

# HACA News

**August 2005**  
**Volume 21 Issue 4**

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## Mission Statement

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

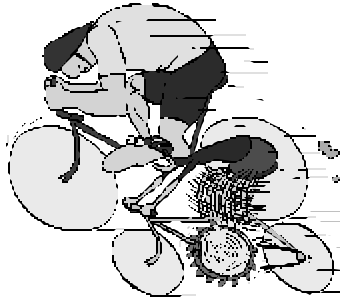
*HACA's mission is to:*

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

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## Educational Symposium

**PLEASE RESERVE THE DATE:** HACA's Educational Symposium and Annual Meeting will be held on Saturday, September 24<sup>th</sup> at the Courtyard Marriott in Tysons Corner. The Courtyard Marriott is located right next door to the Holiday Inn where we have previously held our events. Registration will begin at 8:30 am and we will end with a luncheon at 1pm. Content for the symposium is currently being developed so if there is a topic you would like to have addressed, please contact the HACA office at 703-352-7641.



## Blood, Sweat, & Gears Bike-a-thon

Our annual Blood, Sweat, & Gears Bike-a-thon will be held on Saturday, October 8<sup>th</sup> and will originate from the Reston YMCA. Once again we will offer a 2 mile family fun ride as well as a 25K, 50K and 50 mile ride option. Registration fees are \$25 per family for the family fun ride and \$35 per rider for the other options. Each participant can also elect to raise pledges for the event with the top pledge raiser receiving our grand prize. Each \$50 raised in pledges entitles you an additional chance in the drawing for other fun prizes.

This year, we will be holding a contest for the design on the back of the T-shirt. Please see the ad in this newsletter for details. Your artwork will be due at the HACA office on August 25<sup>th</sup>. The winner will receive a \$100 savings bond.

## Fishing Trip

HACA's 12<sup>th</sup> Annual Fishing Trip, sponsored by Factor Support Network Pharmacy, will be held on August 6<sup>th</sup> and 7<sup>th</sup>. Once again, Bunky's Charter Boat will depart from the dock at Solomon's Island at 6 am on Sunday morning, August 7<sup>th</sup>. Participants in the fishing trip usually gather Saturday evening for dinner and spend the evening at an area hotel so they can rise bright and early for the fishing expedition. Participation is limited to 40 people so get your RSVP in to the HACA office as soon as possible (Call us at 703-352-7641.)



## Calling All HACA Artists!

Design the new t-shirt for the 2005 Blood, Sweat, & Gears Bike-a-thon.

Winner receives a \$100 savings bond &, of course, a complimentary t-shirt.

### Details:

- ◆ Hand-drawn art must be on white paper no larger than 8 ½" long and 11" wide with black ink only.
- ◆ If you submit computer generated art, it must be color-separated in .jpeg or .eps format. Only two colors, black and red, will be used for printing.
- ◆ Submit your art by August 25 to the HACA office. Entries may be submitted by mail or by email: 32521 Old Lee Highway, Suite 3, Fairfax, VA 22030 or [hacacares@aol.com](mailto:hacacares@aol.com).

# Chapter News continued

## Announcing HACA's New Scholarship Program

HACA's Board of Directors is proud to announce the establishment of "The George and Linda Price Scholarship" The mission of the George and Linda Price Scholarship Fund for HACA members with bleeding disorders is to offer financial assistance for the pursuit of higher education and to encourage promising candidates to become future leaders in the bleeding disorders community.

### Background

The Hemophilia Association of the Capital Area's George and Linda Price Scholarship was established to honor the generous volunteerism of George and Linda Price. From the time their youngest son, Greg, was diagnosed with Hemophilia B to the present day, George and Linda have been actively involved with the chapter. They both became members of HACA's Board of Directors in 1984 and served in various capacities on the Board until the mid 1990s. Linda has been a mentor mom to countless newly diagnosed families throughout the years and she has served on the Executive Committee of Region 3 as well as on the Patient Advisory Committee for Wyeth Pharmaceuticals. Linda has also been a sales leader in the chapter's annual Poinsettia Sale. George has served as Chapter President and has chaired several nomination committees. You can still find Linda and George actively participating in events such as our annual Blood, Sweat & Gears Bike-a-thon and willingly sharing an encouraging thought with newly diagnosed families both on the phone and at chapter activities.

