

HACA News

April 2002
Volume 18 Issue 2

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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.

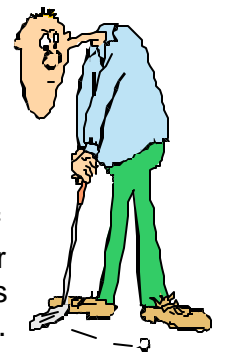
HACA's mission is to:

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

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Johnson & Johnson - Merck to Sponsor DC Hemophilia Open

The Johnson & Johnson - Merck DC Hemophilia Open Golf Tournament will take place at the Gunston Course on Ft Belvoir on Friday afternoon, May 24, 2002. The format will be Captain's Scramble and we will begin with a 2 p.m. shotgun start. Participation as a golfer includes greens fees, carts, range balls, course refreshments, and a delicious steak dinner. We have just been able to confirm our guest speaker for the event will be Mike Kohn, Olympic bronze medal winner with the US Bobsled team.



You can help with this event by:

- 1) Contacting the HACA office (703-352-7641) and asking for your kit to help solicit items for our auction/silent auction.
- 2) Volunteering to help on event day—we need monitors for the special events holes, greeters, people to help with registration, beverage cart drivers, and a photographer.
- 3) Suggesting contacts that might be willing to sponsor holes (\$200) or be a sponsor of the event (\$1500—includes a foursome and a hole sign).
- 4) Signing up to golf (\$150) or to recruit a foursome (\$600).



Welcome

When you call the HACA office, you are likely to hear a new voice greeting you. Lu Desrosiers has joined the HACA staff for 15 hours a week. She will be helping to get information to you in a timely manner and helping to get some of our fundraising and educational materials typed and formatted. We're glad to have Lu helping out in the office and hope that she will get to meet each of you soon.

Summer Camp

We will be sending 9 young people to the Hole in the Wall Gang Camp in Ashford, Connecticut again this summer. Camp is scheduled from June 8-15. Deb DeArmon and Miriam Goldstein will accompany the young people to and from camp and will spend the week serving as counselors/chaperones at camp. Thank you, Deb and Miriam, for your gift of time.

Congratulations

We just heard from Lisa and Axel Freese who re-located to Vienna, Austria this summer. Axel reports that they are adjusting to life in Vienna and are enjoying their time in Austria. He also shared the news of an addition to their family. On January 17th, Maximus Nicholas Frederick Freese joined the family. He weighed in at 8 lb. 14 oz. and was 20 ½ " tall. Maximus is enjoying getting to know his brother, Jens, and sister, Anika. Dad reports that all are doing well.

**Chapter News
continued**



**HIV Seroconversion
in Canada in a
Patient Using
Recombinate®**

NHF Medical Advisory #390
February 1, 2002

A Canadian hemophiliac, who last tested HIV negative in 1999, has tested positive for HIV. All information indicates that the individual in question had other risk factors for developing the disease, and his new HIV positivity was not due to the use of the recombinant clotting factor concentrate.

**Bayer and Aventis to
Establish Joint Venture
for Blood Plasma
Business**

February 20, 2002-- Bayer AG and Aventis Behring announced that they have signed a non-binding letter of intent to establish a joint venture for biological products, including factor VIII products. The implementation of this plan depends on the negotiation of a final agreement and approval by the boards of both companies. Bayer will own a substantial majority interest of the joint venture and will have operational control.

**Curative Health Services
Acquires Apex
Therapeutic Care**

On January 28, 2002, Curative Health Services, Inc. announced they have entered into an agreement to acquire Apex Therapeutic Care, Inc. a specialty pharmacy services company based in Los Angeles, California, for a total purchase price of \$60 million. Curative anticipates that the integration of the two companies will take 30-60 days.

