Fun, Games, and Life Lessons at Hemophilia Camps
HEMOPHILIA SUMMER CAMPS: A SEASONAL TREASURE

Hemophilia summer camps may have different approaches, but they all have common goals. They all strive to give kids with bleeding disorders the camp experience, to teach them about their bleeding disorder, and to show them how to live in a community setting. Find out why children who attend hemophilia summer camp say it’s the highlight of their year.

NEHA FAMILY CAMP: A FAMILY AFFAIR, HEMOPHILIA STYLE

The annual summer camp of the New England Hemophilia Association is held at a beautiful lakeside setting in New Hampshire. The camp provides programs for children with bleeding disorders as well as their parents and siblings. Read about how this camping experience creates a bond for these families that never goes away.

CAMP BOLD EAGLE

The summer camp programs of the Hemophilia Foundation of Michigan, including Camp Bold Eagle, help boys and girls with bleeding disorders move from childhood into thriving young adulthood. The camps provide great fun for the kids, and teach them about bleeding disorders. But that’s not all. Read about how campers learn how to look beyond the confines of a bleeding disorder to the promising future before them.

Note: Through these articles, Coram does not indicate support or endorsement of any particular hemophilia camps.
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Almost across the board, children who attend hemophilia summer camp say it’s the highlight of their year. One young camper said, “It’s better than Christmas.” This isn’t surprising when you consider that most kids with a bleeding disorder are the only ones in their school, if not their entire town, with the condition. They have to explain their bruises, why they can’t take part in some school activities, perhaps why they miss so much school. At summer camp, they are surrounded by peers who get it. They don’t have to explain anything. They are no longer alone. And many of the counselors themselves have a bleeding disorder and grew up going to camp.
Hemophilia summer camps are located throughout the U.S. [You can find a listing, by location, at www.hemophilia.org.] The camps may have different approaches and different rules for who can attend, but they all have common goals. They all strive to give kids with bleeding disorders the camp experience, to teach them about their bleeding disorder, and to show them how to live in a community setting.

“I have seen unlikely friendships develop at camp,” says Tim Wicks, Director of Camp Bold Eagle in Michigan. “Kids, who in other circumstances would never have even met, become friends for life. Some are kids from rural areas and inner cities who see each other at camp year after year and really connect.”

Who Can Go

Most hemophilia camps are open to boys and girls with bleeding disorders. Some camps invite siblings of affected children, and many camps have a weekend family session. Almost all are broken into different sessions according to age group. There are about 45 camps across the U.S. designed for kids with bleeding disorders. Youngsters can start camp as young as six years old (younger for family camps). They can continue with the yearly experience into their late teens. At that point, many continue on as camp counselors.

Safety First

Parents may be nervous about sending their little one with a bleeding disorder into the woods for a week. But hemophilia camps are well-equipped to deal with emergency and non-emergency situations. In fact, a Hemophilia Camp Program Standards document was designed in 1993 by the Nursing Executive Committee of the National Hemophilia Foundation [NHF]. The document was further developed at the 2005 North American Camping Conference of Hemophilia Organizations. [The standards can be found on the NHF website at www.hemophilia.org/node/4327.]

In addition, all hemophilia camps have nursing staff. The nurse will infuse the children according to their schedule for prophylaxis [preventive treatment]. Often this is done in front of another camper, which serves a key purpose.

“I had one camper who was scared to death of needles,” says Ann Mancini, CVS Health Clinical Hemophilia Advisor, who has served as a hemophilia camp nurse. “The camper watched me infuse a fellow camper, who was very calm about needles. After a bit, the frightened camper decided to be brave, too. It was a big turning point.”

The nursing staff also take part in the day-to-day camping experience. They go with campers on boating trips and take part in hikes, zip-lining, and other activities. The nurses are not just authority figures at camp, but fellow campers.

The Big Stick Award

Hemophilia camps make it a big deal when a child learns to self-infuse for the first time [with permission from the parents]. They have a lavish award ceremony during the evening campfire or at the closing ceremonies. During these events, the child...
is presented with an honor that is often called the "Big Stick Award." Everyone there knows that this is a huge step toward independence for the child. The child no longer has to rely on a parent or hemophilia treatment center nurse for infusions. It opens up a whole new world for them.

