

HACA News

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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.*

Hemophilia Association of the
Capital Area
3251 Old Lee Highway
Suite 3
Fairfax, Virginia
22030-1504
(703) 352-7641
Fax (703) 352-2145
E-mail: hacacares@aol.com
www.hacacares.org
CFC #6022

Blood, Sweat and Gears

Our annual bike-a-thon is scheduled for September 14th. The ride will take place along the W&OD trail and we will offer 25K, 50K or 50-mile distance options. The ride will originate at the Reston YMCA located at 12196 Sunset Hills Road. Registration for the 50-mile or 50 K ride is at 8 AM and at 9AM for the 25K ride. Registration cost is \$35 per cyclist. While there is no fund raising minimum, for every \$50 raised, the cyclist will be entered into a drawing for exciting prizes. A picnic lunch will be provided for all participants from 11:30 AM to 1:30 PM.



How you can help: 1) We need people who will help staff the water stops (three) along the ride trail. You will help us provide fluids, fruit, and power bars, etc. for the cyclists and provide communication to home base so we can keep track of the riders. 2) We need people who will help with the picnic—someone to flip burgers, provide food items for the picnic, help set up the food and tables, etc. 3) We need people who are willing to distribute brochures to bike shops, etc. in their area. Please contact the office at 703-352-7641 and we can send you copies of the brochure. 4) We need riders. Again, please contact the office at 703-352-7641 for registration forms.

Educational Seminar and Annual Meeting

HACA's annual meeting and educational seminar is scheduled for October 19th at the Holiday Inn--Tyson's Corner. Sessions begin at 9 AM and are scheduled to run until 2 pm. Box lunches will be served. Our keynote speaker will be Dr. Kathleen Hill from the City of Hope Hospital. She will speak on Translational Bypass Therapy—a method of treatment for nonsense mutations of hemophilia that uses an antibiotic rather than factor for treatment of bleeds. Roundtable discussions on ports and prophylaxis, daycare and preschool issues, pegylated interferon, and joint replacements will also be held. Please reserve the date on your calendar now.



Lynda Mulhauser

Lynda Mulhauser is the new social worker at Children's Hospital. Welcome Lynda. We look forward to getting to know you and work with you.

Best wishes to Jens Freese

Many of our members have met Axel and Lisa Freese over the years. Axel and Lisa currently reside in Vienna, Austria while Lisa is on assignment with the State Department. We have recently heard from them that their 7-year-old son Jens has been diagnosed with Burkett's Lymphoma—a cancer of the immune system. Jens is currently undergoing 4 series of Chemotherapy—each cycle consists of 5 days of chemo followed by 10-14 days of recovery while the body rebuilds. At the time of this writing, Jens had completed his first chemo series of five days of treatment. Things were progressing as well as could be expected. Axel and Lisa are open to any kind of "funny hats" that people would like to send Jens. You can drop a card or note of encouragement to Jens Freese, 9950 Unvie Place, Dulles, VA 20189-9950 or call the HACA office at 703-352-7641 for an e-mail address.

Chapter News continued

Web Site for Parents

A new web site for parents of kids with Infectious Diseases has been launched at www.pkids.org.

Web Site for Teens

A new web site called "Connect" has been developed for people in their teens or 20's by students of that age group. They all have or have had serious illnesses like cancer, lupus, cerebral palsy, diabetes, etc. The goal is for visitors to talk about their illnesses, difficulties, and experiences with other people who are in the same situation. You can read what people have written about themselves and then send us your story. Soon there will be a nationwide network of high school and college age students with serious illness! This will be an amazing way to get support as you go through the tough times of dealing with a serious or chronic illness. Check it out at www.connectonline2k.cjb.net

Labor Day Weekend Camp Out & Education Conference

Hemophilia Access, Inc. invites you to a Labor Day Weekend Camp Out and Educational Conference. The event will be held Friday, August 30th through Monday September 2nd at the HAI Ranch in Nolensville, Tennessee. For more information and registration please call: 1-800-399-7359.

