

Navigator News



SUMMER 2010
Quarterly
Newsletter

Seeing Camp Through My Son's Eyes

Our experience with camp is one of friendship, accomplishment, and fun. Camp, for our son, is a place where he meets new friends, renews old friendships and gains some control over his hemophilia. This will be our son's fourth year at Camp Bold Eagle.

From my perspective, the friendships are the greatest thing that he is going to get from camp. He has a couple of friends that he looks forward to seeing at camp, SpringFest (our annual meeting), and maybe a couple of other times a year. These are friends who also share the common bond of Hemophilia.

I don't think I fully understood this aspect of camp (not having attended a camp myself) until I was sitting in a breakout session called *Aging with Hemophilia* at this year's annual meeting. This meeting had three distinct groups: the over 40 with hemophilia; the 20-somethings with hemophilia; and fathers of children who have hemophilia. The over 40 group was composed of four

men who shared experiences and stories of the time they spent at camps and stories of how treatments have changed over the years. The 20-somethings was composed of eight men (including a young man who did not have hemophilia but "wanted to

It was obvious by the stories that were shared that these camp friendships have played an important role in their lives.

have it". Perhaps this sounds strange but as he explained it, although he did not have a bleeding disorder, his good friends did and he felt left out of that brotherhood) who shared stories of camps that they have attended together and the friendships and brotherhood they have created. The third group of fathers just sat and listened. This is the group that I fit into. It was obvious by the stories that were shared that these camp friendships have played an important role in their lives. I hope and believe that my son will make these kinds of friendships at camp.

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This is also a place where they can gain some control over hemophilia. While we strive to make our son as independent as possible, the assistance and peer pressure at camp helps. Nothing works like peer pressure to get you to do something you don't really want to - at least, in this case, they are positive things. Our son earned his butterfly award (successfully poking yourself) on his first year.

I look forward to hearing all the stories about how fun camp was. Stories of how they "rounded up all the zoo animals", a game they play with camp counselors dressed as animals. The prized animal is the eagle (Camp Bold Eagle). Stories of archery, swimming, crafts, and many other activities. Stories of fun and friendship, not unlike the 20-somethings I met at the annual meeting.

As we prepare for camp this year, our son is excited and gathering all his camp gear. He is looking forward to a great week with his friends. I still expect he will cry when leaving home and cry when he leaves camp to come home. However, these episodes get smaller every year. I think I will be the sad one when he no longer feels the sadness when leaving home.

- Pat Houle

WHY BOB GOES TO CAMP

Many of you might not know how I became involved with the bleeding disorder community. In 1991, I was working in Illinois with a group of people establishing a camp for kids with AIDS. Staff and volunteers from the Hemophilia Foundation of Illinois joined this group. In the end, it turned out that the people from HFI really served as consultants to the rest of us. We were all amazed at how much they knew about camping and the willingness to share everything with us. When this project was finished I asked to become involved as a volunteer with HFI and have been part of the organization ever-since.

After nearly twenty years now it doesn't surprise me that my introduction to this important community was through camping. This is a very common route to a lifelong family commitment to bleeding disorders. Young families faced with dealing with a bleeding disorder are often isolated. Slowly during the first years of their children's lives they develop a relationship with healthcare providers, some other impacted families and the local organization. It is recognized that there are others out there that share a commonality with them, but I believe that many do not feel a connection until that child returns from camp for the first time.

Camp has so much to offer but the most important aspect is that for a short period of time (in Illinois this is one week) each year, everyone has a bleeding disorder. Our kids are the included ones - not the ones excluded for a medical condition. Everything is for everyone. The parents don't need to worry that the neighbor may be holding a birthday party at an arcade and not invite their child because they are not comfortable with the risk of a bleed. No child is faced with an adult suggesting they be a "scorekeeper" because this is the safest way for the adult to assure themselves that they are protecting the child's health. I could go on and on with examples but hopefully you get my point - if you don't, contact me and I can tell you bizarre stories of how our children are isolated each day.