Preparing for Camp

Hemophilia summer camps typically have websites where parents can learn what activities are included. The sites also give contact information so parents can ask questions before sending their child away for a week. If parents have concerns, they should not be shy about contacting the camp in advance.

Before the camp session, the camps will provide parents with a registration form that includes a health information sheet. Sometimes these forms are filled out months in advance, so parents should make sure they let the camp know about any changes after they are filled out. In addition, the camps often require a current physical exam and current vaccinations. The camp will also provide a list of items that the child should bring, such as clothing, insect spray, and sunscreen.

In addition to these preparations, parents should get ready with these steps:

Teach your child to wash their hands briskly with soap and warm water for 30 seconds. If the camp doesn’t have hot water, the child should still soap up using the camp’s hand water pump. They should also use hand sanitizer often. Clean hands are important because much camp food is handheld (such as hot dogs, hamburgers, and s’mores). Also, the close quarters of the cabins make cleanliness important.

Send your child to camp well-rested. Kids will need their energy because in most cases, they will have a higher activity level at camp than they do at home. And if they get tired, the chance of injury is greater.

Provide your child with supportive, closed-toed shoes. The terrain may be hilly and could have a lot of tree roots or other tripping hazards.

Discuss with your child the importance of telling a counselor or nurse if they think they are having a bleed or other medical issue. Often the child is having so much fun they don’t want to miss out on anything by heading off to find the nurse. That could lead to a dangerous situation.

Talk to your child about the feelings they might have while away from home, such as homesickness. Most camps allow email or regular mail contact between the campers and their parents.

Once you feel like your child – and you – are prepared for camp, let them go and enjoy themselves. You will be rewarded by having a “happy camper” who has learned life skills such as leadership and teamwork, as well as new, corny camp songs. Your child will have met other peers with a bleeding disorder and gained a feeling of community. And you might even get a “Big Stick” Award to display.

Sources
The annual summer camp of the New England Hemophilia Association (NEHA) is called NEHA Family Camp. It is located at a conference center in Moultonborough, New Hampshire. It is a beautiful lakeside setting with cabins for each family. Last year, 38 families with 80 young campers attended.

“Our camp is unique in that the whole family is there,” explains Heather Case, NEHA Camp Director. “The youth are involved in a typical camp experience. They enjoy archery, water activities, and arts and crafts. And for the parents, we have social and educational options.”

During the week of camp, the families are welcomed on Wednesday. Thursday and Friday are full of activities and presentations. And camp winds down on Saturday. The age range for children is 1 to 15 years, with a daycare provided for the youngest kids. The other children – those with bleeding
disorders and their siblings – are divided into seven age groups. Each group has age-appropriate activities planned for them.

The 14- and 15-year-olds take part in Adventure Club. This club takes them off-site for a day of special ventures such as a ropes course or a hike in the hills. At ages 16 and 17, campers become junior counselors. And kids ages 18 and up become camp counselors. These two older groups come to camp on Tuesday for training before the families arrive on Wednesday.

**Education Options**

NEHA brings in speakers to talk about a variety of topics, mainly for the parents. Last year, one speaker gave a talk on genotyping. This is the process of finding the genetic mutation linked to a person’s hemophilia. Another guest gave yoga classes, open to both campers and parents. And a therapist spoke about physical activity and offered safe exercise tips for the family.

“We also had a police detective give two presentations about social media,” Heather says. “One was geared toward the counselors and the other toward the parents. She talked about the risks involved, what to watch out for, and how to protect yourself. It was something our community had been asking for.”

Another educational option is the self-infusion classes. There is a family infusion class, self-infusion for kids, and an adult infusion class. Families can go together, or a youngster can go alone. (This depends on age and comfort level.) Sometimes parents who have infused their child stick a needle in their own vein. This allows them to learn what their child experiences. And some of the youth who have already been self-infusing attend the classes to make sure they are doing it the right way.
At the closing ceremony, the campers who have learned to self-infuse for the first time receive the Big Stick Award (see page 5).