Win a Trip to Orlando!

Baxter is sending 5 families to Orlando, Florida, for the National Hemophilia Foundation Annual Meeting that will be held October 31-November 2, 2002. For your chance to win, enter monthly online at: www.hemophiliagalaxy.com/trip.

Superhero Contest

NHF is currently developing a new Superhero comic strip series to be launched in early 2003. The series will be published on the NHF Youthworld Web site and in HemAware Jr. NHF has launched a contest to help them create and name characters for the series. 6 Winners will receive gift certificates from Amazon.com.

About the Superheroes

Trent Stark and Patty Mayer are lab partners at the local Science High School in the year 2021. After school one day, Trent and Patty were working on final projects for physics class. Trent was working on a project on robotics and Patty was working on splicing dinosaur DNA. After a mysterious explosion, the two found themselves changed. Trent was now the owner of four robotic arms and Patty's DNA spliced with a mixture of dinosaur DNA, enabling her to transform into many different types of prehistoric creatures. Trent and Patty have not mastered their powers yet, but they will have to learn along the way.

Meanwhile, many evil villains want to possess their secret powers to try to rule the world. So not only do Trent and Patty have to protect themselves, but they must also fight to thwart the many schemes for world domination.

Contest A (ages 7-10 years old)

Trent and Patty need disguises to protect themselves from evil villains. Your assignment is to make up their superhero names and design their shields.

Contest B (ages 11-15 years old)

Trent and Patty will fight crime against many evil villains. Your assignment is to name and draw a villain.

The deadline for all submissions is **August 31, 2002**. Contact the HACA office at 703-352-7641 or NHF at 1-800-42-HANDI ext 3756 for your Superhero Contest Entry Form.



Calendar of Events

- September 14 Bike-a-Thon
- October 19 HACA Annual Meeting and Seminar
- October 31- November 2
NHF Annual Meeting, Orlando, FL



Baxter Submits File to U.S. FDA

On June 27, 2002, it was announced that Baxter Healthcare Corporation submitted a Biologics License Application (BLA) to the Food and Drug Administration for marketing approval of its hemophilia A treatment, Antihemophilic Factor Plasma/Albumin Free Method, or rAHF-PFM. The BLA submission is the first step in the regulatory process to gain U.S. licensure for Antihemophilic Factor Plasma/Albumin Free Method.

A Baxter spokeswoman said the rAHF-PFM is the next generation of its other hemophilia treatment, Recombinate, which received FDA approval in 1992. The latest generation of the product uses a different manufacturing process that doesn't use any additional human or animal products.

NFH Medical and Scientific Advisory Council (MASAC) Recommendations

MASAC Recommendation Regarding the Recombinant Factor VIII Shortage

MASAC Document #133
June 8 2002

MASAC now recommends a 15% increase in factor usage due to an estimated 15% increase in available product over 2001 levels.

Questions and Answers

These questions and answers were taken from the Hemophilia Foundation of Nevada's *Hemophilia Foundation News & Views*, Volume 11, No 1.

Q: I used Stimate pre-operatively and 12 hours later in conjunction with a recent outpatient surgery. It worked well in that I did not develop any bleeding problems, however, the following day I developed fluid overload, a terrible headache and elevated blood pressure necessitating a trip to the emergency room. My doctor's office staff says they've never heard of fluid overload in conjunction with Stimate use.

