder. Let's review some of the most common. You'll also find lists of accommodations online—these can give you helpful ideas about what's possible, but remember that developing accommodations is highly individualized, and any services and accommodations must match student needs. Avoid the temptation to check off accommodations using a predetermined list or include unnecessary accommodations.

For your child, the most common accommodations will deal with attendance, tardiness, ability and timelines to make up missed schoolwork, ability to visit the school nurse or restroom, and ability to infuse at school.

Attendance is high on the list of problem areas for students with bleeding disorders. Students may miss school because of a bleed in progress, pain from a recent bleed, heavy or painful periods, physician orders to stay off a limb after a bleed, port infections, and so on. And although students with hemophilia and inhibitors are likely

to experience the most absences, everyone is at risk. All it takes is one serious bleed for a student with perfect attendance to suddenly miss several days or even weeks of school. That's why it's good for all students with a bleeding disorder to have a 504 Plan, even if they don't currently need or use the accommodations listed in the plan.

Remember that a student's grade can't be lowered because of excused absences for medical reasons. That is, attendance can't be part of grading (a frequent concern in PE classes). Also, students can't be penalized by assigning them extra work or not letting them participate in an activity. And students must be allowed to make up any work missed.[7]

Accommodations are often written as a series of bullet points and short phrases. But to avoid any confusion, write the accommodation in specific terms. For example, an accommodation for attendance might be "Adjust attendance policy." But what this means isn't clear, so a teacher or attendance clerk might not know exactly how to adjust the attendance policy. A better statement: "All absences for medical reasons, with correct paperwork, will be excused. Parent/guardian will submit a Chronic Illness Verification Form and promptly send in school-required paperwork to excuse each absence. Student will not be penalized by being assigned extra work or being denied participation in an activity due to excused absences." In addition, avoid writing accommodations that would be in conflict with school policies, such as "All absences are excused."

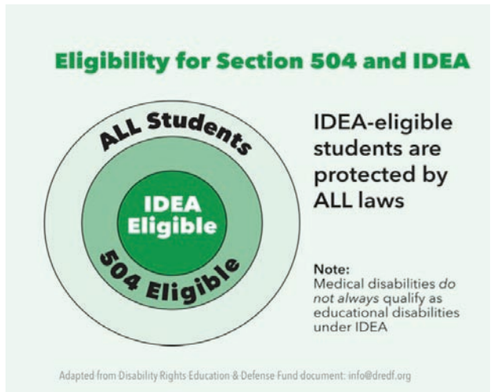
Even though a 504 Plan may offer accommodations for absences, it's not a free pass, and the privilege shouldn't be abused. Avoid the temptation to play the system or encourage your child to do so. A young child who doesn't want to attend school may quickly learn that by faking a stomachache, she gets to stay home. Or an older student with an accommodation that gives him extra travel time between classes may be tempted to use that time to talk to friends. Also, accommodations for absences don't excuse the parent or guardian from following school district guidelines. Failure to submit required paperwork may result in unexcused absences, leading to an "invitation" to the parent and child to attend truancy court or a Student Attendance Review Board.

7. Parents normally must submit paperwork to excuse absences for medical reasons. Some states, such as California, have a Chronic Illness Verification Form or something similar that make this process easier. After submitting the form, completed by the child's physician, parents can then excuse absences due to a specific medical condition without the need for a doctor's note. States also have a Home and Hospital Instruction Program for students with extended absences (usually three weeks or more): a teacher visits the home or hospital, for a limited time, to keep the student up-to-date on schoolwork.

In addition to accommodations for absences, lateness, and making up missed work, be sure your 504 Plan includes accommodations requiring teachers to send the student missing assignments on each day of an absence. Contacting parents and students is a lot easier for teachers now, thanks to school content management software—a website that allows teachers, students, and parents to interact. Typically, teachers have webpages for the classes they teach. They can upload an assignment to the webpage, and students can view it; or a teacher can send an assignment to a single student. Depending on the software, a teacher may also be able to upload an audio or video of the day's lesson.

Although modifications aren't usually part of a 504 Plan, for children with bleeding disorders, a modification concerning physical education often is. This might be permanent, if the child has an inhibitor, target joint, or joint damage; or temporary, until a bleed resolves.