### Eligibility

People living with a bleeding disorder who are active members of the Hemophilia Association of the Capital Area are eligible to apply. Priority will be given to those members who actively participate in HACA activities. Your home must be located in Northern Virginia, Washington DC, or Montgomery or Prince Georges Counties in Maryland. Applicants must be high school seniors, college freshmen, sophomores, and juniors. College seniors who are planning to attend graduate school or students who are already enrolled in graduate school are also eligible.

As mentioned above, priority for these awards will be given to members who actively participate in HACA activities. The applicant will be required to write an essay on the topic: "What I have done to contribute to the bleeding disorders community and how I plan to contribute to the bleeding disorders community in the future." If you are thinking of apply-

ing for this scholarship and know that your activity level with the bleeding disorders community is not what it should be, call the HACA office and we will help you find some activities that will help make that essay easier to write.

### Scholarships

The scholarships are one-year awards in the amount of \$2,500 for a full academic year. We will award two scholarships per year. The scholarships may be used at any accredited nonprofit college, university, or vocational/technical school in the United States. The scholarships will be applied toward a student's educational expenses.

### Application Procedure

Around February 1 of each year, HACA will announce the beginning of the competition for the awards. Applications will be distributed to those who request them by mail or thorough the HACA web site. Detailed instructions are contained in the application. The deadline for applying is May 1<sup>st</sup>. Applications and supporting documents must be postmarked by that date. Applications and supporting documents postmarked after May 1<sup>st</sup> and/or incomplete or faxed applications will not be considered. Scholarship recipients will be notified of their awards on July 1<sup>st</sup>.



## Calendar of Events

August 6-7	12th Annual Fishing Trip Solomon's Island, MD
Aug 21 or 28	Blood Buddies at "Splashdown" in Manassas
Sept. 24th	Edcational Symposium and Annual Meeting, Courtyard Marriott, Tyson's Corner, 9 am
Oct. 8th	Blood, Sweat & Gears Bike-a- thon. Originates at Reston YMCA. Registration at 8 am.
Oct. 28-30	NHF Annual Meeting in San Diego, CA

## 2005 Board of Directors Meetings

General Board Meeting  
September 12, 2005

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.

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## Community Action is Needed

On June 24, 2005 the U.S. House of Representatives completed action on its fiscal year 2006 Labor, Health and Human Services (HHS) and Education Appropriations bill, passing the bill by a vote of 205-15. The bill now moves to the Senate, where action has not yet occurred within the corresponding Labor, HHS Appropriations Subcommittee.

Overall, the House bill provides \$633 million below last year's discretionary spending levels, including a cut of \$295 million to the Centers for Disease Control and Prevention (CDC) budget

and a cut of \$24 million to the Maternal and Child Health Block (MCHB) Grant within the Health Resources and Services Administration (HRSA) The CDC and MCHB are the primary sources of government funding to U.S. Hemophilia Treatment Centers. The House bill did not include the increase NHF requested for HTC funding.

### How You Can Help

Although the news that an HTC funding increase may not be imminent is discouraging, this does not represent the last word on funding. The appropriations bill now moves to the Senate, where the Subcommittee is not expected to schedule a mark-up until September, 2005. This time-frame provides consumers and organizations with a 45-60 day window to influence Senate action and a 60-90 day or longer window to influence the final conference bill. NHF will be meeting with legislators in both the House and Senate to determine whether some increase in HTC funding may still be possible. NHF is also reaching out to the entire community, including the many individuals who helped us address this issue this past spring during NHF's Washington Days, to make a concerted effort to speak to your own legislators about this important issue. Consult the NHF web site at [www.hemophilia.org](http://www.hemophilia.org) and look under News (legislative updates) to find out who you can contact in the Senate to help change the tide of this bill. If you do not have computer access, contact the HACA office at 703-352-7641.

## NHF/ZLB Behring Jr. National Championships

The NHF/ZLB Behring Jr. National Championship in Golf and Baseball will be held on September 10<sup>th</sup> in Pittsburgh, PA. This is the event that HACA hosted last year. If you are interested in taking part in this year's competition, please contact Dawn Rotellini, Executive Director of the Western PA Chapter of NHF at 412-683-2231 or at [wpcnhf@earthlink.net](mailto:wpcnhf@earthlink.net). The final competition will be held on October 8<sup>th</sup> in Orlando Florida. The championship is open to all people with a bleeding disorder between the ages of 7 and 18.

