

HACA News

June 2002
Volume 18 Issue 3

The material provided in HACA News is for your general information only. HACA does not give medical advice or engage in the practice of medicine. HACA under no circumstances recommends particular treatment for specific individuals, and in all cases recommends that you consult your physician or treatment center before pursuing any course of treatment.

Mission Statement

HACA's Vision is to improve the quality of life for persons and their families affected by bleeding disorders.

HACA's mission is to:

- ◆ Educate, support and advocate for persons with bleeding disorders and their families.
- ◆ Network with healthcare professionals.
- ◆ Increase public awareness.

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Calling All TEENS!

Calling all Teens

The Hemophilia Association of the Capital Area and the Maryland Chapter are teaming up to host a teen retreat. The event will be held June 28-30 at the Melwood Retreat Center in Nanjemoy, MD. The retreat is open to young people between the ages of 12 and 17. We are also seeking young men ages 18 or older to serve as retreat counselors.

The days will be filled with supervised activities including horseback riding, canoeing, hiking, swimming, and wall climbing. The nights will be filled with ghost stories and snacks around the campfire. Amr El-Beshir and Paul Brayshaw will be coordinating this event together with the staff from the Melwood Retreat Center. Our young people will be housed in dorms furnished with leather couches and big-screen TVs so their surroundings will be posh. Nursing staff will also be present for the weekend.

There are only **16 slots available** for this retreat so make your reservations today by calling the HACA office at 703-352-7641.

Save the Date

HACA's annual meeting and education seminar is currently planned for October 19, 2002 at the Holiday Inn in Tyson's Corner. We are currently planning roundtable discussions on ports and prophylaxis, Daycare and Pre-School issues, Pegylated Interferon, and Joint Replacements. If you have any other topics you might like to have a roundtable discussion on, please contact the HACA office at 703-352-7641 with your ideas. Dr. Kathleen Hill from the City of Hope Hospital will give the keynote address on Translational Bypass Therapy—a method of treatment for nonsense mutations of hemophilia that uses an antibiotic rather than factor for treatment of bleeds. Registration for the seminar and annual meeting will begin at 8:30 am and the session will end at 2:00 pm.

Patient Notification System

You will find brochures included with this mailing that allow you to sign up for the Patient Notification System. You are urged to complete the form and fax, e-mail, or send it to the addresses listed in the brochure. The Patient Notification System is a free, confidential system put in place to notify you directly should it be necessary to recall any factor products for any reason. Please take the time to avail yourself of this valuable service **today**.



The Bike-a-thon Cometh

Plans for our annual bike-a-thon are rolling along. The Bike-a-thon is scheduled for September 14 and will originate at the YMCA on Sunset Hills Road in Reston, VA. Riders will be able to choose a 25 K, 50 K or 50-mile ride along the W&OD trail. Jim Romano will be chairing this event and will need your help to recruit riders, serve as hospitality hosts at the water stops, help with registration, and flip burgers for the picnic. Won't you call the HACA office today at 703-352-7641 and volunteer to help? Thanks!!

Summer Camp

9 young people and 2 adults will be taking part in the first session of the Hole in Wall Gang Camp in Ashford, CT, June 8-15. Our deep thanks to Deb DeArmon and Miriam Goldstein for accompanying our campers to and from camp and for spending the week

Chapter News continued

as camp counselors. We hope you all have a fantastic time!

NHF Annual Meeting

The NHF Annual Meeting will be held this year at Disney's Coronado Springs Resort in Lake Buena Vista, Florida from October 31-November 2. HACA will be offering partial scholarships (up to \$350 per person for 1 parent and 1 affected child or 2 affected individuals per family) with preference given to 1st time attendees. Contact the HACA office at 703-352-7641 to obtain your application for the scholarships.