A: The ingredient in Stimate is a concentrated form of a medicine called desmopressin acetate. Desmopressin acetate is a synthetic version of a hormone found in the body, called vasopressin or antidiuretic hormone, which helps to control the body's salt and water balance. When a person uses desmopressin, it is very important that they avoid drinking too much fluid or they will retain that fluid and dilute the salt content in their body. This is known as fluid overload and hyponatremia (low sodium in the blood) and it can cause headache, elevated blood pressure and heart rate as well as breathing problems

2002 Board of Directors Meetings

General Board Meeting
September 9, 2002
Executive Board Meeting
TBA

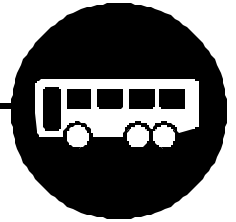
General Board meetings begin at 7:00 p.m. and are open to all interested HACA members. Because of security regulations at our meeting place, please notify the HACA office that you will be attending. Directions and site will be shared

from fluid in the lungs. In rare cases, it may cause seizures. When people are given Stimate they should be instructed to drink only the amount of fluid needed to quench their thirst and not to drink large quantities for 24 hours following its use. I do not know why your doctor's office staff did not know of this side effect. It is well known and listed in the manufacturer's insert. You also took 2 full doses in a 12-hour period, which may have contributed to your problem. Stimate is generally very effective and well tolerated but certain precautions such as avoiding excessive fluid intake must be followed.

Q: My doctor told me to use Stimate every day to prevent nosebleeds. Is this appropriate?

A: No. Stimate should be used to stop a nosebleed once it has begun, but it is not to be used to prevent nosebleeds. Stimate works by boosting the level of von Willebrand factor and factor VIII in the bloodstream by stimulating the release of these two proteins from their storage sites in the body. Once the levels are boosted, a person with VWD or mild to moderate hemophilia A who is experiencing bleeding will be more likely to form a blood clot. One of the results of frequent, repeated use of Stimate is tachyplaxis. Tachyplaxis is a diminished response from a medicine with each subsequent use. In the case of Stimate, the first dose will yield the best response. With each subsequent dose in a short period of time, defined by the drug's manufacturer, as more often than once every 48 hours, each dose will yield a lesser response since the body has not had ample time to replenish its stores. If a person were to use Stimate daily, as you were told to do, the body would never have time to replenish its stores and you would likely get little or no response from the doses. I recommend you clarify this with your doctor and also learn more about Stimate by reading the manufacturer's insert provided in each box or readily available on line at www.allaboutbleeding.com.

School Issues



Preparing for the School Year

Starting off the new school year well requires laying the groundwork before the first day of school. Educators and parents agree that the best foundation is a meeting of parents with a school administrator, the child's new teacher, the school nurse and often the physical education teacher. A nurse or social worker from the child's treatment center is a helpful addition, as (s)he can provide information about hemophilia and the child's specific health needs.

What to Cover at the Meeting

Participants at the meeting should review specific information about the child's bleeding disorder as well as determining the child's individual educational and medical needs. School personnel should be assured that the child does not bleed any faster than other children. Prophylaxis should be explained if the child is on a program of prophylaxis. The nature of bleeds and the response expected from the school should be covered, especially in cases of emergency, such as any injury to the head, neck, and throat. School personnel should understand how to contact the parents and should have the name and number of the child's doctor and hospital.

The majority of children with hemophilia can participate in almost all school physical activities except contact sports. Any temporary or permanent exceptions for your child should be spelled out.

Finally, problem areas for the child should be discussed, such as the child's preference about disclosing his bleeding disorder to other students and the need for school personnel to avoid the appearance of preferential treatment (e.g. relaxation of rules) for the child. Don't expect to settle everything at this meeting. Though important, it should only be the beginning of your ongoing dialogue with the school.

You may wish to use your HTC as a resource for this meeting. In addition, the chapter has free booklets for educators and school nurses. You may want copies of these to give to those on school staff who should understand your child's needs. *HANY's Hemophilia Outlook, Summer 2002*

Editor's note: The HACA office has several sample letters on file that have been developed by chapter members for school personnel. Contact the HACA office at 703-352-7641 if you are interested in receiving any of that information as well as any pamphlets for school personnel.