## New Medicare Rule Excludes Clotting Factor

On June 27, 2005 the Centers for Medicare and Medicaid Services (CMS) issued an interim final rule, giving physicians who treat Medicare patients the choice of opting into a new Competitive Acquisition Program (CAP). CAP will allow participating physicians, who administer certain injectable drugs covered under Medicare's Supplemental Medical Insurance (Part B), to obtain these drugs only from specific vendors. These vendors would then bill Medicare directly.

NHF and HFA had joined with others in the bleeding disorders community and with industry to express concern to both the Secretary of Health and Human Services and CMS, about how the inclusion of clotting factor in CAP might threaten the ability of people with bleeding disorders on Medicare to access the full range of products. NHF argued that clotting factor did not meet the statutory definition of a physician-administered drug and, therefore, should be explicitly exempt from CAP.

Drugs covered under the new Medicare Part D Prescription Drug Benefit are excluded from CAP. Fortunately, self-administered treatments such as intravenous immune globulin (IVIG), immunosuppressive drugs and hemophilia clotting factor will also be excluded from the program. In short, the interim rule specifically mentions excluding hemophilia clotting factor. Any future consideration of its inclusion in the program will be subject to a proposed rule and public comment.

## Industry News

### Severe Hemophilia A Research Endeavor (SHARE)

Harris Interactive Healthcare Research invites you to join a research panel for people with severe hemophilia A who are 18 years or older or for the caregivers of people with severe hemophilia A. SHARE is an effort to learn more about treatment options for severe hemophilia A. Participants will be asked to provide information regarding treatment trends, attitudes, and quality of life. Participation is voluntary and involves completing two 12 to 20 minute surveys over a period of 6 months. Compensation of up to \$150 is offered. For more information contact Harris Interactive at (877)336-8164 or e-mail [share@harrisinteractive.net](mailto:share@harrisinteractive.net).



### Novo Nordisk

Novo Nordisk announced a 4.65% price increase in NovoSeven Factor VIIa (Recombinant). The price increase took place on June 1, 2005.

### Wyeth

Wyeth is pleased to introduce its Factor Resource Program. The program was developed to allow hemophilia patients to get the ReFacto or BeneFIX they need.

The Factor Resource Program includes:

◆ Wyeth Insurance-Coverage Program

Provides up to 12 months of free hemophilia factor product to program patients experiencing a lapse in insurance coverage. In addition, participants will receive assistance tracking their insurance cap and identifying alternative sources of insurance.

◆ Wyeth Patient Assistance Program

Provides a supply of Wyeth hemophilia product, at no cost, to hemophilia patients who are without insurance and who meet other eligibility criteria.

◆ Wyeth Reimbursement-Information Line

If you should have questions about reimbursement for your Wyeth hemophilia product, call the reimbursement-information line.

Information on program enrollment is available from the Wyeth website, [www.hemophiliavillage.com](http://www.hemophiliavillage.com), or you can call the Wyeth Hemophilia Hotline at (888)999-2349.

### Bayer to Begin Trials for Enhanced Factor 8 Product

On June 29, 2005 Bayer Biological Products (BP) announced that it has been granted permission by the Food and Drug Administration (FDA) to begin Phase I clinical trials for a new formulation of its recombinant factor VIII product, Kogenate®.

This new formulation uses PEGylated liposome technology patented by the Dutch company Zilip-Pharma, to produce a longer-acting factor product. Prolonging Kogenate's half-life would result in fewer infusions for hemophilia A patients.

The investigators for the Phase I trial are Jerry Powell, MD, from the University of California-Davis Medical Center in Sacramento and Diane Nugent, MD, from the Children's Hospital of Orange County in California.

# Fall is a Good Time For an Insurance Check

By David Linney

It is good to set aside time at least once a year to check out one's insurance coverage. Fall is a good time, as it is when many employers notify employees about changes to their health and drug plan coverage or offer open enrollment. This is because a large number of employers have a January 1 renewal date for their insurance plan coverage.

Fall is also a good time to check out the status of other things before the year's end, including: dependent coverage; annual and lifetime limits; insurance authorizations (or referrals); medical bill balances; and flexible spending account balances.