**Adults Connect**

“I think if you talk to any parent who comes to camp, the main thing they enjoy is seeing their kid having fun with their friends. But they also appreciate the chance to connect with other parents and make that network stronger.”

NEHA Family Camp has a mixture of families. Some have been coming back for years, and others are attending for the first time. But newcomers aren’t new for long. They are quickly embraced by the other parents and campers.

Camp offers many chances for parents to share with each other. Among these opportunities are the “rap sessions.” Parents come together at a certain time and place, and talk about anything they want to discuss. These talks may focus on things such as how they handle having one child with a bleeding disorder and other children who don’t. For example, they share how they handle attention-seeking behavior from one child or the other. Through these experiences, the parents create bonds that go on from year to year, much as their children do.

**Campers Connect**

The campers, split into smaller age groups, bond while they enjoy all the camp activities. However, they also bond with their counselors, many of whom have been campers themselves. The counselors either have a bleeding disorder or have a sibling or close friend who does.

“Last year we had a child who went to self-infusion class but just couldn’t do it,” Heather says. “Then he asked his counselor to go with him. After the camper watched his counselor self-infuse, he was able to do it himself. For that child, it was different watching his counselor self-infuse than just being shown how to do it by the nurse.”

The counselors know that their job as role model and mentor is important. The older staff teaches the counselors how to gain and keep the respect of the younger campers. For these young adults, how they learn to handle themselves during camp goes beyond the camp experience. The same skills that help them to be good counselors translate to job skills or success at school.

Unaffected siblings also have a chance to connect with each other. In addition to taking part in all the camp activities with their brother or sister with a bleeding disorder, these siblings have a special event of their own.

“We know the siblings sometimes feel left out,” Heather says. “So they have a pizza lunch and a speaker.”
Families Bond

Every morning, the families come together for “morning circle.” The staff makes announcements and there is an “ice-breaker” game to get the day started. In the evening, the families come back together at campfire. They sing songs and share stories about things that happened that day.

Each family has its own cabin, and there is time built into every day for them to connect. They can go for a walk on the beach or to the ice cream shop on the property. In the evening, there is a two-hour period between dinner and campfire that is built in as family time.

While camp can serve to strengthen family bonds, it can also help parents appreciate their children’s growing maturity.

“There are a lot of really special moments at the family camp,” Heather says. “One child would never have gotten up in front of her school to sing. But at campfire, she stood up and led the group in a song. It’s such a safe and supportive environment. The kids really feel like they can show who they are.”

A Lasting Connection

As with many hemophilia camps that are just for children, NEHA Family Camp is the only time many of these families see their camp friends. But the support they give each other and the laughter they share creates a bond that never goes away.
The summer camp programs of the Hemophilia Foundation of Michigan (HFM) help boys and girls with bleeding disorders move from childhood into thriving young adulthood. The camp programs provide great fun for the kids and teach them about bleeding disorders.

But that’s not all. The programs also teach the kids skills such as leadership and team building. While enjoying their time at camp, the campers learn how to look beyond the confines of a bleeding disorder to the promising future before them.

“Our summer camps are different from those of a YMCA or church camp,” says Tim Wicks, HFM Camp Director. “We have the same staff who come back year after year. We see 50-75% of the same staff because they grew up going to our camps. They went from being campers to being counselors-in-training. Or they went on to become counselors or staff, or even directors.”

Tim came through the ranks himself. He has severe hemophilia A and started going to camp at age 15. The camp programs are a passion for him, and he has seen them grow over the years.

Today, the camp has an exciting range of programs that focus on several stages of growth. These programs are carefully designed for kids ages 6 to 19 years.

Camp Bold Eagle

Camp Bold Eagle is located on the edge of Big Blue Lake in Holton, Michigan. It is the HFM’s main camp for boys and girls ages 6 to 13. The camp offers activities such as archery, boating, swimming, arts and crafts, and nature exploration. It also offers an
HiC (Health Information Center). Through the HiC, the youngsters learn about their bleeding disorders and those of others. Kids who are interested (with their parents’ permission) can also learn about self-infusion.