Women's Day Out

9 women gathered at the home of Susan Yamamoto on April 21 to learn how to make quick and easy centerpieces and to watch Chef Kevin Johnson demonstrate homemade crab and mushroom raviolis. Everyone was treated to a dinner prepared by Chef Kevin after the demonstration. Even though the weather was rainy outside, the sunshine of friendship shone brightly inside that day. Our deep thanks to Susan and her family for making their home available for this event; to Kathi Baumgart and Elsbeth Hoff for demonstrating the centerpieces and making one for each woman to take home, and to Kevin Johnson for the cooking tips and the tasty meal.

Congratulations

Congratulations are extended to Kirsten and Spencer Duggan. Kirsten was a recipient of a college scholarship from the Hemophilia Federation of America. Spencer won first place in the art contest in his age category during the recent annual meeting of the Hemophilia Federation of America.

HACA Advocates for Access and Support to HTC's

Members of HACA convened in Washington DC as part of NHF's Annual Washington Day on Friday, March 8, 2002. Armed with position papers and research demonstrating significant reductions in mortality and morbidity associated with comprehensive care provided by hemophilia treatment centers, we held legislative appointments with staff members from the offices of Senators Allen and Warner and Representatives Davis, Moran, and Wolfe. Members from the Maryland chapter made similar visits with staff members from the offices of Senators Sarbanes and Milkuski and Representatives Erlich, Hoyer, Morella, and Wynn.

Specific support was requested from the legislators on two issues critical to the bleeding disorders community: 1) including language in the final Patient's Bill of Rights that would assure direct access for individuals with hemophilia to the network of federally funded Hemophilia Diagnostic and Treatment Centers and 2) requesting support urging the Labor, Health and Human Services Appropriations Committee to increase funding available for the Maternal and Child Health Block Grant with \$3 million in new earmarked funding for HTC's. The Maternal and Child Health Bureau's (MCHB) funding has remained steady for 20 years. The MCHB funds are used to cover costs of non-reimbursable services such as nursing and social work. The HTC's cannot continue to provide adequate care if funds are not increased.



Local advocacy from consumers and their families and friends is essential to maintaining support in Washington, Richmond, and Annapolis. If you are interested in joining HACA's ongoing advocacy efforts, please call the HACA office at 703-352-7641.

Janice Farmer Retires

We wish all the best to Janice Farmer on the occasion of her retirement as social worker at the Hemophilia Treatment Center at Children's Hospital. Janice and her husband plan to "see the world" for the next few years. Janice, we thank you for all the care and attention you have lavished on this community for the past four years. You have touched our lives deeply. We'll miss your smiles and your energy.

Sincere Sympathy

Our sincere sympathy is extended to George Price and his family. George's mother, Harriett, passed away on April 16th after a battle with

	<h3>Calendar of Events</h3> <table border="0"> <tr> <td>June 8-15</td> <td>Hole in the Wall Gang Camp @ Ashford, CT</td> </tr> <tr> <td>June 28-30</td> <td>Youth Retreat</td> </tr> <tr> <td>September 14</td> <td>Bike-a-Thon</td> </tr> <tr> <td>October 19</td> <td>HACA Annual Meeting and Seminar</td> </tr> <tr> <td>October 31- November 2</td> <td></td> </tr> </table>	June 8-15	Hole in the Wall Gang Camp @ Ashford, CT	June 28-30	Youth Retreat	September 14	Bike-a-Thon	October 19	HACA Annual Meeting and Seminar	October 31- November 2		
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cancer. We wish her family comfort in their memories of her and support from those who love them.

Bayer Announces Voluntary Recall of Recombinant Factor VIII

NHF Medical Advisory #391
April 1, 2002

Bayer Corporation is voluntarily recalling one lot of Kogenate® Antihemophilic Factor (recombinant) because the lot failed to meet potency requirements when stored over 2 months at room temperature. Ongoing studies have demonstrated that this lot failed to consistently meet minimum allowable potency requirements (80% of label value).