Remember: Accommodations are changes that remove barriers to learning. They level the playing field for children with disabilities. They do not, as some people believe, give your child an unfair advantage over other students.



Individuals with Disabilities Education Act
IDEA is a federal education law that requires schools to serve the educational needs of eligible students with disabilities. IDEA fulfills the right to FAPE by providing special education services, including accommodations and modifications.

Unlike Section 504, which has a broad and inclusive definition of disability. IDEA's definition is narrow and limited. To be eligible for services under IDEA, a student must have disabilities that fall under one of 13 categories. Your child with a bleeding disorder may qualify under the category "Other Health Impairment." But having one of the 13 disabilities doesn't automatically qualify a child under IDEA. To be eligible, a student must...

- have a disability and, as a result of that disability, must…
- need special education and related services to make progress and benefit from the general education program.

In other words, the disability must negatively affect your child's educational performance; this is not a requirement of Section 504 support. Students who are eligible under IDEA need more support to succeed in school than just 504 Plan accommodations that "level the playing field." Almost all students with bleeding disorders are eligible for 504 Plan accommodations, but the restrictive IDEA requirements mean that relatively few qualify for special education services provided by IDEA. (See diagram above.)

Students who qualify for support under IDEA are offered an Individualized Education Program. An IEP is a legal document that spells out a child's educational goals and the services and support the school will provide. It's written specifically for your child's needs by members of a multidisciplinary team including the parent/guardian, general education teachers, special education teachers, special education coordinator (or someone with the authority to commit resources), school psychologist, and people who know your child or his condition and are invited by you or the school district.

IDEA recognizes that the parent/guardian is the child's most important advocate; unlike Section 504, IDEA assigns the parent many rights and responsibilities. You might be overwhelmed by your first IEP meeting: many people are present, education jargon is confusing, and you're unaware of your rights and what services are available. That's why it helps to bring a friend, so you can discuss things later. Your HTC may be able to send a social worker to the IEP meeting, or prep you on services. You may want to bring an advocate with you, someone familiar with your rights under IDEA who can represent your interests. Parents of other special education students may be able to recommend an advocate. In many cities, you can find special education advocates and lawyers who will assist you for free.

Warning: Set ground rules ahead of time for whoever you invite to the IEP meeting. The people you bring should be friendly, collaborative, and professional—you and the rest of the IEP team are all on the same side with the same goals. Some advocates who view IEP meetings as "us versus them" may be confrontational or combative—definitely not the way you want to start your first IEP meeting! On the other hand, every state, school district, and sometimes schools within a district have different viewpoints and cultures. If your child's school refuses to provide the services your child needs (and which are prescribed by law), then initiate a grievance process to get help. (See box, pg. 15, "When Your 504 or IEP Request Is Denied.")

For students who are eligible under IDEA, the extra support can mean the difference between academic failure and success. Yet some parents of children with bleeding disorders refuse to take advantage of Section 504 or IDEA. Why? Sometimes, it's because of a single word: "disability." Some parents resent even the suggestion that their child has a disability. Some parents don't want their child to be stigmatized by the label "special ed." But the special ed of a few decades ago is not the special ed of today. Negative perceptions of special ed are based on outdated, false information and myths.[8] Don't let the fear that your child may be labeled "special ed" stop you from getting her the help she needs. And don't hide the fact that she's using these services—let your family and friends know what special ed really is.

So, before sending your child off to school, cover all your bases. Ensure your child's healthcare by starting the process of developing an IHP and ECP early—several months before school starts. And to protect your child from falling behind academically, ask for a 504 Plan or an evaluation for IDEA eligibility. And don't worry about labels! Do what's best to help your child succeed in school.

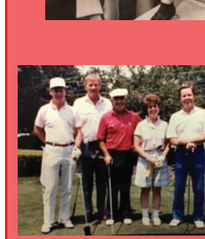
8. "10 Myths Parents May Hear About Special Education," available at www.understood.org.