Campers who learn to self-infuse are given the Butterfly Award. This involves a big ceremony with the camper at the center of the celebration.

“That’s a huge step towards independence for these kids,” Tim says. “We make a big deal out of it.”

Camp Bold Eagle has two sessions. Each is designed with age-appropriate activities and education. The first is for kids ages 6 through 10, and the second for ages 11 through 13. More than 50 volunteers work together to design the structure of Camp Bold Eagle. The volunteers include people with hemophilia and medical professionals. They also include students from the University of Michigan Medical School.

The first session is fun for the younger kids. But the second session is even more exciting.

“Each day, kids from one cabin swim across the lake and back,” Tim says. As with all activities, safety is emphasized. “Of course, they are closely supervised. And there are safety boats and lifeguards in the water.”

The second-session camp also includes an activity called PAC, or Personal Adventure for Campers. The campers choose a skill they want to learn. Skills may include outdoor cooking, junior lifeguard training, or boating skills. The campers spend an hour each day learning the skill. And at the end of the week, they perform it for their fellow campers.

“One of the big things they can choose [for PAC] is Solo Prophy,” Tim says. “They go out into the woods by themselves and use the outdoor skills they have learned all week. They learn to make a fire and take care of themselves medically. They infuse by the light of the fire or with a flashlight in the shelter they have built. If they don’t have to infuse, they will do other types of first aid. Of course, there is staff nearby, but the kids have the feeling of being alone. It gives them the chance to get away from people and into their own heads.”

The kids are out in the woods from about 10:00 p.m. until 1:00 a.m. At the end of that time, the kids meet up and come out of the woods. They are greeted by a group of 10 to 15 cheering staffers.

“The look on their faces is amazing,” Tim says. “You can see they are humbled by the cheering crowd. But they are proud of what they have been able to do on their own.”

Eagle Outpost

This camp is for teenagers ages 14 to 16. At this camp, which they attend two years in a row, they transition from being campers into thinking of themselves as leaders. Eagle Outpost takes place at a different campsite from Bold Eagle. The campers
travel across Michigan in a 15-passenger van and enjoy high-adventure activities. These include ropes, zip-lining, and river kayaking or canoeing.

“We explore the Upper Peninsula, and go to Mackinac Island and Sleeping Bear Sand Dunes. At all locations, the campers are responsible for setting up the tents. They also plan and shop for the meals, and prepare them. They are supervised by adults, but they are doing the work. This gives them the chance to step up and be in charge. Sometimes we call them CITITs – Counselors-In-Training-In-Training.”

At Outpost, the teens learn to be more responsible and gain adult skills. The camp takes the kids away from Camp Bold Eagle for a reason. They are distanced from the children they have been with at camp through the years. When they return, they are a “new face” and are able to command more respect.

“When they come back to Bold Eagle, they haven’t been cabin buddies with anyone the year before,” Tim explains.

**Counselor-In-Training Program vs. Eagle Expedition**

After Eagle Outpost, the teens and staff decide together the next step the teens will take. The teens can go on to become Counselors-In-Training. Or, they can pursue the other option for teens 16 and up, which is Eagle Expedition.

“At Eagle Outpost, we find out if they have what it takes to be a Counselor-In-Training,” Tim says. “Not all of them are. I think every kid can be a leader; it just depends on what kind of leader. It takes a certain type of person to be out front and say, ‘Follow me.’ But there is also leading by example and by doing what’s right. Not every kid is going to be a counselor, but the goal is that every kid who comes through camp is a good person. We teach them ways to be helpful to others.”

The Counselor-In-Training (CIT) Program is the next step toward becoming a staff member at Camp Bold Eagle. The program focuses on communication and leadership skills. The training takes place at another camp prior to staff orientation and Camp Bold Eagle sessions.
Camp Old Beagle

At Camp Bold Eagle, there is one day between the session for the younger campers and the session for the 10- to 13-year-olds. Camp employees use this day as a one-day staff camp. Three years ago, a staffer quipped that this camp should be called Camp Old Beagle. Since then, Camp Old Beagle has evolved into a weekend staff alumni retreat.