Lot Number: 670J039A
Expiration Date: May 24, 2002
Labeled Potency: 250 IU/vial

MASAC Releases Update of Its Guidelines for Recombinant Factor VIII Usage

MASAC Medical Recommendation #131

At its most recent meeting, NHF's Medical and Scientific Advisory Council (MASAC) revisited its guidelines for recombinant factor VIII usage and has updated those guidelines in response to an anticipated 10% increase in the amount of available factor this year. The guidelines suggest an increase of 10% and recommends making the resumption of immune tolerance induction a high priority. For the full text of this recommendation, visit NHF's Web Site at www.hemophilia.org or call HANDI at 1-800-42 HANDI.

MASAC Recommendation #130— The Use of Therapeutic Ultrasound to Aid in Blood Resorption

In light of the poor theoretical foundation and lack of proven clinical effectiveness of ultrasound, along with the potential danger of deep heat and cavitation effects, MASAC does not recommend its use in the hemophilia population for the resorption of blood. MASAC will review emerging data as they become available and will modify this recommendation if new data warrant a change.

MASAC Recommendation #133— Standards and Criteria for the Care of Persons with Congenital Bleeding Disorders

MASAC also revised this document that outlines comprehensive standards of care and lists of services that should be provided by hemophilia treatment centers (HTCs).

2002 Board of Directors Meetings

General Board Meeting
June 24, 2002
Executive Board Meeting
TBA

General Board meetings begin at 7:00 p.m. and are open to all interested HACA members. Because of security regulations at our meeting place, please notify the HACA office that you will be attending. Directions and site will be shared with you at that time.

For a copy of the complete text, log on to www.hemophilia.org or contact NHF's HANDI information services at 1/800/42 HANDI

Insurers Reduce Drug Coverage

Insurance companies are revising the way they categorize drugs, resulting in steep increases in costs to consumers. To the familiar division between generic drugs and brand name drugs (the latter generally requiring a higher co-pay), insurers are adding another category for newer brand name higher priced drugs. Some of these new drugs are not included on the company's formulary, that is, the list of approved drugs for which it designates co-pays. Insurers are also experimenting with other cost-cutting arrangements—four or five tiers with diminishing percentage coverage or penalties for buying higher priced drugs that they deem only marginally better than lower priced drugs.

The purpose of this change is to encourage customers to choose the least expensive generic and brand name drugs, thus reducing the insurer's cost. There's not much you as a consumer can do except check your prescriptions against an insurer's formulary and read your benefits package carefully. To check your insurance plan's formulary, see your employer's or insurer's Web site or contact your company's benefits department or insurer.

Mail orders, at least for drugs you take regularly, may be one way around the higher drug categories. Because it costs the insurer less, the co-pay

is generally less than it would be if you filled your prescription at a local pharmacy (*Hemophilia Outlook*, HANY, Spring 2002)

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Study Warns About Long-Term Catheter Use

(From *Blood*, American Society of Hematology, 9/15/01)

Researchers at the University of Texas warned that children with hemophilia might be at an increased risk of developing blood clots from long-term use of central venous catheters. In a study of 15 boys with severe hemophilia, all of whom had a tunneled, internal CVC placed in a subclavian vein for at least twelve months, eight patients had evidence of a blood clot deep in the vein near the injection site. The longer the catheter had been implanted, the more likely the presence of a clot. However, no patient has had a clinically apparent pulmonary embolism or symptomatic postphlebotic syndrome.

Researcher's Conclusions:

Patients can get by with catheters for four years. After that, a catheter has the potential to cause harm. However, the benefits of using a catheter for up to four years to administer factor to young patients, whose veins are often difficult to access, outweigh the risks. Hemophilia patients using catheters for infusion should be monitored for the development of blood clots.

Doctors and Research Scientists Gathered for NHF's Fifth Workshop on Gene Therapies for Hemophilia

Doctors gathered at the Children's Hospital of Philadelphia on April 12 and 13 to review the latest evolving developments in treatment for hemophilia. The workshop included over 45 scientific presentations. In addition to treating hemophilia, researchers discussed the use of gene transfer therapy to deliver genes to treat other genetic and acquired diseases.