## Employer Insurance Plan Changes

Employers usually consider making changes to their insurance plan prior to the plan's renewal date. The renewal date can take place any time of the year, although the most common is the first of the year.

At the time of plan renewal, employers may or may not make changes to their insurance plan. Some employers may keep the same insurance plan with no changes. Other employers may keep the same plan but make changes to it. Still other employers may replace the current health plan, drug plan or specialty pharmacy plan with a new health plan, drug plan or specialty pharmacy plan.

Any changes should be reviewed carefully. Changes can affect your coverage and your out-of-pocket expenses. Changes may involve any of the following: services covered; actual coverage for services; providers that can be used (factor product vendors, doctors, hospitals, physical therapists, etc); annual limits; lifetime limits; authorization (or referral) requirements; out-of-pocket costs (deductibles, copayments and coinsurance); and premium costs.

In checking out any plan changes, be sure to review how coverage for factor products may be affected.

## Open Enrollment

Open enrollment allows employees to make changes to their employer's health plan once per year. In open enrollment programs, employees can add family members, change providers or select a different health plan (if the employer offers more than one health plan).

Enrolling in a new insurance plan or adding a family member to a current insurance plan is a way to get new health insurance coverage. Many times, this can mean

improved benefits and a new lifetime limit.

When more than one health plan is offered, verify and compare the benefits of the different plans – particularly coverage for factor products. For assistance, contact the employer, hemophilia treatment center or factor product vendor.

## Dependent Coverage

One should check his policy for age limits for dependent children. Coverage will vary from policy to policy; however, dependent coverage for most group policies will commonly end when a child turns 19, if not going to school full time, and at 25 if not a full-time student and claimed as a dependent.

Review actual coverage with the child's present and future educational and vocational plans. Anticipate when dependent coverage will end and work with the child to have new insurance in place.

## Annual and Lifetime Limits

For a new plan, check out annual and lifetime limits. If factor product costs affect limits and there is a choice of plans, make sure that the dollar amount of any limit is adequate before selecting the plan.

For a current plan with the same or "new" benefits, it is important to know what the dollar limit is and the dollar amount "used". It's wise to call the insurance company to verify these figures. Monitor the amount "used" on a regular basis. If the limit is threatened, consider alternate coverage long before benefits will end.

## Insurance Authorizations (or Referrals)

Some managed care health plans require authorization for factor products, infusion therapy, clinic visits (for bleeding disorders), etc. Similarly, some drug plans and specialty pharmacy plans require authorization for factor products.

Is an authorization needed? Is authorization current? Check out the end date and number of visits/services/factor product orders remaining on current authorizations. Work with providers to have a new authorization in place well in advance of the current authorization end date.

## Review of Medical Bills

It is important to review medical bills on a regular basis to

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## Fall is a Good Time for an Insurance Check (continued)

make sure that account balances have been paid. It may also be important to monitor medical bills prior to the end of the year for tax purposes and to maximize the use of flexible spending account dollars.

Prior to any review of medical bills, it is important to understand one's insurance coverage and specifically what one is liable to pay. Bills come from providers – factor product vendors, doctors, hospitals, laboratories, pharmacies, etc.

An actual review of medical bills includes a review of: provider billing charge totals by date of service; insurance payment(s) by date of service (shown on an "Explanation of Benefits" (EOB) statement received from the insurance company); balances one owed; and balances one has paid.

For questions, first contact the providers to verify charges, the date of insurance billing and receipt of payments from insurers and oneself. Then (if necessary) contact the insurance company to verify the receipt of the provider bill and the issuance date of payment(s).

Avoid collection by communicating with patient account departments and making timely payments.

### Flexible Spending Accounts

For individuals who have set aside dollars on a pre-tax basis for healthcare, dental care and over-the-counter drug expenses through employer flexible spending accounts (FSA), most plans require expenses to be submitted with a date of service in 2005. One should check one's 2005 contribution amount and make sure that dollars have been expended before the end of the year.

In determining one's 2006 contribution amount to a FSA, be sure to take into account any changes in insurance plan out-of-pocket costs.

Performing a regular check of insurance coverage (and more often if needed) is a good idea for everyone. It is particularly important for individuals with more expensive medical conditions who have a large number of ongoing medical bills.