Camp starts out each day around a flag pole with a moment of reflection. There is nothing remotely religious about this activity but it is one of the most spiritual times of my life. I don't get through most of these mornings without a tear (but those of you who know me know that I'm a big softy). To hear our young people stand in front of their peers and openly express what it means to be part of the group is truly astounding. Most of us can't get teenagers to grunt once for yes and twice for no, let alone tell us how they feel. We all are, and must continue to be, proud of the great children we are all raising.

This experience, while it may only last one week, permeates the rest of the year and for most of us our entire lives. How many people out there - I'm talking to you - are still friends with their cabin mates from their first year at camp? How many of you are now counselors yourselves at camp? How many of you have decided to pursue a career serving others because of what you learned at camp? It would be great if we could find a way to quantify the positive outcomes from camp but I'm not sure there is a number that goes that high. When I talk with other colleagues who work in other areas of social service they are always amazed at how many people with bleeding disorders are truly involved with HFI. They want to know what the secret is to getting people to be a part of their own organization. I tell them that there are a variety of reasons but none more important than our camping program. From this one activity each participant has the opportunity over the years to develop thousands of relationships that can aid them in living a strong, independent and healthy life.

In closing, I want to talk directly to new families that are still a little unsure of sending their son or daughter to camp for the first time. We understand this reticence. You have been caring and protecting your child for the past seven to ten years largely all by yourself. Know that we are here for you to help you (mom and dad) get over your uncertainty. We will help you in any way we can because this will be a terrific experience for your child. I'm proud to report that the camping program for children with AIDS that the Hemophilia Foundation of Illinois helped start continues to grow and develop - as does our camp. We will be holding the 38th session of Camp Warren Jyrch, from August 8 - August 14 this year. I can't wait!!

Bob Robinson, Executive Director
Hemophilia Foundation of Illinois

LUNCH BOX WISDOM

Bacteria that cause foodborne illness grow rapidly in certain types of food.
1 in 4 people get food poisoning each year!

TIPS FOR KEEPING LUNCH CLEAN AND COOL

Food can become unsafe to eat within 2 hours at room temperature (in an hour or less at temperatures between 90-140 degrees)

- Start with clean hands and a clean preparation space
- Wash the inside of the lunchbox and ice packs daily
- Use an insulated lunch box or bag every day
- Buy an ice pack and use it every day
- Make sandwiches the night before and chill it until ready to put in the lunch box
- Use an insulated container for hot foods (to send hot foods fill with boiling water first, let stand, empty and add hot food)
- Ice packs should even be used on cold days

KEEP US COLD

- Meat, poultry, fish (lunch meat, chicken nuggets, homemade tuna salad)
- Eggs (Egg salad, hard boiled eggs, mayonnaise)
- Milk, soft cheese, yogurt
- Peeled or cut fruits and vegetables
- Fruit juice from open containers (not juice boxes)
- Pasta salad

WE ARE SAFE AT ROOM TEMPERATURE

- Bread, crackers, cereal
- Peanut butter
- Whole, uncut fruit and vegetables
- Fruit cups or unopened canned fruit
- Dried fruit
- Unopened juice boxes
- Hard cheeses, nuts, and seeds
- Unopened cans of tuna, poultry or meats

KEEP US HOT

- Soups, chili, casseroles, baked and refried beans (from open containers)
- *Do not allow to cool to room temperature in your lunch box and then reheat to eat.

For more information on food and lunchbox safety, visit:
http://healthymeals.nal.usda.gov/nal_display/index.php?info_center=14&tax_level=2&tax_subject=231&topic_id=1201

SUMMER FUN PUZZLE

S	U	N	G	L	A	S	S	E	S	P	F	I	S	H	R
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E	N	X	W	O	M	M	K	F	R	N	Z	O	M	P	A
C	A	Q	U	Q	E	A	S	O	D	Y	O	B	P	L	D
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|-----------|-------------|
| barbecue | pool |
| baseball | rollerblade |
| beach | sail |
| bike | sand |
| boating | scuba |
| camp | sea |
| canoe | shell |
| fireworks | skateboard |
| fish | sun |
| frisbee | sunglasses |
| hike | vacation |
| hot | warm |
| ocean | watermelon |
| picnic | |