**Aventis Behring Announces Prion Testing
Research**

At the December annual meeting of the American Society of Hematology, researchers from Aventis Behring, L.L.C. announced a new, highly sensitive, specific and rapid test being developed for prions. Prions are the infectious proteins thought to be responsible for Bovine Spongiform Encephalopathy (BSE) and its human form, variant Cruetzfeldt-Jacob Disease (vCJD).

This unique test is called the Conformation Dependent Immunoassay (CDI). According to Aventis Behring, the CDI detected small amounts of prions that were intentionally introduced ("spiked") into normal individual and pooled plasma donations. Aventis is using the new technology to evaluate the ability of its manufacturing processes to remove spiked prions. The resulting data will be part of Aventis's assessment and management of the theoretical risk of vCJD prions in blood or plasma.

There is no accurate test for CJD. Over the past five years, many companies have announced tests for CJD prions, but an accurate and sensitive blood or urine test for CJD prions remains elusive. Aventis has invested more the \$20 million toward understanding prion science. If the CJD test proves sensitive enough to detect minute levels of prions in blood, it will be a major breakthrough in CJD research. For more information: www.aventisbehring.com/AventisBehring/NewsAndEvents/AvPrionTest2001121801.asp *Parent Exchange Newsletter, February 2002*

**FDA Approval Granted on New Blood
Screening Test March 1, 2002**

The Food and Drug Administration (FDA) gave its approval yesterday for a new test to screen blood donations for the viruses that cause AIDS and hepatitis C. Two biotechnology companies, the Chiron Corporation and Gen-Probe of San Diego, developed the test. It is believed that the test, which might eventually become mandatory nationwide, could significantly improve the safety of the nation's blood supply. However, some collectors and suppliers of blood and blood products have raised objections because of the test's high costs. *NHF Web Site: www.hemophilia.org*

Calendar of Events

April 21	Women's Day Out
May 24	Golf Tournament on Fort Belvoir
October 31-	November 2
	NHF Annual Meeting, Orlando, FL

First Book on vWD Now Available!

A Guide to Living With von Willebrand Disease is the first book exclusively devoted to helping people manage the issues of living with the world's most commonly inherited bleeding disorder. Until now, no comprehensive resource has been available to the approximately three million Americans suffering from vWD—most of whom remain undiagnosed and untreated, due to lack of awareness and misconceptions about bleeding disorders.

A Guide to Living with von Willebrand Disease is written by Renée Paper, R.N., in collaboration with Laureen A Kelley, and made possible by a grant from Aventis Behring, L.L.C., a manufacturer of treatments for bleeding disorders.

Free copies are available from several sources: [The HACA chapter office has several copies—call 703-352-7641 to receive a copy] LA Kelley Communications, Inc., (800) 249-7977, or the company website at www.kelley.com. Call the Aventis Behring Choice Member Support Center at (888) 509-6978. Or see the first comprehensive website devoted exclusively to the education, guidance and support of people who have or suspect they have vWD, at www.allaboutbleeding.com. *Parent Exchange Newsletter, February 2002* [Ed. Note: For a free subscription to the Parent Exchange Newsletter, contact Kelley Communications. The Parent Exchange Newsletter is now available in PDF format also.]

Gene Therapy Update

Food and Drug Administration (FDA) gave Avigen clearance to continue human clinical testing of Coagulin-B after the trials were halted due to the discovery of a trace amount of DNA from the gene therapy in the seminal fluid of a participating patient. After a pause in the trials, tests confirmed that the trace DNA cleared the patient's body (the patient suffered no adverse side effects). The trials resumed, even though, according to *The New York Times* (January 8, 2002), "the possibility of risk has not yet been dispelled."

The trials, in which patients receive adeno-associated virus (AAV) vector containing the factor IX gene via infusion into the hepatic (liver) artery, were started in June 2001. The research and development of Coagulin-B will continue as a team effort between Avigen and Bayer Corporation. Under the collaboration, Bayer will help Avigen conduct late-phase clinical trials for Coagulin-B and take part in the regulatory approval processes. NHF's *eNotes*, February 2002

2002 Board of Directors Meetings

General Board Meeting
June 16, 2002
Executive Board Meeting
April 8, 2002

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.