-from *Hemaware*, Volume 9, Issue 5

## Hole in the Wall Gang Camp

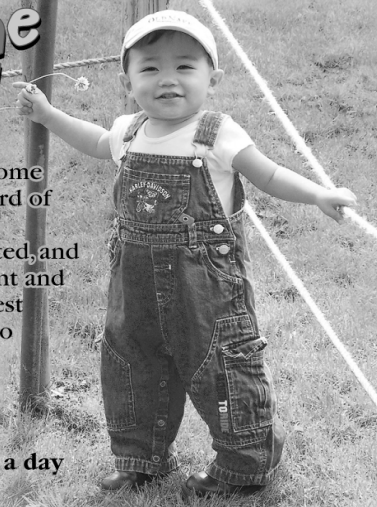
Ten of our members attended the Hole in the Wall Gang Camp in Ashford, CT from June 10-16: Jack Downing, Spencer Duggan, Matthew Gates, Will and Ben Hubbert, Paul Hutchinson, John Newman, Hunter Plaines, Anne Rowe and Cody Shegan. Everyone had a great time with arts & crafts, pottery, woodworking, sports and recreation, boating, fishing, swimming and theatre.

"I love camp and I want to stay all summer," says Anne Rowe, age 8. "The best part was archery and the horses. Last year I received an award for horses and again this year!"

Long-time camper, Spencer Duggan, says, "Camp is a great place to get away from home and school."

Our sincere thanks to Miriam Goldstein and Martha Downing for giving their time and energy to be chaperones for our campers, both during travel and the week at camp. Thanks also to Harvey Gates, Sr. for traveling with the young people to camp.

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# The Good-Enough Mom

By Ziva Mann

When the author, Jane Smiley, wrote an essay entitled, "Can Mothers Think?" she was raising a serious and subversive question. Books like the oh-so-simplified "What to Expect When..." series treat motherhood like something requiring a twelve-step program, in which the inmate is to be gently educated, gently prepared, and so is eased in to the chaos that is motherhood. Smiley's point is simple: is motherhood a thing that comes from the gut, or is it a product of head and heart? Or maybe it's all hormones and sleeplessness?

Apparently, it all depends on whom you ask. In the February 21, 2005, issue of *Newsweek*, Judith Warner described motherhood as a dreadful combination of neurosis, feminism and society's failure. Leaving aside the challenges of homemaking, she describes "*women who had surrendered their better selves—and their sanity to motherhood...Who—like myself—appeared to be sleepwalking through life in a state of quiet panic.*" Well, sure. What first time mother hasn't wanted to turn to anyone or everyone, and admit her incompetence? "No, really—I can't do this job. Here, you take the baby!" Young moms dream about someone official who comes up to them and says, "Sorry, there's been a mistake—you aren't really supposed to have the baby." Let's say this out loud: parenting is overwhelming, bewildering, and some days requires a stiff drink, if not two.

Warner has not, apparently, investigated the soothing affects of a bubble bath and a good scotch. "*Women today,*" she roars, "*mother in the excessive, control-freakish way that they do in part because...they are unsupported...by society at large. And because they can't humanly, take everything onto themselves, they simply go nuts.*" There is truth in her anger. And yet, as the mother of a three-year-old boy with hemophilia, I have a community. It was part of the package deal that came with the diagnosis. Here's how our shipping manifest read on the day of the diagnosis:

*Enclosed: one baby, slightly complex; one gaggle of doctors; one group of nurses; one large insurance headache. Bonus: one group of friends who will always, always understand.*

When Elisha ended up in the hospital for the umpteenth time, a group of hemophilia moms, or hemo-mommies, showed up with fruit, videos, hugs, and their kids. We understand each other, support each other, and wail to each other. Judith Warner should meet my friend Meredith, who once described parenting to me as an event where "*you only have two hands and you have sixteen different flaming swords you are juggling at once.*" These ladies get it. When I recently became pregnant for a second time, I turned first to my hemo-mommies, knowing that even better than friends and family, this gang of women would understand the choices, the risk, and the hopes behind the pregnancy. So, no, Ms. Warner, I am

not as you claim "unsupported"; I have a community—an in spades. Sharing the challenges of mommy-hood with these ladies has been crucial. But still, Warner is right on some points: even with this wonderful support, you really can go nuts.