From The Editor's Desk

Amy E. Clarke, RN Program Manager, Hemophilia

navi-gate

Pronunciation: \ˈnɑ-və-gāt\ Function: verb
 Inflected Form(s): navi-gated; navi-gating
 Etymology: Latin navigatus, past participle of navigare, from navis ship + -igare to drive
 Date: 1588
 intransitive verb
 1 : to travel by water :
 2 : to steer a course through a medium
 transitive verb
 1 a : to sail over, on, or through
 b : to make one's way over or through
 2 a : to steer or manage (a boat) in sailing
 b : to operate or control the course of (as an airplane)

There are many instances in life when we navigate... Does this mean doing it all alone? Even Columbus used a compass, the stars, his crewmates.... the water may be choppy at times and there are always potential obstacles to work through or go around....

So where am I going with this?

A new diagnosis can be frightening and overwhelming. There are tools to navigate those waters. Talk to the physician or nurse about being paired up with parents who have been where you are now. Reach out to the local bleeding disorder chapters as well. They are an amazing resource and can help you get plugged into the community at a pace that is comfortable for you.

Your child is heading off to preschool or kindergarten for the first time. Getting a plan in place to ensure proper care is provided can be daunting. It does not have to be. There are resources that will aid you in getting that care plan in place. Your child, too, now begins to take a more active role in what they do and do not want their classmates to know. And what they told their friends last year may not be what they want known this year. For many this is completely uncharted waters. Networking with other parents who have been there, with their now older children, can help you gain some perspective and peace of mind.

What about when your child is old enough to attend camp for the first time? Like most parents, this can be a scary time. Potentially the first time you truly have to let go and entrust the care of your child to others. Talk to other parents beforehand. If you get the opportunity, ask some of the older boys about their experiences at camp. Many of them have been attending since the first year they were old enough. Many of them go on to become counselors and actively involved in the bleeding disorder community outside of camp.

These are just a few of the areas we navigate through living with a bleeding disorder each day- there are many more. The important thing to remember is that there are always people there to help you negotiate your way through the rocks and set a course for smoother sailing.



Expansion & Renewal in Flint

With the help of a \$61.5 million Michigan Economic Growth Authority (MEGA) tax credit, Diplomat is moving its corporate offices from Swartz Creek to Flint and plans to add 1,000 jobs in the next five years, and as many as 4,000 by 2028. To support this growth, Diplomat purchased a 340,000 square foot building at the former General Motors' Great Lakes Technology Centre complex on Saginaw Street in Flint, MI.

Phil Hagerman, Diplomat's President and CEO said, "We anticipate making significant investments in the Technology Center, including building a state-of-the-art distribution hub to control Diplomat's nationwide network, and a national patient call center."

In discussing Diplomat's continuing re-invention, Hagerman continued, "We will be expanding our capabilities to offer our patients treatments in new disease areas with the latest pharmaceutical products. The MEGA grant allows us to respond to the additional opportunities of healthcare reform in an already high-growth industry."

For more information visit:
<http://projectpromise.diplomatpharmacy.com>

S	U	N	G	L	A	S	S	E	S	P	F	I	S	H	R
J	A	Q	R	P	D	V	F	Q	K	A	R	B	Q	T	O
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U	S	H	E	L	L	I	E	A	O	Q	Y	E	W	G	E
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T	A	B	L	A	N	T	W	V	M	A	B	O	P	A	Z
D	E	U	I	J	O	L	O	S	B	O	A	T	I	N	G
V	A	C	A	T	I	O	N	U	L	I	U	E	H	S	D
Q	X	S	S	X	U	I	S	N	P	I	C	N	I	C	C

PUZZLE KEY

Your Child's School and You: A Partnership Janet Brewer M. Ed

With the lazy days of summer coming to an end, thoughts of school begin to move to the forefront. As a parent/caregiver of a child with a bleeding disorder, back to school means a new teacher(s) to train about your child's unique health needs.

There are two federally mandated plans that all school age students are entitled to. States also are mandated to provide special education services or related services and accommodations to children with a diagnosed disability.