Resources for Parents and Guardians
Understood.org: www.understood.org
Good information on 504 Plans and IEPs, with many excellent resources (though sometimes buried on the website, and found only by following links in articles)
Department of Education: www.ed.gov
Parent and Educator Resource Guide to Section 504 in Public Elementary and Secondary Schools
WrightsLaw: www.wrightslaw.com
Deals with special education law and advocacy, with articles on most aspects of special ed

Through the years...

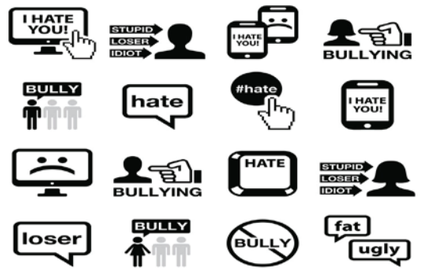
DENNIS KEELTY
40TH ANNIVERSARY
2019
HEMOPHILIA MEMORIAL GOLF CLASSIC

Monday, August 19, 2019
at
Plainfield Country Club



Today....

40 Years later ...
It started in 1979 as a Pro-Am. Over the years we tweaked it, changed the format, added a 50-50, eliminated the pros, etc..., all to insure the most enjoyable day possible for all who played golf, as well as the best possible outcome for HANJ. It took a few years, but the Dennis Keelty Memorial Golf Tournament became, and remains, the leading fundraiser of all HANJ Special Events. Our most sincere gratitude goes out to all of our sponsors, donors, and friends who helped to make this happen.



Bully Goes High-Tech

How parents can help kids cope in the age of cyberbullying

Bullying has moved beyond the schoolyard to the digital playground. Cyberbullying, the use of technology to threaten, intimidate, harass, embarrass or target another person, has been a growing problem. About 21% of children ages 12 to 18 report being the victims of cyberbullying through a combination of text messages, social media apps and online gaming platforms, according to StopBullying.gov, an educational website managed by the US Department of Health and Human Services. The consequences for victims can be both immediate and long-term, including decreased self-esteem, increased anxiety, depression, difficulty in school, self-harm and even suicide.

Unfortunately, most children who are cyberbullied do not tell their parents. According to the youth advocacy nonprofit DoSomething.org, just 1 in 10 children tell an adult if they're being cyberbullied.

Magnifying the situation is that many kids, bullies and victims alike, operate anonymously, using apps or accounts that mask their identities, says Julie Hertzog, director of PACER's National Bullying Prevention Center, an organization based in Minneapolis.

Instead of expending a ton of energy trying to stay ahead of the technology curve, Hertzog suggests that parents consider the following when educating their kids about cyberbullying.

1.TALK WITH YOUR KIDS EARLY ABOUT CYBERBULLYING, AND KEEP THE CONVERSATION GOING.

Cyberbullying can start with simple texting. So before your child gets his or her first cellphone, discuss digital safety. Hertzog says. Establish how you will monitor your child's online safety. Explain privacy issues, and address cyberbullying, directly "It's important for kids to know that they have a right to be safe on their cellphone just like they have a right to be safe in school. It should be a good experience, " Hertzog says.

2. CONSIDER A "PREVENTION THROUGH EDUCATION" APPROACH.

If your child is being targeted based on his or her bleeding disorder or any other medical condition, a little education can go a long way. "When kids don't understand someone else's differences, they're more likely to react to it, and sometimes in inappropriate ways," Hertzog says.
It's up to each child and family to decide what they feel comfortable sharing, but peer education can be a positive approach to developing empathy in other children, Hertzog says. "There are so many kids who want to do the right thing, but we have to help them know what the thing is to do."

3. DON'T DISMISS IT. LISTEN CLOSELY AND BE SUPPORTIVE.

Cyberbullying is an imbalance of power. It's not something your child can simply ignore, Hertzog says. The wrong thing to say: "Just stay off your cellphone or computer." Because so much of life is now online, including schoolwork, that's not realistic.
"What we hear universally from kids who are bullied is the statement "I feel so alone," Hertzog says. "Have the conversation. Find out the details. You want to make sure the child feels supported. You want to make sure that they know you're there for them."

Involving children in the solution to cyberbullying gives them some of the power back!