Dealing with the Stress of

School Re-opening

"Our sons don't have to incur an injury or over-use a joint to develop a bleed," says Su Reiser, the mother of Nicholas and Christopher. "For Chris and Nick, the first few of days of school can create stress that leads to a bleed". This year Nicholas will be entering high school for the first time. Christopher, who is going into his junior year, will be faced with a new schedule and new teachers. Su and her husband, Carl, have volunteered to share the approach they use to handle the stress:

- 1. The preparation starts long before the first day of school with a floor plan of the school.**

Get one from the school and study it with your son. Locate the cafeteria, the gym, the nurse's office and the auditorium.

- 2. Request your son's schedule before school starts.**

"We plan our vacations so that we will not be away when the schedules arrive. With each of the boys, we review the schedule with the floor plan in front of us. Before they go to school, they know where each class will be held. We minimize the use of stairs and travel distance to classes"

- 3. Before school opens, arrange for a tour of the school.**

Some school districts offer a summer program that helps incoming students learn the layout of the school. Otherwise, make sure that you and your son tour the school before the first day of school. If no one else is available, a janitor may show you the building.

- 4. Make an appointment for your son to meet the guidance counselor and the school nurse.**

Make sure that the school nurse and the guidance counselor know your son and are familiar with hemophilia and how to reach you during the day.

School Issues (continued)

(Continued on page 7)



The Hemophilia Association
of the Capital Area
is Pleased to Announce
The Consumer Development Scholarship

What is the Consumer Development Scholarship Program?

The Hemophilia Association of the Capital Area (HACA) encourages patient and family attendance at the National Hemophilia Foundation (NHF) Annual Meeting and is able to offer partial scholarships to people interested in attending! The goal of the Consumer Development Scholarship Program is intended to enable people affected by bleeding disorders to improve the quality of their lives and become leaders in the Metro DC bleeding disorders community.

There are four long-term outcomes HACA hopes to achieve with the Consumer Development Scholarship program:

1. To increase patient and family awareness of national efforts being made on behalf of the bleeding disorders community.
2. To increase Metro DC area patient and family participation in these national efforts.
3. To increase networking opportunities for Metro DC area patients and families.
4. To develop a level of patient and family commitment to the Metro DC area bleeding disorders community.

What is the National Hemophilia Foundation Annual Meeting?

This year the NHF is holding its 54th Annual Meeting in Orlando, FL.. Over 1,000 healthcare providers, consumers and their family members will attend the NHF Annual Meeting October 31- November 2, 2002 at Disney's Coronado Springs Resort. Educational sessions and exhibits will highlight the current issues concerning treatment of hemophilia, von Willebrand disease and other bleeding disorders and the complications associated with these disorders. This is also a tremendous opportunity to network and get involved in the bleeding disorders community at the national level.

This year the NHF Annual Meeting will highlight the following topics:

- Updates on CDC Research
- Caregiver Burnout
- Psychosocial Aspects of Pain
- Marital Issues
- Tailored Programs for New Families
- The Ins and Outs of Insurance Issues
- The Ever Popular Youth and Adolescent Program
- And much more.....



Key Steps
Today for
Giant Strides
Tomorrow

Who can apply?

Any individual or family member of an individual with a bleeding disorder who resides in the Metro DC area. A limited number of scholarships are available. HACA's executive committee will evaluate each applicant based on personal circumstances, financial need and willingness to serve the bleeding disorders community. Priority will be given to individuals with bleeding disorders, parents of young children and spouses of individuals with bleeding disorders. If sufficient funds are available, consideration will be given to siblings and other family members.

What is the scholarship award?

- Eligible individuals will receive up to \$400 to subsidize the cost of hotel accommodations and up to \$350 for transportation.
- HACA will also provide up to \$350 transportation funding for a second family member to attend.
- The awards will be made on or before September 10, 2002.

Where do I get an application?

In order to be considered for a scholarship, interested individuals must complete an application. Applications can be obtained from the HACA office at 703-352-7641. Completed applications must be postmarked by August 30, 2002. Faxed or e-mailed applications will not be accepted.