Advisory Committee on Blood Safety and Availability- Department of Health and Human Services

On January 31, 2002, I (Lew Collins, RNC) attended the sixteenth annual meeting at the Hyatt Regency Capitol Hill Hotel in Washington, DC. While, as last year, the focus was on global issues related to blood safety and availability, this year's meeting also addressed lessons that could be learned from the events of September 11, 2001 that would strengthen the safety and availability of the United States' blood supply.

The high blood donation rate after the terrorists' attacks resulted in a release of units not fully tested and an inadequate availability of needed reagents for testing. Since the airline industry was shut down, there were transportation problems. There was a shortage of emergency-trained phlebotomists. A platelet shortage occurred on day 6 and day 7. The error rate was higher as staffs were overworked. Over collection also resulted in a larger than normal rate of units that expired and had to be discarded. Hospitals that were not currently licensed for blood collection, but had held a licensure in the recent past, were allowed to collect blood.

In the future, collection should be based on medical need. The public needs to be educated and disaster plans must be

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established.

Waiting List for Hepatitis Drug

Due to insufficient supply of the hepatitis C (HCV) drug, PEG-Intron, Schering-Plough Corporation announced potential plans to start a waiting list for patients who need the treatment. The medication, which offers patients the convenience of once-weekly dosing, experienced an overwhelming response since its release onto the market in 2000; this demand has caused the supply dilemma.

The waiting list would apply only to newly enrolled patients, and they can expect to begin treatment with PEG-Intron within 10 to 12 weeks. The company said it started an "access assurance" program in October 2001, aimed at tracking how much of the drug is needed and added that patients presently on the drug would be granted a continued supply. Currently, 60,000 patients in the US are enrolled in the access assurance program. The drug is produced at Schering-Plough's production facility in Ireland and the company is building another facility in Singapore to make PEG-Intron and other products.

Due to the planned delay, the American Liver Foundation issued an advisory reassuring current patients on HCV therapy in order to ease fears. Experts estimate that fewer than 5% of patients would require immediate PEG-Intron treatments, and in those cases, conventional, non-pegylated interferon alpha treatments may be effective, depending on the individual's medical history. (Source: Reuters) *NHF's*

eNotes, March 2002

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 for 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 preventative 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 26 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. [[Pediatrics](#), December 2001]

ACOG Recommends Von Willebrand Screening

The American College of Obstetricians and Gynecologists (ACOG) released, "Von Willebrand's Disease in Gynecologic Practice," a committee opinion recommending von Willebrand disease (VWD) screening for adolescents and adult women with heavy bleeding or menorrhagia. This is the first time ACOG has issued a committee opinion about VWD. The recommendation also suggests that hysterectomies for excessive menstrual bleeding should not be performed without screening appropriately for bleeding disorders. *NHF's eNotes, March 2002*

A Child's Best Advocate:

Does this scenario sound familiar? It's 10 p.m. Your child has fallen down, and his ankle is swollen. You have no factor at home to infuse. You rush over to the nearest hospital emergency room and sit in the waiting room.... and wait, and wait, and wait. Finally, after three hours, you're called into the treatment room. The first thing the nurse calls for is an X-ray. Afterwards, the doctor on call agrees to infuse your child with factor and calls the pharmacy for a vial. Finally, at 2 am. – a full 4 hours after the injury – your child is infused.

Scenes like this one are played out nightly in emergency rooms across the United States. "With more and more people on home infusion, there are far fewer people going to the ER for factor treatment," explains Karen Wulff, hemophilia nurse coordinator with the Louisiana Comprehensive Hemophilia Care Center. "As a result, doctors and nurses have less knowledge and experience to treat people with hemophilia, because they see them so rarely."

That's why it is important for patients and families to learn when a trip to ER is warranted and when to wait.