For additional highlights from the workshop, be sure to read the special selection on gene therapy in the

upcoming July/August issue of *HemAware* magazine. (NHF's eNotes, May 2002)

SSA Re-opens Comment Period for Rules Changes on Qualifying for Disability

In November 2001, the Social Security Administration (SSA) published proposed changes to their rules that would make it more difficult for some individuals with bleeding disorders in need of assistance to qualify for disability. The period for comments has now been extended until June 17th.

The problems with the proposed changes included the fact that they were drafted based on the assumption that all hemophilia patients are currently on prophylaxis. They also failed to recognize all the many complications and co-morbidities facing patients with bleeding disorders, and they used a harder to meet set of criteria for patients with severe von Willebrand Disease than for individuals with severe hemophilia.

You can base your comment letter on the one from NHF

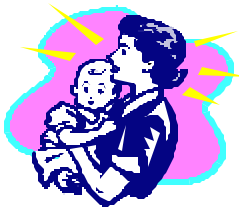


(available online at www.hemophilia.org/news/registrative_lu_04_25_02b.htm which includes all of the important

Developmental Milestones and Children with Bleeding Disorders

From the CDC workbook, *Basic Concepts of Hemophilia*

As happens with any child, different stages of development require different responses from us as parents. This is no different for children with bleeding disorders. Since our job as parents is to protect our children from harm while fostering their sense of independence and accomplishment, it helps to know what to expect at the different development milestones along the road to adulthood.



Newborns

Very few bleeding problems usually arise while a child is a newborn; if they do, they will most likely have to do with the following:

- Slow and persistent bleeding at the circumcision site. Many children with hemophilia are diagnosed because of this. If your son was circumcised shortly after birth, you may have noticed bleeding. The bleeding may stop on its own, or a topical (surface) medication or stitch may have been applied.
- Raised bruises. Your child may get a bruise on his rib cage where you hold him, or on his feet or legs if he/she bangs against the crib or dressing table. Unlike normal fat bruises, children with hemophilia or other bleeding disorders usually have raised bruises. Expect to see some bruising; it is normal in children with hemophilia and not a cause for alarm.
- Teething. As baby teeth begin to erupt (around 4-6 months of age), your child may have some bleeding or spotting. This is rarely anything to worry about and most parents report no bleeding with teething.

Toddlers

Children start to sit up around 6 months, and they begin to walk from about 10-12 months. Be prepared for falls and bruises! Help your child understand that he can run, but on soft surfaces such as carpeting or grass. As your child becomes steadier at walking and gets a little older, teach him/her to go up and down stairs safely (perhaps by sliding down on his bottom or crawling down backwards on his hands and knees). Install proper childhood safety devices where necessary. Encourage your child to be as independent as he/she can be while remaining safe.

During the walking and climbing stages, your child may have the first major bleed. The toddler stage is prime time for a child to receive head bumps and mouth bleeds from trips on the stairs or falls out of the crib. At this stage, your child may not be able to tell you where or how badly it hurts. Never second-guess a head bump. Always call your treatment center and ask what to do when your toddler has bumped his head. Together, you will come to a decision, based on the strength of the blow and the severity of the child's disorder.

Although this can be an upsetting time for parents, try not to panic. It's important for you to try to establish a sense of normalcy. If you are calm, your child will imitate you. Children take many of their behavioral cues from the adults around them. Being prepared makes it easier to stay calm – have medicine handy, including first-aid as well as factor concentrates; have your doctor or treatment center phone numbers easily available; and keep a little pack of supplies with you at all times, even for local trips.

Some parents feel that preventing their child from getting his first infusion is an important goal, because it means they have been good parents in protecting their child. Other parents are actually relieved at the first infusion because it is an event they have expected and dreaded for so long. The more informed and prepared you are, the calmer you will be.