It might be okay for that other kid to fall down, you think, but mine just can't afford to. It might be okay for that other kid to rebel, but what if mine stages a coup just when I need him to sit still for some factor? Our houses must be perfectly baby-proofed, our anxieties completely under control (an anxious parent raises an anxious child, right?), and we must always be emotionally available to care for our kids, given their extra challenges. At my hemo-mommy nights out, inevitably someone dreams about the joys of sticking the kid inside a padded bubble. If only we could enclose the problem in a bubble and somehow eliminate the chaos—then it would all be under control and we could get down to the real business of parenting, rather than this crisis control. Right? Nope. What's the hemo-mommy equivalent of always having dinner on the table? Never running out of tegaderms? Always catching the kid before he catapults himself off the sofa? Down the stairs? Not gonna happen—those little twerps move at light speed. My family is famous for a head bonk visits to Boston Children's ER. Let's face it: life happens, and for my son, much of it seems to happen headfirst. And so long as he's a happy, energetic (oy) kid, this is a life I can stand to lead.

Admittedly, for Elisha's first six months, I was Warner's perfect mom. I was also a nut case. Now that I'm more tired, cranky, and experienced, my choices have changed. For me, I intend to set aside Warner's "Perfect (and overstressed) Mom" and instead to celebrate the "Good-Enough Mom". This lady is my kind of girl: she probably cooks a lot of pasta, she never dusts anything ever, and she actually tells her family that sometimes she needs five minutes to herself. Her kids know that chocolate is probably the cure to what ails her, and will remind her that she loves them even when she's grumpy. And yes, sometimes she has to admit to the hematologists that the kid fell—and no, she didn't quite see what happened. Most of all, she lets herself fall apart and trusts the validity of her own emotions. Let me say this again: this is a tough job. I don't think a Martha Stewart could do it. So why not accept being "good enough"? Embrace the fact that your kids don't wear mittens, or sometimes drink juice that's been sitting out all day! So what if dinner came out of the freezer! The bottom line is that at the end of the day, everybody is fed and in more or less one piece.

In embracing the Good-Enough Mom, I run smack up against people like Warner. Judith Warner implies that mothers have no choice, and that we're wired so that we

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## Life Lessons

By: Kirstin Duggan

The excitement of what was to come was so close that I could taste it. I was soon leaving home to go four hours away to college and live on my own for the very first time. Having hemophilia was the last thing that I was worried about. Seeing my friends and hometown for the last time for a long time was my number one priority. My mom took care of all of the worrying about the important things for me, like how I would receive my factor living on campus, how close it was to the nearest hospital, and finding a hematologist in the area in case I needed one. I just kept thinking to myself that I would be alright and everything would work out. Boy was I wrong!

My homecare company came up with a plan for me to receive factor and supplies. The "best" hospital in the area was only five minutes down the road. But mom had no luck finding a hematologist. After making some calls, my mom was told that the hospital had the capability to take care of patients with bleeding disorders so her worries drifted away, until one crazy night.

Feeling extremely rebellious, as most freshmen in college do, I made an interesting decision for a mild hemophiliac. I got my tongue pierced! I thought that I would be fine. I would just keep the slurpees coming and the hospital down the street could take care of treating me. It was time to learn a lesson of a lifetime.

I arrived at the hospital with my factor in hand, still shrink-wrapped with the prescription label on the package. The first thing that should have tipped me off to leave was when the all the emergency room personnel asked me, "What is hemophilia?" The second thing was they accused me of bringing illegal drugs into the hospital and asking them to administer it to me. It was by no means illegal, it was my clotting factor! So I asked them if they

had my factor, or any factor IX products available. They told me it would be longer than 24 hours before they received it. Eventually, after speaking with my hematologist at home and my mom a few times, they finally believed me.

The final straw was after being there for five hours, it took two nurses and over ten sticks and they still could not hit a vein. I was extremely bruised up and in pain. I was exhausted and just wanted to go home, bleed or no bleed. When I tried to leave, two orderlies came after me, blocking the door and threatening to strap me down. They couldn't let me leave because I was under their liability. But why would I want to stay when they had no idea what they were doing? I felt uncomfortable being there and I felt, at times, like they were putting me at risk rather than helping me. Eventually, I sneaked out of the hospital and went home.

The next day, my university health center took care of me. Surprisingly, they knew more about how to handle my situation than the hospital emergency room. They referred me to a hematologist in the area. Although he had never treated a hemophilia patient, let alone a woman with a bleeding disorder, he was better than I ever expected.