4. INVOLVE YOUR CHILD IN THE SOLUTION.
"It's so important to listen to your child, because they know their culture, they know their social nuance," Hertzog says. "You're giving them some of the power back in this situation, and you're not going to do anything that makes them uncomfortable." To help families address cyberbullying incidents, PACER created a downloadable student action plan (see bottom of page for link) -
Rita Colorito

CYBERBULLYING HOW-TO

Recognize the signs and know what to do
An awareness of the signs of cyberbullying can help you notice if it may be happening to your child and start a conversation with him or her. If your child is being cyberbullied, it's important to know how to address it.

KNOW THE WARNING SIGNS
Any type of bullying can cause changes in your child's personality. According to StopBullying.gov and KidsHealth.org, kids being cyberbullied may exhibit the following additional warning signs,

- Increases or decreases in the child's electronic device usage
- Being angry or upset during or after using their device
- Being nervous or jumpy when getting a text, email or instant message
- Hiding their screen or device when others are around
- No longer wanting to use their device
- Avoiding discussing what they're doing on their cellphone or online
- Opening or closing many social media accounts

BEWARE:
Spending more or less time then usual on a device could be a sign of cyberbullying

Most children who are cyberbullied do not tell their parents or another adult.

STEPS YOU CAN TAKE
Each cyberbullying case is different, and thus the solutions will be different. If you suspect cyberbullying, there are concrete steps you can take to become an effective advocate for your child.

Keep a detailed record. Take a screenshot of harassing or threatening posts or other harmful content.

Block the child doing the bullying. Be sure to review your child's privacy settings to make sure only approved friends have access to him or her on social media.

Report it to the proper authorities. Most schools and social media platforms have anti-bullying policies. Report the incident to the police if your child receives physical threats or another potential crime or illegal behavior has occurred. The Cyberbullying Research Center has a list of bullying laws by state (see information below).

DOWNLOAD THE "STUDENT ACTION PLAN AGAINST BULLYING":
pacer.org/bullying
>>LEARN ABOUT BULLYING LAWS IN YOUR STATE: cyberbullying.org

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27th Annual Kelly Brothers Scholarship Benefit
In Memory of Bob and Dennis
Saturday, August 17, 2019
at
Friendly Sons of the Shillelagh

Managing Family Stress

How parents and children can handle life with a bleeding disorder

Stress. No one wants it, but everyone has it. And when you add a chronic illness like a bleeding disorder, that can exacerbate symptoms, says Peg Geary, MA, MPH, a former social worker at the New England Hemophilia Center and current project manager at the Boston Hemophilia Center.

When left unchecked, stress can affect a person's thoughts, feelings, behavior and body. It can cause everything from headaches and fatigue to anxiety and social withdrawal.

Five helpful strategies

Families in the bleeding disorders community can use a variety of strategies to help mitigate stress. Here's what Geary recommends.

1. TUNE IN TO YOUR CHILDREN.
Being different is a big stressor for children. Maybe your child is anxious because he can't play contact sports and everyone else can, Geary says. You can pick up on subtle cues if you pay attention. "You know your child better than everyone else, and you know when something is wrong," Geary says, if you see changes in your child's behavior, like increased anger or other signs of stress, take note.

2. SUGGEST A TALK, BUT DON'T GO OVERBOARD.
If you notice a problem, try to engage your kids in a nonthreatening way. You can gently ask if anything is bothering them. "But don't try to force your kid to talk," Geary says. "Just see if the issue comes up in conversation." If it does, you can lead the chat by giving examples of how you coped with a stressful situation when you were young, she says. Then listen and help your child develop a solution.

3. PROTECT YOUR KIDS AND HELP THEM HELP THEMSELVES.
It's tempting to comfort your kids about every hiccup, but it may not be the best thing for them, Geary warns. "You can protect kids so much that they don't develop their own coping skills," she says. "Then when they enter adulthood, they don't know how to deal with stress and pressure." So let them study for that exam and work through their anxiety partly on their own.

4. MAINTAIN BALANCE.
It's hard to see your kids feeling anxious, but don't amplify issues unnecessarily. If you do, your kids will follow your lead—and you don't want them more on edge, Geary says. If you're feeling stressed, try to resolve the issue using your own coping skills. You can still tell your teenager , for instance, that you're concerned about him self-infusing on that camping trip. But try to process your feelings before you help your children process their own.