Preschoolers

Preschoolers can begin to understand a little about bleeding disorders. Use this time to offer simple explanations for why infusions are necessary. You might say, "You need factor to make the hurt go away." Since children, at this stage, are familiar with the infusion procedure, this is a good time to teach self-control for the needle stick. You could say, "The needle hurts, I know. Let's count to three while we do the poke." Offer praise any time your child sits still, but do not criticize or belittle him for squirming or crying. Give your child limited choices such as which arm to use, or whether to sit on a chair or table. You may also find it helpful to distract your child during the infusion by reading a book, telling a story, or showing a favorite toy. Children this age like to have a

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TT Virus: A Recently Identified Virus Contaminating Recombinant and Plasma-Derived Clotting Factor

In 1997, medical researcher in Japan identified a virus in the blood of several patients who had contracted hepatitis apparently from transfusions of blood or blood products. Because the type of hepatitis afflicting these patients could not be identified as being caused by any of the known hepatitis viruses, the researchers were left with the question of whether it was caused by this new virus. The virus was named Transfusion-Transmitted Virus and is commonly referred to as TT Virus or TTV. TTV was soon identified as being the first known human circovirus. Other members of the circovirus family cause disease in livestock and birds.

Until the development of improved blood screening tests and processing methods to inactivate or remove viruses, hepatitis was a common risk of blood transfusion and plasma product usage. Hepatitis can be a very dangerous disease. In addition to causing acute or immediate severe sickness, over the long term it can also lead to cirrhosis or to liver cancer, both eventually fatal. Most hepatitis cases are caused by a handful of known viruses, or by exposure to toxic chemicals. However, there are still some cases each year for which the cause is unknown. Therefore, the identification of a possible new hepatitis virus is a significant event that can immediately spur intense research. The story of the research on TTV provides an interesting demonstration of how scientists approach such a problem. It also demonstrates the danger of jumping to conclusions before all the facts are known.

As an aside, when scientists talk about a "new" virus, they usually mean a virus that has recently been discovered. Most often, the virus has been around for a long time, but no one had ever noticed it. New viruses such as HIV, the AIDS virus, do appear from time to time, but there are thousands, if not millions, of viruses in nature that have existed for eons but just have never been identified.

A number of early studies appeared to show a strong correlation between the presence of TTV and the occurrence of hepatitis. The studies would typically find a much higher prevalence of TTV infection in patients with hepatitis compared to the general population. Alarmingly, other studies showed that clotting factor concentrates are often contaminated with TTV. One study even showed that recombinant clotting factor VIII concentrates were also contaminated with TTV. This was distressing because the recombinant products are

usually considered to be free of the risk of transmitting viral diseases. These results raised great concern that here was yet another risk for people with hemophilia and others who are treated with blood and plasma products.

However, scientists are rigorously trained not to jump to conclusions. Just because something looks like it is happening, and even if it seems to make sense that it should be happening, that does not prove that it is happening. A correlation only means that two things are happening at the same time; it never proves that one causes the other. It takes much more study to provide enough evidence to show that one thing causes another. Thus, just because some patients with unexplained cases of hepatitis seemed to also have high levels of TTV, that does not prove a thing.

As it has turned out, TTV probably does not cause hepatitis or any other serious human disease. As more was learned about the virus, it was discovered that it has a large number of subtypes. That is, TTV can occur in various forms that have slightly different characteristics. Variation is the rule of nature. Except for identical twins, very few organisms, from humans all the way down to bacteria and viruses are exactly alike. To help understand how this was a problem for research on TTV, think about what would happen if a team of alien scientists from another planet were studying the earth and discovered the human being. From that one discovery, they might decide that humans have two arms, two legs, and brown hair. If they went looking for organisms that fit that criteria, they could miss a lot of humans that did not have brown hair.