Set the Stage

Before ever stepping into the ER, families can pave the way for an easier visit. Arrange a visit to your local ER before a crisis occurs. Call your HTC and ask for the names and locations of emergency rooms frequented by their patients, because these hospitals will be more familiar with treating hemophilia. Then,

call the head nurse at the ER and make an appointment to drop in.

Find out whether the hospital has a "fast track" – a process for making sure that the sickest or most badly injured people are treated first. Then learn how to get your child on the "fast track" if he has a serious bleed.

If you have other children, set up an emergency babysitting plan with a relative, friend or neighbor in advance.

Fill out a card with details about your child's condition and treatment. Make copies of the completed card and keep them everywhere you might be in an emergency.

Most of all, understand the limitations of an ER. "Most ERs take a very long time," says Mary Hudson, nurse at the Vanderbilt Hemostasis and Thrombosis Center. "What might take 20 minutes to treat in an HTC can take 6 hours in an ER because of the triage system." (Triage refers to hospital procedures established to ensure that people with the most serious illnesses or injuries are treated first.)

"That's why – if you infuse at home – it's important to give factor before you go to the ER, if possible," says Susan Zappa, nurse at Cook Children's Medical Center in Fort Worth, Texas. "Once you get to the hospital, the ER can then handle the broken arm or sliced finger beautifully." *Newsbrief, March, 2002*

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Prenatal Gene Transfer for Treating Hemophilia

Gene transfer therapy performed on fetuses with hemophilia has produced positive results in animal models, and researcher have high hopes for possible human trials. The research suggest that fetuses may have the ability to take up genes that can simulate the production of clotting factors better than infants can. Plus, their immature immune systems cause them to be less likely to form antibodies that can prove to be problematic.

Scientists transferred the human clotting factor IX (FIX) gene into late stage mouse fetuses via their muscles, abdominal cavities, or vascular systems in utero, resulting in a high level of gene expression of plasma concentrations of FIX. However, plasma concentrates of FIX decreased continuously after birth in most mice. The researchers also noted that none of the treated animals developed any evidence of undesirable immune response activity following clotting factor gene therapy. (Source: *Blood Weekly*, 3/14/02; primary source: Sustained Delivery of Therapeutic Concentrations of Human Clotting factor IX: A Comparison of Adenoviral and AAV Vectors Administered in Utero, *The Journal of Gene Medicine*, Jan/Feb 2002; 4(1): 46-53). NHF's

NHF Annual Meeting Impressions

Paul Brayshaw...The 53rd Annual NHF Conference in Memphis, TN, was actually the first annual meeting I have ever attended, but definitely not the last. Everything people say about these events is true; a couple thousand people in attendance, overwhelming amounts of new information on research, therapies, and techniques, and filled with fun.

I began on Friday, a day after NHF kicked off the meeting. Once I was able to find my room and navigate the Opryland Hotel, I only missed a few sessions. However, I was not to be dismayed. My first session on Creutzfeldt Jacob disease brought me up to current knowledge with a broad overview and newly recognized histology of the prion-related disease.

Sessions were available for attendees to better understand the situation with the factor shortage. Individuals affected by hemophilia could attend various discussion groups designed for all ages. Experts sat on panels to share their points of view with regard to product politics, the community perspective, and issues relevant to effective advocacy. If conference goers wanted to know about hemophilia in the workplace, sessions were available to discuss insurance ideas, disclosure protocol, and disability status. It seemed that every possible area was considered in order to accommodate all interests, including meal-time.

The manufacturers and home health care companies sponsored relaxed events in the evening so participants could mingle and enjoy the local attractions. On Friday, I attended a dinner that included live entertainment while touring the Nashville skyline on a classic river boat. The Saturday event was at a local Nashville bar that included unlimited food, live music and some good ole' line dancing.