“This past September, we had about 40 to 45 former staff members and medical directors,” says Tim Wicks, Camp Director for the Hemophilia Foundation of Michigan (HFM). “They dated all the way back to our first camp in 1969. Through Camp Old Beagle, people can come back to this place that impacted them so much.”

Camp Old Beagle takes place in the same location as Camp Bold Eagle – on the shores of Big Blue Lake in northern Michigan. The Beagles enjoy some of the activities the regular campers do such as boating, canoeing, and archery. And of course, they gather around the campfire at night.

“The first night at the campfire, we had a ‘Why are you here?’ discussion,” Tim says of the first session of Camp Old Beagle. “We had the first medical director, and camp directors from the first several years. It was really interesting to hear about how the camp has evolved through the years.”

The HFM reaches out to the former directors and staffers. These people come from all over the U.S. to Camp Old Beagle. For those who have drifted away over the years, it’s a chance to reconnect. Many take it as a chance for them to become involved again in HFM activities beyond summer camp.

These days, the Old Beagles may pass on trying the ropes course. However, the memories of the magical days at Camp Bold Eagle are as fresh as when they attended camp in their youth.

Eagle Expedition is a different kind of leadership camp. The teens go to Northern California and go whitewater rafting, rock climbing, and sea kayaking. They make camp, sleep out under the stars, and see a different part of the world than Michigan.

“It’s a leadership and team-building camp,” Tim explains. “The river is a great metaphor for life. If you are paddling your raft or kayak and there is a rock in the middle of the river, you need to look where you want to go instead of at the rock. If you look at the rock – the obstacle in your way – you are going to go right to it.”

Also, if the teens are in a six-person raft going down the river, they have to work together to make the raft go where it needs to go. That develops team-building skills and builds trust.

Teen Retreat

This weekend event occurs at the beginning of November. It brings together 25 to 30 teens with bleeding disorders ages 13 through 19, and 12 adult staffers. The group meets at a camp or conference center. In addition to high-adventure activities such as high ropes courses and zip-lining, the teens discuss important issues. They talk about bleeding disorders, and they focus on a theme important to becoming an adult. Past themes have included facing fears, advocacy, and being a savvy consumer. They have also included the global community, and career and college planning.

The retreat comes at a good time for these kids.

“The teen years are a crucial time of transition,” Tim says. “Plus, the retreat [which takes place in the fall] is a nice buffer for the kids who can't wait to get back to camp.”
Bleeder and a Buddy

Another weekend retreat, called Bleeder and a Buddy, allows teens with a bleeding disorder to bring a close friend to camp to see what it’s all about. They take part in camp activities such as ropes courses, but there are team-building and leadership activities as well. In addition, the friend learns more about bleeding disorders. They also learn what to do in case of an emergency.

“This is important for safety. Often when a teen is off doing something [and a bleed might occur], they are going to be with that friend or boyfriend or girlfriend.”

Last year the retreat occurred over Halloween, so the campers took part in activities designed to help them “face their fears.” They faced a fear of heights with high ropes, fear of the dark with a corn maze, and bleeding disorder-related fears.

MYLIFE

The Michigan Youth Leadership Initiative for Education [MYLIFE] is a planning retreat. A group of 8 to 10 teens is hand-picked by Tim to be members of MYLIFE. The group meets at retreat centers and campgrounds around the state of Michigan. They design programs for the Teen Retreat and Bleeder and a Buddy. They also plan programs for another HFM event, the SpringFest family retreat. The group changes from year to year as older members age out and younger members move into leadership roles within the group.

A Meaningful Retreat

The bottom line for Tim Wicks and the HFM is for the kids who come to camp – especially the teens – to leave as more self-assured, responsible, and helpful people. Even though it only lasts one week, campers are eager to return year after year. Throughout the experience, the kids have fun with their friends. But they also learn skills for a successful life that doesn’t focus on their bleeding disorder.
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