That is essentially what happened with TTV. Before they realized that there could be a large variation in TTV, researchers only looked for viruses that had the same exact characteristics as the first TT viruses that had been discovered. Obviously, they missed a lot. Once they realized that they should be looking for TT viruses that fit a much broader range of characteristics, they discovered that most people in the general population are infected with TTV. TTV apparently is just something that most people pick up as they move through life. Since the general population does not appear to be afflicted with a TT-caused disease, the current view is that infection with TTV is probably harmless. The reason that blood and plasma products are so often contaminated with TTV is because most blood and plasma donors are

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How Having Hemophilia Can Affect Academic Achievement

Children with the chronic bleeding disorder hemophilia may frequently miss school because of bleeding episodes that leave them fatigued and in pain. To better understand the academic challenges children with hemophilia face, researchers from a hemophilia treatment center in Indianapolis studied the effect of bleeding episodes on academic achievement in children with hemophilia.

One hundred thirty-one boys 6 to 12 years old who had hemophilia (nearly all those with the disease were male) were enrolled in the study. The number of bleeding episodes, missed days of school, limitations of physical activity, and the types of treatment for hemophilia the boys received was recorded. The boys also took academic tests that measured their achievement in math and reading.

On average, the boys had experienced 12 bleeding episodes in the previous year, but there was a significant difference between boys who received preventive therapy (prophylaxis) with clotting factors and boys who were treated only when a bleeding episode occurred. Boys who received prophylactic therapy had an average of 6 bleeding episodes, whereas boys who were treated only at the time of the bleeding episode had an average of over 25 bleeding episodes.

Academically, boys who had 11 or fewer bleeding episodes during the course of the study had higher scores in total achievement and math than boys who had 12 or more bleeding episodes. Children who had been treated with long-term prophylactic therapy and who had 11 or fewer bleeding episodes in the year before enrollment in the study had significantly higher scores in total achievement, math, and reading, when compared to children who had 12 or more bleeding episodes during the same time period. Overall, children who had more school absences had lower scores in math, reading, and in total achievement.

What This Means to You: If your son has hemophilia, minimizing school absences should be a consideration in his treatment. Talk to your child's doctor about the best ways to prevent and manage your child's bleeding episodes. If your child does miss school because of illness, communicate with your child's teacher so that he'll be able to make up missed schoolwork and tests.

Source: Pediatrics, December 2001

Reviewed by: Steve Dowshen, MD

Date reviewed: January 2002

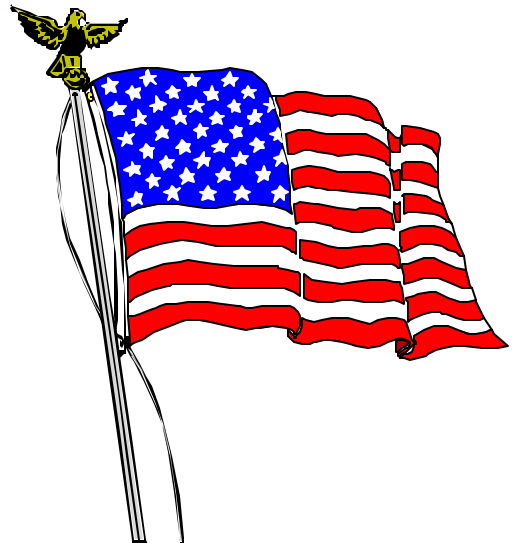
infected. Some recombinant products are also

TT Virus (continued)

contaminated because all of the first-generation recombinant products contain albumin as a stabilizer and albumin is derived from plasma.

Thus the TTV story turned out to have a happy ending. However, it also demonstrates a dilemma that medical science has to deal with all of the time. Until you have enough information, how do you decide how to react to something like the news of a new, possibly dangerous virus that appears to contaminate most clotting factor concentrates? Everyone wants to choose the safest course of action, but it is not always clear what that is. The potential for harm exists no matter what you do. Striking the right balance in the absence of complete information is a real challenge, one that we must keep watching.