The NHF Annual Conference was a great way to get caught up on the latest research and technology important to the hemophilia community. My understanding of the issues was greatly enhanced, all while meeting some very nice people. If you are considering next year's event be assured, you will not be disappointed.

Lew Collins...I attended the NHF Annual Meeting in Nashville with my family. I attended the nursing track in order to obtain CEU's to maintain my RNC status. The information I received was invaluable, but the physical layout of the facility was a nightmare. The Opryland Hotel was very beautiful with its acres of tropical gardens, but getting from one session to another required a lot of walking and climbing stairs. Some people never found certain rooms. My two sons experienced joint bleeds from the excessive amount of walking.

The pre-conference symposium that discussed why some people bleed more than others was interesting. As more research is done, they have found additional components necessary to establish clotting. Updates were given on current gene therapy trials. The study by Dr. White from Chapel Hill, N.C. did meet with some problems. I was very relieved that my older son decided not to join the trial due to time constraints with college and some of his

concerns with the gene therapy trial itself.

The bonds of friendship established at these meetings continue throughout the year. My children and I keep in contact with people by phone or email on a regular basis.

Deb DeArmon...I enjoyed many of the talks but I think my favorite was the one on Transitions. Both Barbara Carroll and Mavis Harrop gave good information, but the hit was Craig Wright, a 19-year-old with hemophilia. We got to hear it right from the "horse's mouth". Lots of things look good on paper, but when a real life experience is available, nothing can match it. Listening to Craig helped me to remember that I need to let go a little more each day. Things won't always be perfect but that's OK. I was also reminded to keep an open and honest relationship with my child. Craig said that hemophilia had a positive impact on his growth in life, and if he had it to do again, he would choose hemophilia. I think I already knew all these things in my heart, but it doesn't hurt to get a reminder once in a while.

While strolling around all the vendors and displays, I happened to stop and chat with a gentleman named Ashok Verma from the Hemophilia Federation of India. I already knew that the situation in India was bleak and our conversation really confirmed it. Ashok told me that the average number of units a person with hemophilia receives each year is about 2000. Now if that were my child, it would mean that he only got infused 2 times a year, and that's not even close to being what he would need. Ashok did say that the number of units per infusion was much lower than the number we would use here based on the patient's weight. It doesn't take a mathematician to figure out that the level of care is far below a decent standard of life. As we talked, I learned of a program called SAVE ONE LIFE Inc. By making a donation, you could actually help a young man not only receive medical care, but also educational training so he could begin to support himself. So now, as part of our Christmas present to others and ourselves, we have a young man by the name of Arun under our care for one year. I guess I would have to say that learning about and being a part of SAVE ONE LIFE was definitely the highlight of my trip to Nashville.

Jamie DeArmon...Here are some of the things that I liked about my trip to Nashville. The Opryland Hotel was so big! We had a waterfall and palm trees outside our balcony. I liked the trip to the science center. There were a lot of cool things to do there. The best was this experiment using balls. It was kind of like the game MouseTrap. Our youth group played this game called "The Game of Life". You got to pretend you were a grown up. You had so much money and had to spend it on college to get a diploma and on things like health insurance. I met some new friends playing the game. I also enjoyed the sports guys and hearing their stories.

The closing party at the Wild Horse Saloon was great. My friends and I did some break dancing in front of the stage while everyone else was doing line dances. I had a fun time at the NHF meeting and plan to go next year

Should I Apply for Supplemental Security Income for My Child with a Bleeding Disorder? *By*

Many parents of patients I counsel ask about applying for SSI for their child. I tell parents that it is important to first understand SSI benefits and eligibility requirements. After doing so, it will be easier to determine if and how SSI may be able to help their child(ren).