5. GET PROFESSIONAL HELP WHEN NEEDED.
If periods of stress stretch from days to weeks, you may need to seek help. Also reach out if you or a loved one feels so overwhelmed that going to school or work is difficult. And if family members are thinking about hurting themselves—or if you are—talk to a trusted social worker, counselor or another professional, Geary advises.

Geary advises turning to your hemophilia treatment center first. There, you'll find staff who know you and your family and can quickly direct you to helpful resources.

By Leslie Quander Wooldridge

Caregivers Need Care, Too

Making self-care a priority is the key to maintaining your own health

Any form of extended caregiving can be emotionally and physically taxing. That's why it's important for caregivers to try to relieve their stress wherever and whenever possible. "That often starts by simply knowing that it's OK to ask for help and to take some time for yourself," says Vicki Kind, MA, a clinical bioethicist based in Granada Hills, California, and the author of The Caregiver's Path to Compassionate Decision Making (Greenleaf, 2010). "If you don't take care of your own needs, you will destroy yourself."

Follow Kind's advice on how to care for someone close to you and take care of yourself at the same time.

Four useful ways to care for yourself

1. MAKE A WISH LIST.
"Put down all the things that would help you, whether they be practical, emotional, financial or informational," Kind says. Then keep the list with you to pull out when people ask how they can help. Some of the things you might include are kitchen cleaning, a call every day to check how you're doing, a meal once a week—and stay to eat and talk with you.

Make a wish list ….keep the list with you to pull out when people ask how they can help.

Remember… Caregivers, YOU need to take care of yourself, too.

2. GO LONG DISTANCE.
Friends and family don't have to live close by to offer support, Kind says. Family members can listen to doctor appointments on speakerphone, order groceries online or help set up automatic bill payments.

3. THINK BIG.
Try going outside your immediate family for help. See if a local high school requires students to fulfill community services hours. Contact local resources, such as nearby Area Agency or Aging, and see if they have ideas.

4. REMEMBER THE GOOD STUFF.
Being a caregiver may sometimes feel like a burden, but it can also give you a sense of purpose and be incredibly meaningful. "There's a certain joy that comes with just showing up and being there for someone else," Kind says. "It's fulfilling on many levels—and you can often develop a richer, deeper relationship because of it."

By Amy Lynn Smith

Volunteering & Hemophilia

By
Issaiah Williamson

I have moderate hemophilia A and I know about the many challenges that come with having a bleeding disorder. However, I never saw it as a bad thing. My hemophilia is a part of who I am and led to my unique experiences. More importantly, hemophilia has allowed me to get to know people I wouldn't have known otherwise. Having hemophilia has allowed me to get involved with the Hemophilia Association of NJ and go to two serious fun camps, the Double H Ranch and The Hole in the Wall Gang Camp.

These camps give kids with chronic or life threatening illnesses a chance to have fun and enjoy themselves. At camp, children can play and have fun like normal kids without having to worry. That way, they can look back at experience all the good times at camp and forget about having to deal with their illness. While I was at camp, all I could think about was having fun and playing with the other campers and counselors. I wanted to become a camp counselor so I could give back to the camps that gave me some of my best childhood memories.

To me and so many others, camp is a paradise full of smiles, fun and happiness. Camp is a place where you can be as unique and silly as you want – even the counselors! In addition to the countless fun activities, the people and the friendships are what make camp so special. During the ride to camp, new campers are usually nervous and afraid to talk, but camp is able to create a tight bond between the kids. By the time we leave camp, those same campers could spend the whole ride home talking to each other about their week. It's amazing how campers go from total strangers to best friends in only a few days.

I have been volunteering and working for the camps for the past five years and have been fortunate enough to get to know many of the campers and staff. I volunteered at both camps this summer, and I saw a lot of familiar faces. I can relate to some of the campers' experiences and share stories. At Double H, I saw several of my former campers from previous years, and even a few I had earlier this summer! I have been able to bring some of those connections and experiences back home because several campers I had are also from NJ and go to HANJ events. I think that being able to talk to campers outside of camp has helped me build on my friendships.