Factor IX News, February 2002



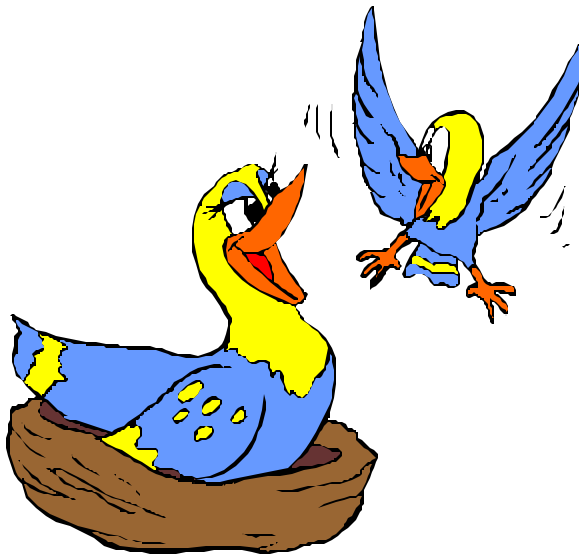
Transition: Leaving the Nest

By Michael Fitzpatrick from NEHA News (Spring 2002)

I don't know about you but I don't always like changes. I like things to stay the same, which is safe. Change can be scary. What if something goes wrong? Having a bleeding disorder can add another layer of concern to change. With good planning, though, it doesn't need to be a frightening event.

A big change a person can face is going away to college. I am both excited and nervous at the same time. I am excited and nervous about living on my own and making all new friends. Who will help me if I have a bleeding episode or trouble with my schedule? In fact, whether you are leaving home to work or go to school, many of these issues are the same.

I have listed below some of the things that need to be done in order to help smooth the transition from the care of my parents to making decisions myself:



1. Start participating in decisions about your medical care when you are in high school. Talk with your doctors and nurses and help to make the decisions that are best for you. Be aware of what your own needs are around your health issues. Learn early to be pro-active around your health needs.
2. Whether you are staying at the same treatment center or not, let your HTC know where you will be going. They can check for you on the nearest HTC and local hospital. You should then contact the new center and introduce yourself. When you arrive at school make an appointment to meet with the health services people

immediately (if it is possible, you might do this before arriving).

3. Have your current HTC send them your medical information. The health services and local hospital may want to contact your HTC to educate themselves about your needs. This is something you may want to suggest. Depending on whether you self-infuse all the time, some of the time, or not at all will influence your decision on where to store your factor and materials. Since I do not self-infuse (due to poor vein access), I will store some factor at both the health services and the local emergency room. If you self-infuse, you will need a refrigerator in your room (this is also good for snacks and sodas!)
4. It is your choice who you want to tell about your hemophilia. Choose wisely.
5. For those going to college, it will be important to let your advisors know if you cannot carry a full load due to health issues. For those starting work, being honest with your supervisor may help to lessen problems in this area.

With planning, education, and assistance, transition does not need to be frightening. I am not anticipating that the care surrounding my hemophilia will be a big problem. I want my biggest problem to be where to find the best French fries in town!

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Developmental Milestones

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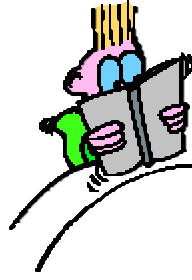
“job.” Let your preschoolers help in some way - by holding the bandage or rotating the factor bottle. You may also want to talk with your nurse coordinator or physician about the advantages and disadvantages of a topical anesthetic cream.

Stress rules to teach your preschooler limits. Two- to four-year-olds seem to know no bounds. You will need to be consistent and patient to stress safety rules. Repeat them daily. Your rule may include things like:

- No crossing the street unless holding hands.
- No jumping on the bed.
- No pushing or hitting.
- Always wear helmet and pads when bike riding.

At this stage children are also trying to handle their emotions – which also may seem to know no boundaries. A child may blurt out how much he hates his bleeding disorder or have a tantrum. Try not to deny the child’s feelings, no matter how awful or embarrassing they seem to you. Acknowledge the child’s feelings and help your child identify what they are, by saying, “You sound really mad. I can see why you might feel that way.” When your child is calmer, you can help him/her explore other ways to vent feelings – through art or playing with puppets or toys. Help your child to channel emotions so that his venting is not personal. Do not allow him to say, “I hate you.” At night, when he is resting, ask him how he felt, what he wishes would happen, what he could do differently next time. Read stories to your child about his bleeding disorder. Ask your child how he might like to handle infusions. What would he/she like to bring to the emergency room or the treatment center next time? What advice he/she would give to another child who has a bleeding disorder?