[IDEA-Individuals with Disabilities Education Act 1974-Amd.2004](#)

IDEA requires states to provide a "free appropriate public education" to children with disabilities so they can be educated to the fullest extent possible with other children. If qualified, children are provided with special education AND related services under an Individualized Education Plan.

Disabilities Include:

- Physical, sensory, mental or emotional
- Emotional disturbance
- Orthopedic impairment
- Hearing-Vision impairment
- Autism
- Traumatic brain injury
- Other Health Concerns
- Specific Learning Disability
- Multiple Disabilities

If your child is diagnosed with any of the above disabilities AND they require specialized instruction- they qualify for an Individualized Education Plan.

Specialized instruction is defined as adapted instruction designed to meet the unique need of the child with a disability. The content, methodology or delivery of instruction is changed to ensure the child's access to the general curriculum.

[Section 504 of the Rehabilitation Act of 1973](#)

This Act's focus is on non-discrimination. It maintains that "no otherwise qualified individual with a disability will be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance".

[American with Disabilities Act 1990](#)

ADA is almost like an extension of Section 504. It provides for the elimination of barriers related to accessibility for the disabled to buildings, transportation, and communication.

Both 504 and ADA provide related services and accommodations to qualified individuals with a disability through a 504 plan. Its intent is to provide access or remove barriers to participation. It provides students with the same rights and services as their "NON Disabled Peers".

[How a Bleeding Disorder Fits In:](#)

[IDEA-Other Health Impairment](#)

IDEA defines Other Health Impairments as due to chronic or acute health problems such as asthma, attention deficit disorder, or hemophilia and adversely affects a child's educational performance.

[ADA/504-Medically Related Disability](#)

ADA/504 defines a Medically Related Disability as a physical or mental impairment which substantially limits one or more major life activities or those basic activities that the average person in the general population can perform with little or no difficulty. The individual has a record of such impairment and is regarded as having such impairment.

[How Does My Child Qualify?](#)

[If there are no academic, behavior or emotional concerns:](#)

Make an appointment with your building principal/ADA coordinator, teacher (s), and school nurse and ask to develop a 504/ADA plan.

[If there are academic, behavior or emotional concerns:](#)

Write a letter to your child's teacher asking for a formal evaluation process stating your concerns and submit it to the school. The school has an obligation to complete all assessments in the areas of suspected disability (ies) within 60 calendar days.

When assessments are complete:

1. A meeting will be scheduled
2. Reports will be shared with you regarding your child's abilities
3. The Student Assist Team will then decide if your child
 - a.has a disability
 - b.requires specialized instruction in order to make process

Remember: Disability + Specialized Instruction = Individualized Education Plan

Disability + Related Services/Accommodations = ADA/504

[What are Related Services?](#)

Related services may include:

- Speech/language therapy
- Audiology (hearing loss)
- Psychological
- Physical/Occupational therapies
- Counseling
- Rehabilitative counseling
- School health services
- Transportation

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For example:

If you are comfortable with your school district's physical therapist then PT could be included on your child's ADA/504 plan and they could receive physical therapy during the school day. Providing the therapist with additional information on physical therapy with an individual with hemophilia will probably be necessary, as well as contact information from the ordering physician to be sure the therapist proceeds slowly.

What Accommodations Can Be Provided?

Reasonable accommodations are provided to remove barriers related to access. For example: If your child is on crutches, ambulating safely in the hallway is a barrier. Allowing extended travel time around the building removes that barrier. Other reasonable accommodations may include:

- Walkie Talkies for nurse and recess/duty aides
- Extended travel time around building
- Permanent pass to the school nurse
- Medications, needles, and supplies maintained and locked in the nurse's office
- Schedule of physical education activities several days in advance
- Extra set of books at home
- Extended time for homework/make-up work
- Regular email contact from teachers regarding missed assignments
- All medically related absences are excused with no loss of credit
- Note takers
- Tutoring due to absences

Maintaining open and honest communication with your school district enables your child to be more successful. Stating your needs in a detailed, positive manner yields better results. Most school districts are very responsive, but they are working with tight budgets and are often understaffed. Letting them know that you appreciate their efforts on behalf of your child goes a long way.