My volunteer work for HANJ and the camps has opened new possibilities for me. My first time volunteering for both camp and HANJ was in 2015 as HANJ's chaperone for the hemophilia campers. Volunteering with HANJ allowed me to travel to the camps, while going to camp has led me to get more involved with HANJ. Since then, I've been able to do it every year, and I have become a lot more involved with the Association. I never thought that doing volunteer work could be so rewarding.

I participate with HANJ more than ever and go to as many meetings as I can. My family started attending meetings over the past year, and we have learned a lot about what's going on in our community. I have been trying to do more volunteer work for HANJ so I can help with their efforts in the bleeding disorders community. I encourage others to do the same – you never know what people you may meet or what opportunities may come your way!

Straight from the Kitchen of Our HANJ Executive Director, Stephanie Lapidow

Butternut Squash & Turkey Chili

Ingredients

3 teaspoons olive oil
1 pound 99 percent fat-free ground turkey
1 medium onion, diced
3 cloves garlic, minced
1/4 cup chili powder
1 tablespoon ground cumin
2 teaspoons ground coriander
3 tablespoons tomato paste
Kosher salt
1 small butternut squash, peeled, seeded & cut into 1/2-inch cubes (about 3 1/2 cups)
28 oz. can chopped tomatoes
Two 14 oz. cans black beans, drained & rinsed
1/4 cup chia seeds
Freshly ground black pepper
1 to 2 tablespoons apple cider vinegar

Directions

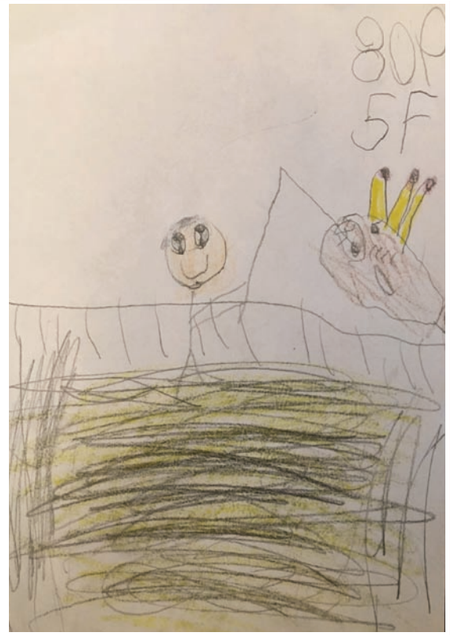
1.) Heat 1 1/2 teaspoons of the oil over medium-high heat in a large Dutch oven. Add the turkey and cook, breaking up chunks with the side of a wooden spoon, until browned, about 5 minutes. Push the turkey to the edges of the pan, leaving the middle empty. Reduce the heat to medium and add the remaining 1 1/2 teaspoons oil, then the onion and garlic to the center of the pan. Cook, stirring occasionally, until the vegetables start to soften, about 3 minutes. Add the chili powder, cumin and coriander and stir about 30 seconds. Add the tomato paste and 1 teaspoon salt and stir until the paste begins to darken in color, about 30 seconds. Then add the squash, tomatoes and 4 cups water, scraping the bottom of the pan to release any stuck bits. Bring to a simmer, adjust the heat and simmer, uncovered, until the chili has thickened and the squash is tender, 35 to 40 minutes.

2.) Stir the beans and chia seeds into the chili and heat through, about 5 minutes. Season with an additional 1/2 teaspoon salt and a few grinds of pepper, then taste the chili and stir in up to 2 tablespoons of vinegar. Spoon the chili into bowls and serve.

SUMMER CAMP

Camp can be an integral part of a patients' journey towards independence. HANJ provides transportation each year to camp for eligible members. Please consider sending your child to one of the sessions. There are two sessions of camp each year. Hole In The Wall Gang Camp and The Double H Hole In The Woods Ranch Camp. We always like when our campers send us a letter or picture about how much they enjoyed themselves at camp. Please see the pictures below provided by our member, Nicholas Arredondo, age 7 from his experience at Hole in the Wall Gang Camp.

Nicholas swimming with his friends in the pool at camp.



