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
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
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 the 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 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.

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.

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 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. ATHNadov 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, 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.

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 ATNH (American Thrombosis & Hemostasis Network) Data Set. This is a voluntary program conducted by HTC’s with support from ATNH to improve the health of people with coagulation disorders. Patients will also be educated about any other available studies that they might be eligible to participate in. Please note that any individual receiving medication through the HTC to treat their bleeding disorder must be seen by the HTC on an annual basis.

Travel Letters: Are you going to be 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.

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

Please contact us at the Hemophilia Treatment Center to sign up for one of the above programs or to request further information 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@RWJhb.org Fax: (973) 391-0048

St. Michael’s Medical Center

School Visits: 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 (973) 877-2967.

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

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 Joanne Rodriguez, Social Worker at (973) 877-2967.

Insurance:

Please feel free to get in contact with us if any questions, issues or concerns arise during the year. Please call The Blood Research Institute at (973) 877-5340 to schedule your next visit.

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.

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

Individualized Sessions:

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.

Psychosocial Yearly Evaluations:

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.

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
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!

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.

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!

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!

Presented in both English and Spanish

HANJ Pharmaceutical Educational Programs

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An IHP is designed to ensure that a child’s medical requirements are 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; during school; during field trips; and in after-school 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. 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 specialties may have more than one nurse on staff who are trained in bleeding disorders.
- 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 establishes national 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. 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.

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1. An Individualized Health Plan may also be called an Individualized School Health Plan or Individualized Healthcare Plan.
www2.ed.gov/about/offices/list/ocr/504faq.html
Private schools often deny that they are subject to federal laws. However, many state courts and school districts have interpreted Section 504 in such a way that it is applying to private schools in some instances.

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 subject to discrimination under programs or activities receiving federal financial assistance." 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.

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's bleeding disorder suffers from a bleed or other complications, he could be greatly limited in several of these activities, and this would qualify him for support under Section 504. Parents of children with bleeding disorders should share this information in their child's Section 504 plan.

IEP: Individualized Education Plan
Section 504 support does not replace an IEP. IEPs and 504 plans are separate documents, and together they can form a comprehensive educational plan for special education, but do not replace it. "IEP" is the umbrella term for both documents.

IEPs and 504 Plans are designed to address a student's unique needs and goals. IEPs focus on the child's performance in school, while 504 Plans address any academic, functional, and social needs that may arise at school. Both plans are designed to ensure that the student receives a free and appropriate education (FAPE) in the least restrictive environment (LRE).

What is the difference between an IEP and a 504 Plan?
IEPs are for students with disabilities, while 504 Plans are for students with any condition that limits participation in school. IEPs are intended for students who are identified as having a disability, while 504 Plans are for students who may not have a disability but are still protected under Section 504.

When Your 504 or IEP Request is Denied
When your 504 or IEP request is denied, you have several options to resolve disagreements with the school:

- Mediation
- Alternative dispute resolution
- Impartial hearing
- Complaint to the Office of Civil Rights (OCR)

IDEA offers parents specific ways to resolve disputes:

- Mediation
- Due process complaint
- Resolution session
- Civil rights
- State complaint

504 Accommodations for a Bleeding Disorder
When your child's bleeding disorder affects his ability to learn, you may need to request accommodations under Section 504. Accommodations are changes that make it easier for your child to access the curriculum and participate in school activities.

What are accommodations and modifications?
Accommodations are changes that are made to help your child access the curriculum and participate in school activities. Modifications are changes that are made to help your child learn the material. Accommodations and modifications are made to help your child succeed in school and achieve his goals.

504 Plan accommodations are changes that are made to help your child access the curriculum and participate in school activities. These accommodations may include:

- Individualized Education Plans (IEPs)
- Accommodations for standardized tests
- Accommodations for special education

IEPs and 504 Plans are designed to ensure that your child receives a free and appropriate education (FAPE) in the least restrictive environment (LRE). These plans should be based on your child's unique needs and goals.
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 important for 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 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 permitting them to participate in an activity. And students must be allowed to make up any work missed.

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 for 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 and 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 a student who doesn’t want to do extra work or be penalized for missing an activity may quickly learn, from neighboring students, that by faking a stomachache, she gets to stay home. Or an old er student 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 school to attend truancy court or a Student Attendance Review Board (STAR) hearing.

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 email 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.

In 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 setting.

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 rest of IDEA means 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 language 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 sit next to you and work with you on 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 under IDEA 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 points 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 through your state’s education department. (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. Don’t let the fear that your child may be labeled “special ed” stop you from getting 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 IEP and ECP early—several months before school starts. And to protect your child from falling behind academically, ask for an evaluation before starting the school year, to secure IDEA eligibility. And don’t worry about labels! Do what’s best to help your child succeed in school.

References:


Department of Education: www.ed.gov

Parent and Educator Resource Guide to Section 504 in Public Schools, Wrightslaw: www.wrightslaw.com

Resources for Parents and Guardians United, Online: www.understanding.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).
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.
Stay empowered by the possibilities.

Bully Goes High-Tech
How parents can help kids cope in the age of cyberbullying

Cyberbullying 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.

How parents can help kids cope in the age of 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.

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. “It’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.”

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 Takeda, dedicated to pursuing advancements in hemophilia for more than 70 years.
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

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

Visit cyberbullying.org

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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.

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
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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.

3. THINK BIG.
Try going outside your immediate family for help. See if a local high school requires students to fulfill community service 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
Reprinted with permission from HemAware Magazine© National Hemophilia Foundation 2019

Make a wish list …keep the list with you to pull out when people ask how they can help.
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!
Young Adults and Insurance
Considerations When Deciding on a Health Coverage Plan

For more information, visit b2yourvoice.com to download Young Adults and Hemophilia B.

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. 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.

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.

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, co-insurance, and co-pays for covered services, plus all costs for services that aren’t covered.

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.

How much is the monthly premium? A premium is the amount paid for the insurance coverage.

“Il t 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. 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:

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.

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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, 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 (FVIII) and the dose and schedule to use for breakthrough bleeding 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
  - weight gain
  - 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.

What medical conditions, including if you:

- are pregnant or plan to become pregnant. It is not known if HEMLIBRA may harm your unborn baby. Female rats who are able to become pregnant should be kept controlled (sterilized) before 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 Medication Guide for information on how to prepare and inject a dose of HEMLIBRA, and how to properly throw away (dispose of) used needles or syringes.

- Store HEMLIBRA properly.

- Keep all packaging out of the reach of children.
- This product is for subcutaneous injection under your skin (subcutaneous).
- Do not give HEMLIBRA to a child unless you are sure the injection is being given by a healthcare provider.
- Store at room temperature (59°F to 86°F [15°C to 30°C]). Do not freeze.
- 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).

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

- are pregnant or plan to become pregnant.
- are breastfeeding or plan to breastfeed.
- have any of the following conditions:
  - fast heart rate
  - shortness of breath
  - swelling in arms or legs
  - stomach (abdomen)
  - decreased urination
  - dizziness
  - numbness or tingling
  - fever
  - cough
  - diarrhea

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.

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.

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

What are the possible side effects of HEMLIBRA?

The most common side effects of HEMLIBRA include:

- redness, tenderness, swelling, 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 59°F to 86°F (15°C to 30°C). Do not freeze.

Store HEMLIBRA in the original carton to protect the vial 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: eculizumab-khw

Inactive Ingredients: L-ascorbic acid, L-histidine, L-histidine monohydrochloride, and mannitol.

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Genentech page 1

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