During this age, avoid blaming your child for his/her bleeds. Children tend to see things in good or bad terms. Blaming a child for doing what he does best – being an active child – may make your child see himself, rather than his behavior, as bad. Assure your preschooler that he is good, and that everyone falls at some time. Reinforce that when he/she falls or gets hurt, there is something he can do to feel better. This will help your preschooler feel comfortable about telling you when he has a bleed. Remember that bleeds are part of a normal life for children with hemophilia. Help your child to



remember this as well.

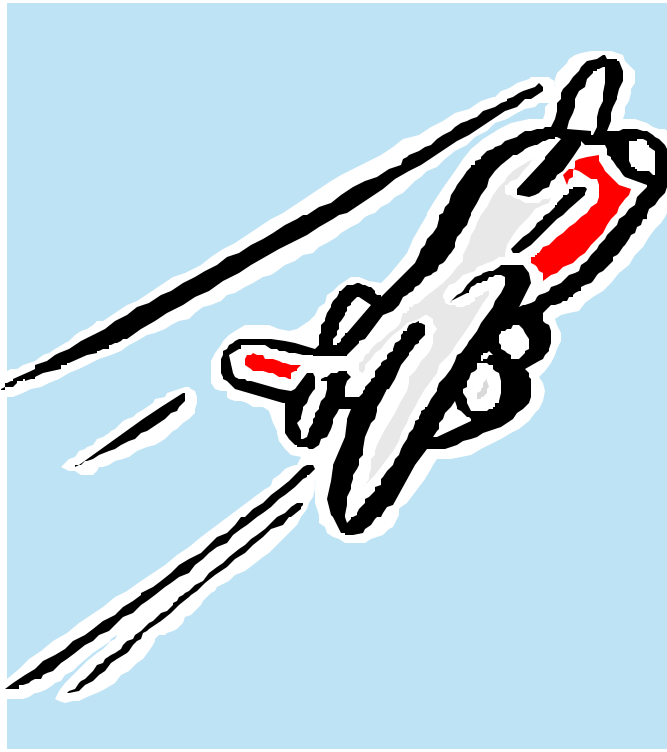
School-Age Children

By five or six, your child is ready to meet the world and be away from your care for a good part of the day.

Although your child may have had some experience in daycare, at school he/she is in an environment with other independent, mobile children, and is capable of making some basic decisions for him/herself. School is an exciting time for children and a potentially nerve-racking time for parents. Things will be easier if you prepare your child, his school, and yourself in advance. Remember that teachers are extremely busy and that they are entrusted with children with a variety of issues. Be patient and sympathetic. Do be sure, however, to make your child’s teacher aware of responses that should be avoided:

- Over-protection (excluding the child from activities);
- Singling the child out (announcing his/her bleeding disorder);
- Ignoring the problem (not believing your child when he/she says it hurts);
- Overreacting and favoritism.

Another issue you may face is what to do when your child misses occasional school days due to bleeds. Most children on current treatment products do not miss much school. However, when it does happen, your child’s teacher will help you work with your child to make up the work missed. Another challenge may be what to say to your child when he realizes that he/she is different from his new friends. Your treatment center is used to dealing with these issues and your social worker or nurse can help you come up with potential solutions. Remember if you see your child as wonderful and full of potential, your child will more easily see him/herself that way too. Focus on all that is wonderful about your child. You will learn that the bleeding disorder can and will be just another part of life.



When everything seems to be
going against you,
remember that the airplane
takes off against the wind,
not with it.

Henry Ford,
Founder of Ford Motor Co.

HACA News

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