Nicholas fishing and catching an 80lb 5ft fish at camp.

Young Adults and Insurance

Considerations When Deciding on a Health Coverage Plan

For more information, visit b2byourvoice.com to download *Young Adults and Hemophilia B.*

This content is brought to you by Pfizer.

For young adults with hemophilia, having insurance is a crucial step in becoming independent; the annual costs of treating hemophilia can make access to health care coverage a necessity.[1] Appropriate health insurance can be provided through an employer and is an important factor to consider during a job search, but there are other options to explore for purchasing insurance outside of employment as well.

Timing can be key: There may be a waiting period before a recently hired employee is covered under a new policy, or there may be open-enrollment dates to keep in mind for other health insurance options.

Questions to Ask About Health Insurance Plans

When deciding on a health care plan, here are some of the important points to consider, as well as the definitions of some key terms in understanding health insurance.

What are the plan's exclusions and/or limitations? *Exclusions are health care services for which your health insurance or plan doesn't pay.*[2]

Is clotting factor covered?

Does the plan offer product choices for clotting factor?

Does the plan cover visits to your primary care provider and your hemophilia treatment center?

Are referrals required, and if so, for which services? *A referral is a written order from your primary care doctor for you to see a specialist or get certain medical services.*[2]

Is there a lifetime or yearly limit or cap? *A limit or cap is the maximum benefit paid by the insurer; some insurance companies have caps on certain costs.*

What are out-of-pocket costs for the in-network providers versus the out-of-network providers? *Out-of-pocket costs are your expenses for medical care that aren't reimbursed by insurance. Out-of-pocket costs include deductibles, coinsurance, and co-pays for covered services, plus all costs for services that aren't covered.*[2]

What is the annual deductible for in-network providers versus out-of-network providers? *A deductible is the amount you pay for covered health care services before your insurance plan starts to pay.*[2]

How much is the monthly premium? *A premium is the amount paid for the insurance coverage.*[2]

> "It is important for [young adults], especially those with a chronic condition, to realize the necessity of having health insurance, as well as knowing what it takes to maintain that insurance."
>
> — Joy Mahurin
> Reimbursement Specialist

Maintaining Health Insurance

People living with hemophilia should keep in mind the potential for a lapse or gap in health insurance. In most cases, young adults may stay on their parents' policies until age 26.[3] However, it's important to be aware of the potential for a lapse in coverage after age 26 and prior to having a policy of one's own through an employer or the Health Insurance Marketplace. One option to retain medical coverage is Consolidated Omnibus Budget Reconciliation Act (COBRA) coverage. Other options may be state-sponsored individual Health Insurance Portability and Accountability Act (HIPAA) insurance plans and even Medicaid (for those who are disabled or who meet income requirements). In addition, for those who struggle to keep up with health care costs, some National Hemophilia Foundation (NHF) chapters have programs that can assist with paying deductibles, co-pays, and premiums.

References: 1. Chen SL. Economic costs of hemophilia and the impact of prophylactic treatment on patient management. *Am J Manag Care*. 2016;22(suppl 5):S126-S133. **2.** US Centers for Medicare & Medicaid Services. Glossary. Healthcare.gov Web site. https://www.healthcare.gov/glossary/. Accessed March 28, 2019. **3.** US Department of Health & Human Services. Young adult coverage. HHS.gov Web site. https://www.hhs.gov/healthcare/about-the-aca/young-adult-coverage/index.html. Accessed March 28, 2019.

PATIENT AFFAIRS LIAISONS

Patient Affairs Liaisons are Pfizer hemophilia employees who are dedicated solely to providing support to the community. Your Pfizer Patient Affairs Liaison is available to help you access the support and information you need. To find your Patient Affairs Liaison, go to hemophiliavillage.com/support/patient-affairs-liaison-finder or call Pfizer Hemophilia Connect at 1.844.989.HEMO (4366).

Pfizer

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 Peter Marcano (petermarcano@gmail.com, 201-401-7080) or Rajh Odi (odi.apd@gmail.com, 862-215-7944) 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)(3) organization. You will receive a receipt when we receive your donation for tax purposes.