Sources: Federal Regulations Part 300

Growing Older With Hemophilia

No one likes growing old. Unfortunately, we do not have the ability to stop the aging process. The aging process brings several challenges for someone with hemophilia. These challenges come in several forms. Forty years ago the prospects of someone growing old with hemophilia were very limited. With the medical advancements and the availability of clotting factor, people living with a bleeding disorder have the ability to live well into their 70's and 80's. The aging process presents other challenges as well. It is very important as we grow older to continue to take care of our bodies. Your body is like a car, take care of it and it will take care of you. Many hemophiliacs are starting to have medical problems that were not thought to be possible not that long ago. Many hemophiliacs are now facing heart disease, high blood pressure, and other disease that occur as we grow older. It is very important for all of us to get regular checkups, not only with our hematologist, but with our primary care physician as well. We should also strive to maintain a balanced diet and maintain a healthy weight. If we take the time to take of ourselves, we have the ability to live a long happy life.

Entitlement

Entitlement is a word that seems to be thrown around in our world more and more every day. There are many people who believe that the hemophilia community is one of entitlement. I see a different perspective on this situation. I have witnessed over the past several months how our community members come together to help each other. We are able to see this at our local chapter events and at the NHF annual meeting. Families come together to educate and help each other navigate the challenges of living with a bleeding disorder. So much more needs to be done for our community. My wish is for all of us to become more involved with our local chapters. If you ever have an opportunity, try volunteering at a local chapter event. I believe you will get more out of it than you will put into it. We are all part of the bleeding disorders family.



Fresh Fruit Kebabs With Lemon Lime Dip

Serves 2

INGREDIENTS

4 ounces low-fat, sugar-free lemon yogurt
1 teaspoon fresh lime juice
1 teaspoon lime zest
4 to 6 pineapple chunks
4 to 6 strawberries
1 kiwi, peeled and dice
½ banana, cut into ½ inch chunks
4 to 6 red grapes
4 wooden skewers

DIRECTIONS

In a small bowl, whisk together the yogurt, lime juice and lime zest. Cover and refrigerate until needed.

Thread 1 of each fruit into the skewer. Repeat with the other skewers until the fruit is gone. Serve with the lemon lime dip.

Summer Corn Salad

Serves 4

INGREDIENTS

1 tablespoon lime juice (more to taste)
1/4 teaspoon salt
1/8 teaspoon black pepper
5 teaspoons olive oil
4 ears of cooked or grilled corn, removed from cob
1-1/2 cups cherry tomatoes, halved
1/2 cup finely chopped cucumber
1/4 cup finely chopped red onion
1 green pepper finely chopped
1 jalapeno pepper, seeded, finely chopped (optional)
2 tablespoons minced fresh parsley or cilantro

DIRECTIONS

In a small bowl, whisk the lime juice, salt and olive oil; set aside. Transfer to a salad bowl; add the corn, tomatoes, pepper(s), cucumber, onion and parsley. Drizzle with dressing and toss to coat. Let stand for 10 minutes before serving or refrigerate until chilled.

Cuban Black Beans and Rice

INGREDIENTS

1 cup long-grained white rice
1 Tbsp olive oil
1 medium to large onion chopped
1 bell pepper (can use stop light pack too) chopped
2 cloves garlic, chopped
Salt and pepper to taste
1 tsp cumin
2 15.5 oz black beans - rinsed
1 tsp dried oregano
1 Tbsp red wine vinegar

4 radishes, cut into 1/2 inch pieces
1/4 cup fresh cilantro

DIRECTIONS

Cook rice according to directions on package. meanwhile, heat the oil in a large saucepan over medium-high heat. Add the onion, bell pepper, garlic, 1 tsp salt and 1/4 tsp pepper. Cook, stirring occasionally, until soft (5 to 7 minutes). Stir in cumin and cook 1 additional minute.

Add beans, oregano, and 1 cup of water. Simmer for 10 minutes covered. Add the vinegar and smash some of the beans with the back of a fork to thicken. Serve beans over rice and top with radishes and cilantro.

This recipe is easily doubled or tripled and goes well with grilled chicken.



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