(Continued from page 5)

5. **Take your son to meet the gym teacher.**

Discuss with the gym teacher a way that your son can opt out of class, if necessary, without looking foolish in front of his peers. When Chris Reiser goes to the sidelines and bends down, the gym teacher will ask what he's doing. If he replies, "I'm tying my shoelace," the teacher recognizes this as a signal that Chris is dropping out of the game. *(The gym teacher thought this was such a good idea he suggested it to another student who had a different problem.)*

6. **A week before school opens, begin school bedtime and wake-up hours.** If you infuse before school, plan time for this as well.

7. **Plan well-rounded meals to be sure that your youngster is eating a balanced diet and is well nourished for school.**

Find out about snacks and foods available at lunch period.

8. **Do what you can to minimize fears.**

For instance, Su has been reminding Nicholas that every one is afraid of their first year at the high school. No one wants to look like a nerd. His unspoken fears are no different than those of his friends. Christopher also talks about his freshman year at the high school.

From the Summer 2001 issue of *Other Factors*



Discipline and Children with a Bleeding

Many parents of a child with a bleeding disorder wonder how the disorder will affect their ability to discipline their child.

The point of discipline is to teach self-control. Self-control is vital to healthy self-esteem, how a child views himself. When children's self-esteem is high, they usually feel that they can control their own behavior and make their own decisions about their behaviors. Discipline, which is not the same thing as punishment, helps children learn self-control because it provides consequences. As parents, you always have a choice of which consequence to deliver. It is possible to raise a child with a bleeding disorder who knows and respects firm limits, has a strong sense of right and wrong, and has good self-control – without using physical punishment.

Discipline methods include rewarding, penalizing, and ignoring. Each has benefits and drawbacks, and each has an effect on the development of a child's self-esteem.

Rewards

When a child is responsible for earning a reward – whether it's an object he/she wants or a special activity – the child feels good about himself and his abilities. He can choose to earn the reward or not to earn it. This gives him a feeling of control over his life, the key ingredient to healthy self-esteem. A reward is different from a bribe. Rewards are given in recognition of achievement, while bribes are used as a “carrot” dangling in front of a child's nose. Rewards are something a child earns. For instance, you might say, “You can earn a sticker every time you sit still for your infusion. After you earn 5 stickers, you can trade them for special play time with Mom or Dad.” If used properly, rewards shape behavior in a positive way. Rewards work best when they are small. They don't even need to cost money. If you use rewards that are too big or expensive, children begin to get motivated by the material object rather than by a sense of achievement.

Penalties

These should be used only as a last resort. Penalties will control behavior in the short run and should be enforced calmly and privately, without emotion. Allow your child to vent his anger in words – as long as it is not destructive or directed personally to someone.

- ❖ Corporal punishment is the least effective penalty. Spanking, hitting, and striking causes physical and emotional pain. Physical punishment can cause a child to obey in the short run, but it must be dropped as the child outgrows this form of discipline. This type

of punishment generally teaches a child that the bigger person controls the situation and does not help him to learn self-control.

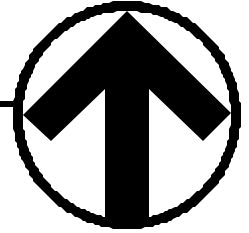
- ❖ A less physically harmful penalty is “timeout” – having a child sit in a chair by himself away from distraction. This is a common penalty and it usually is effective because it removes your child from the source of trouble, helps both of you calm yourselves and gain more self-control, and does not involve risk of physical injury. Time out is not effective if it is enforced with anger, goes on for too long a time based on the child's age, or if it is unsupervised. The rule of thumb for timeout is one minute for every year of age. For example, three minutes for a three-year old is sufficient. If your child's behavior does not improve after one time out, try again by putting him in another time-out until his behavior improves.
- ❖ Logical consequences, another form of penalty, are punishments related directly to a bad behavior. If a child throws toys, then toys are removed for the rest of the day.
- ❖ Natural consequences are another form of punishment that offers logical outcomes for your child's behavior. If a child leaves toys, like chalk, out in the driveway after he/she has been asked several times to pick up the chalk, then rain might ruin the chalk or a car might run over it. Your child learns, without personal involvement from you, the consequences of his actions.