Name: _____

Address: _____

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

Phone: Cell/Home : _____

Amount of Donation: _____

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

What is HEMLIBRA?

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

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

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

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

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

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

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

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

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

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

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

See "**What are the possible side effects of HEMLIBRA?**" for more information about side effects.

What is HEMLIBRA?

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

Hemophilia A is a bleeding condition people can be born with where a missing or faulty blood clotting factor (factor VIII) prevents blood from clotting normally.

HEMLIBRA is a therapeutic antibody that bridges clotting factors to help your blood clot.

Before using HEMLIBRA, tell your healthcare provider about all of your medical conditions, including if you:

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

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

How should I use HEMLIBRA?

See the detailed "Instructions for Use" that comes with your HEMLIBRA for information on how to prepare and inject a dose of HEMLIBRA, and how to properly throw away (dispose of) used needles and syringes.

- Use HEMLIBRA exactly as prescribed by your healthcare provider.
- **Stop (discontinue) prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis.**
- **You may continue prophylactic use of FVIII for the first week of HEMLIBRA prophylaxis.**
- HEMLIBRA is given as an injection under your skin (subcutaneous injection) by you or a caregiver.
- Your healthcare provider should show you or your caregiver how to prepare, measure, and inject your dose of HEMLIBRA before you inject yourself for the first time.
- Do not attempt to inject yourself or another person unless you have been taught how to do so by a healthcare provider.
- Your healthcare provider will prescribe your dose based on your weight. If your weight changes, tell your healthcare provider.
- You will receive HEMLIBRA 1 time a week for the first four weeks. Then you will receive a maintenance dose as prescribed by your healthcare provider.
- If you miss a dose of HEMLIBRA on your scheduled day, you should give the dose as soon as you remember. You must give the missed dose as soon as possible before the next scheduled dose, and then continue with your normal dosing schedule. **Do not** give two doses on the same day to make up for a missed dose.
- HEMLIBRA may interfere with laboratory tests that measure how well your blood is clotting and may cause a false reading. Talk to your healthcare provider about how this may affect your care.

What are the possible side effects of HEMLIBRA?

- See "**What is the most important information I should know about HEMLIBRA?**"

The most common side effects of HEMLIBRA include:

- redness, tenderness, warmth, or itching at the site of injection
- headache
- joint pain

These are not all of the possible side effects of HEMLIBRA.

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

How should I store HEMLIBRA?

- Store HEMLIBRA in the refrigerator at 36°F to 46°F (2°C to 8°C). Do not freeze.
- Store HEMLIBRA in the original carton to protect the vials from light.
- Do not shake HEMLIBRA.
- If needed, unopened vials of HEMLIBRA can be stored out of the refrigerator and then returned to the refrigerator. HEMLIBRA should not be stored out of the refrigerator for more than a total of 7 days or at a temperature greater than 86°F (30°C).
- After HEMLIBRA is transferred from the vial to the syringe, HEMLIBRA should be used right away.
- Throw away (dispose of) any unused HEMLIBRA left in the vial.

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

General information about the safe and effective use of HEMLIBRA.

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

What are the ingredients in HEMLIBRA?

Active ingredient: emicizumab-kxwh

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

Manufactured by: Genentech, Inc., A Member of the Roche Group,
1 DNA Way, South San Francisco, CA 94080-4990
U.S. License No. 1048

For more information, go to www.HEMLIBRA.com or call 1-866-HEMLIBRA.
This Medication Guide has been approved by the U.S. Food and Drug Administration
Revised : 10/2018

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

Genentech
A Member of the Roche Group

The Hemophilia Association of New Jersey
cordially invites you to join us at

CASINO NIGHT

A night of casino gambling, prizes & silent auction featuring a buffet and an open bar

Business Casual

SATURDAY, OCTOBER 26, 2019
7PM TO 11PM

Pines Manor
2085 Route 27, Edison, NJ

RSVP by October 11th

For Tickets:
Call Mary Lou Billings, Special Events Coordinator
at Tel: 732-249-6000

or visit: http://hanj.org/event/casino-night/

Make Checks Payable to:
The Hemophilia Association of NJ
197 Route 18 S, Suite 206 N
East Brunswick, New Jersey 08816