This was one of the biggest life lessons that I have ever learned. Do your research and know what you are getting into! Even if a hospital claims they have the capability to take care of you, check it out for yourself and see them before you have a real problem.

Things get very busy and hectic when leaving for school, or anywhere, but always think of the necessities because you never know when you are going to need them.

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[www.FactorSupport.com](http://www.FactorSupport.com)

**Factor Support Network** was founded by families with hemophilia over 10 years ago to help the community and empower consumers to make the best choices possible.

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# SHARE OUR VISION

## A Whole New Outlook for People with Hemophilia and Their Families



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### EDUCATION

- Educational workshops for patients, caregivers and health-care professionals
- A variety of educational resources to help you improve your health and well being
- [Hemophiliagalaxy.com](http://Hemophiliagalaxy.com)

### REIMBURSEMENT ASSISTANCE

- Factor Assist and Factor Plus: compassionate care programs for eligible patients that help maintain access to therapy during insurance lapses or lack of insurance
- Support of national advocacy and reimbursement programs

- Healthcare Economics Department: an advocacy and insurance coverage resource for patients, providers, and medical professionals, 1-800-968-9937

- Reimbursement hotline 1-800-548-4448

### COMMUNITY SUPPORT

- Support for local hemophilia chapter and national foundation programs
- Hemophilia summer camp support
- Sponsorship of National Hemophilia Foundation's Clinical Fellowship Program

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**Baxter**

(Continued from page 7)

can't help becoming stressed, overwhelmed automatons. I'd argue that a mom of a kid with a chronic medical condition needs to become instead a mother who thinks, who rewrites her wiring to become the kind of parent she wants to be. For me, as a mother who thinks—sometimes—I've fixed my hopes on imperfection. I believe that living a life that is imperfect, loving but sometimes tough, might be a reasonable choice. Let's face it: life will never be 100% picture perfect for our kids, so why try and live up to that? There will always be a bleed right before the big game, the day of the party, during that crucial outing. Imperfection is here, it's unavoidable, and I think it might be a valuable lesson for our kids when they see it in action. Each time we drop one of Meredith's flaming parental swords, our kids watch us handle the accident and they learn from our resilience. Our willingness to take responsibility for our mistakes helps them learn to accept their own; our handling of a crisis gives them tools for accepting those same crises. And perhaps this is just my fantasy, but I think that our kids can learn even from our collapses, as they see that the ever-caring parent is a person who needs some time to themselves. Constant strength is a myth that my son won't learn, if only because I don't think he can afford that fantasy.

Parenting is a series of difficult choices, of finding your way through the thicket of what people tell you to do and the pictures our society paints of the happy family. My choice is to tell Hallmark to take a hike. I'll be darned if my priorities are having the perfect accessories for a birthday party, or making sure that my son doesn't learn on his own that some kinds of games end with a bruise. It means living in the middle of a sort of gentle chaos, but it's one in which a stressed out hemo-mommy might just find herself going...sane.

**Books about imperfect mothering:**

An Innocent, A Broad, by Ann Leary

Mothers Who Think: Tales of Real-Life Parenthood, edited by Camille Perl and Kate Moses

Sleeping Through the Night...and other lies, by Sandi Kahn Shelton

Reprinted from NEHA News, Spring, 2005

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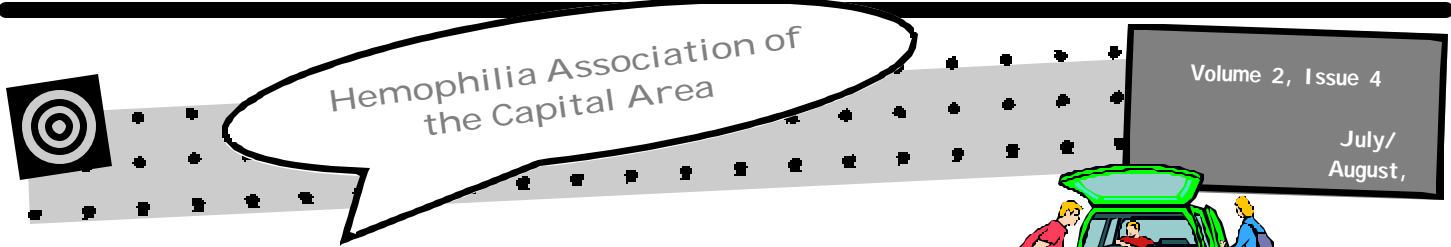
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## YOUNG PEOPLE'S PAGE