Ignoring

This approach is successful for very young children. While it might not stop a tantrum immediately, over time your child will learn self-control when no one pays attention to him/her for throwing himself on the floor and screaming. If the behavior is dangerous, such as head banging or hitting, you can stop the behavior using the least amount of attention possible. In fairness to your child, tell him before and after that you will ignore this kind of behavior at all times. When he/she learns what the consequences of certain behavior will be, your child can begin to make decisions about his behavior. This is the beginning of self-control. Ignoring him/her also allows natural consequences to take place. There is no need to create a contest of wills between the parents and the child.

(Continued on page 9)

Expect to Pay More for Health Care in



Health care costs continue to rise at an alarming rate. Employers have been hit with tremendous premium increases. To try to reduce or better manage costs, many employers have changed insurance plans. Many employers are also requiring employees to pay more for insurance premiums and more for out-of-pocket costs (deductibles, co-pays, co-insurance and co-insurance limits).

In 2002 or 2003, some employers may offer a high deductible/medical expense allowance plan. As medical expense allowances will be much less than the deductible, individuals with high cost medical conditions (like hemophilia and related bleeding disorders) could be paying a lot more in out-of-pocket costs for their health care through these types of plans.

NOTE: For any new insurance plan, review benefits and any restrictions as to which providers you can use. Also, pay particular attention to coverage of your factor products; follow-up with your insurance carrier or factor product vendor for help to verify coverage.

Watch Your Lifetime Limits

We all know that factor products are incredibly expensive and can threaten insurance lifetime limits. But are you staying on top of monitoring these costs?

- Do you know the amount of your insurance lifetime limit? (Call your insurance carrier.)
- Do you know the amount of the lifetime limit you've used? (Call your insurance carrier.)
- Do you know how much your factor product costs per unit? (Call your factor product vendor.)
- Do you know approximately how much factor product (total units) you use in a year? (Multiply the number of units per treatment **times** the number of treatments per year.)
- Do you know approximately what your factor product costs are per year? (Multiply total units per year **times** the cost per unit.)

Use this information to monitor the impact on your lifetime limits and to help with insurance planning. Consider other regular medical costs as well as unexpected costs in your planning as well.

Excerpted from an article by David Linney published in the Spring, 2002 *The Great Lakes Hemophilia Foundation Headline News*.

(Continued from page 8)

Discipline (Continued)

Which discipline method will work best for your family?

Try to consciously choose a philosophy of discipline, one that reflects your family values. Choosing a philosophy of discipline is a family decision and is best if based on the child's needs and temperament. Think long-term. What type of adult- what type of parent – do you want your child to become?

Your treatment center has experience dealing with discipline issues. The treatment center social worker or nurse coordinator can help you develop discipline strategies. Discipline works best if balanced with praise for the desired behavior. Remember if you see your child as wonderful and full of potential, your child will more easily see him/herself that way too.

DISCIPLINE WORKS BEST WHEN

- You let your child know what is expected in different situations.
- You are consistent in following an inappropriate behavior by a consistent consequence.
- You include humor or distraction.
- You allow, when safe, for natural consequences of the action to occur.
- You offer choices while being firm.
- You keep discipline age-appropriate.
- Discipline teaches instead of punishes.
- Discipline does not become a personal conflict.
- Your child is assured that he is loved unconditionally.

From the Spring, 2002 issue of *The Great Lakes Hemophilia Foundation Headline News*



**If you want children
to keep their feet
on the ground,
put some responsibility
on their shoulders.**

Abigail Van Buren

HACA News

3251 Old Lee Highway, Suite 3
Fairfax, Virginia 22030-1504

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