### Road Trip Fun

Are you ready for a road trip? People in the United States will take 275 million trips this summer - many of them traveling by car. The most popular destinations are the beach, to visit friends and family, and scenic drives. Sometimes when you're on the road, there isn't a whole lot to look at. For those times, you'll need to keep yourself busy. Here are some ideas:

- ◆ Bring a small map or road atlas. Use stickers to track your family's progress.
- ◆ Create a trip box that includes stickers, pipe cleaners, pens, paper, etc.
- ◆ Draw. You can draw what's outside your window or make a game out of it by drawing a picture of someone that you know and making everyone guess who it is.
- ◆ Start writing in a trip journal and keep track of what you do each day on your vacation. Add photos later.
- ◆ Read aloud - a scary story or a mystery are great choices.
- ◆ Make up your own story and draw the illustrations to go with it.
- ◆ Listen to a book on tape or CD.
- ◆ Listen to music.
- ◆ Sing silly songs that you might be too old for, like "Old MacDonald," "B-I-N-G-O," and "She'll Be Coming Around the Mountain" - or even Christmas songs if you're in the mood. For added fun, make up your own silly songs with your family's help.
- ◆ Snooze.
- ◆ Play "I Spy."
- ◆ Play the license plate game by trying to spot as many different states as you can.
- ◆ Play "20 Questions."
- ◆ Play travel games, such as checkers, that have magnetic pieces that won't slip off the board.
- ◆ Play the "My favorite" game by picking your top five songs, books, ice cream flavors, sports heroes etc.
- ◆ Have a spelling bee or trivia contest. Bring index cards to write down words or questions.
- ◆ **Don't** fight with your brother or sister!

Reviewed by: Neil Izenberg, MD, and Steven Dowshen, MD  
 Date reviewed: June 2003  
[//www.teenhealth.org/kid/closet/games/road\\_trip.html](http://www.teenhealth.org/kid/closet/games/road_trip.html)

Happy July/August Birthday to:	
Jason Drew Wilkins	July 7
John Marin Arenaz	July 12
Ryan Lynch	July 29
Eric Mitchll Blount	August 7
William Morris	August 8
Chase Platt Scarano	August 11
Douglas DuMais	August 13
Ishaan Babbar	August 18
Curtis Hoffman	August 20
Rick Starkey	August 23
Sean Dews	August 30

### The Hole In The Wall Gang Camp

By Spencer Duggan

The Hole in the Wall is great. At camp, everyone gets along, no matter what. Whether you're a camper or counselor, you always meet new friends. You can choose your afternoon activity and you end the day with cabin chat. The food's great, the rules aren't too strict and it's the best place to get away from it all or just to kick off your summer!

Every day after lunch is the afternoon sign up for activities. Choices include: theater, fishing and boating, The Creative Zone, nature, archery, sports and rec., and sometimes, recording music and hanging with the clowns. It gets better. Everyday the activities staff offers different stuff like fishing with funny bait like blueberries and chicken ( that bait doesn't work too well), or the ping pong tournament.

Everything to eat is Paul Newman brand, but why complain? The food is great thanks to the chefs! During every meal, Leo, the keyboardist, plays music while you eat which can be relaxing. After the meal, the campers get up and dance. The songs pump you up for the day, either if the campers shake their bushy tails, or bounce around the room. The meals are fun for food and dancing!

Everyday is exciting and energizing, but what better way to end the day than with cabin chat? The campers get in their beds maybe after a round or two of silent ball. The lights dim down and the candle comes in. The head counselor gives us a topic and either campers or counselors can speak freely. There are only two rules: One mic, one speaker and stay on topic. After everyone, or everyone who wanted to, has spoken, the candle goes out and the campers doze off and sleep 'till the next day.

The activities, the songs and the people all can make your summer the best summer. The HITWGC makes memories, good times and smiles on everyone's faces. The place is the greatest place on earth.

(Editor's Note: If this sounds like a great time to you, look for news about applications for next year, usually available in January. Come join the fun!)

# HACA News

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