General Information about SSI

SSI is an income maintenance program for the disabled with lower income and few assets. SSI benefits include a monthly check and, in 36 states, Medicaid eligibility. In the remaining 14 states, the Medicaid program is administered independently of SSI. Also known as Medical Assistance and Title 19, Medicaid is a government-sponsored health insurance plan for lower income individuals who meet income and eligibility requirements. Medicaid is a government-sponsored health insurance plan for lower income individuals who meet income and eligibility requirements. Medicaid typically pays close to full coverage for most medical services, including factor products. (Note: Medicaid is available through other benefit programs in addition to SSI). For additional information about Medicaid, contact your state Division of Health or your local Department of Health and Social Services. A recently enacted law created a special program to insure children. It is called the Children's Health Insurance Program (CHIP). For information about CHIP in your state, visit the Web site: www.insurekidsnow.gov.

SSI has financial and disability eligibility requirements. First, financial requirements must be met. For children, the income and assets of parents living in the same household as the child, as well as the income and assets of the child, are considered. If your family makes too much money or has too many assets, then the SSI application will be denied. After financial eligibility is approved, disability is reviewed.

Having a diagnosis of hemophilia or von Willebrand disease (and meeting the financial eligibility requirements) does not qualify a child for SSI. To be considered a disabled person by SSI, a child (under age 18) must have "... a medically determinable physical or mental impairment or combination of impairments that causes marked and severe functional limitations, and that can be expected to

cause death or that has lasted or can be expected to last for a continuous period of not less than 12 months."

A child's medical condition must meet the Social Security Listing of Impairments for disability. For bleeding disorders, the listing categorizes an inherited coagulation disorder as:

- A. Repeated spontaneous or inappropriate bleeding; or
- B. Hemarthrosis with joint deformity

Other Considerations and Information

- Your child may not qualify for SSI if he/she is on prophylaxis and has very few (or no) breakthrough bleeds and no serious restrictions of activities or developmental delays. SSI may determine that there were not a sufficient number of "spontaneous" bleeds to meet disability requirements. For example: The parents of two boys with severe hemophilia B that I counsel applied for SSI for their sons. One boy, on demand therapy, was approved. The other boy on prophylaxis (with no breakthrough bleeds) was denied.

- Once approved for SSI, your child must continue to meet income, asset and disability requirements, or else benefits will terminate.

Increases in income from a new job, a pay increase, overtime earnings or even certain months when you get an extra paycheck can affect eligibility on a temporary (month to month) or a permanent basis.

If you depend on SSI for insurance coverage through Medicaid, keeping under SSI allowable income levels may be a big deterrent to making a higher income. If earnings and continued SSI eligibility for Medicaid is an issue, check out other insurance options, including: employer insurance, state CHIP plans, other Medicaid programs, state high-risk plans (in the approximately 29 states that have such plans), etc.

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Obstacles & Opportunities: Adolescence and Chronic Illness

Excerpted from an article by Michael Coffino

Adolescence is a time of interesting and diverse transition, both psychologically and biologically. When coupled with chronic illness as a factor in a young person's life, this stage can serve to either empower or dismay an adolescent later in life. Many parents are still wary of letting their children take strides associated with normal adolescence, a time of experimenting and risk taking. A child's development in this area will be influenced by how the child's parents have viewed his/her illness in the years leading up to adolescence. If the family is willing to take the child's illness in stride instead of fostering an attitude that the child is "sick" (and can't live up to the expectations the parent may have had), the child will most likely have a healthy attitude regarding his/her disorder.

Many parents tend to be overprotective with their children either out of fear for the children's safety, or as a way to make up for all the children have suffered. Overprotective parents, though, only reinforce the feeling that the child is helpless, to both the child and to the parents themselves. Paul Brayshaw, a young man with hemophilia, was fortunate to have parents who afforded him the space to grow. "My parents allowed me the freedom to participate in numerous activities in ways that encouraged me to learn and respect my limitations related to hemophilia. They also made room for many compromises."

Most adolescents are a great deal stronger emotionally than parents realize, and a clear line of communication between parent and child will indicate to the parent when there is a need to offer assistance. Parents should attempt to understand the child's need for independence during the adolescent stage, even though it may be frightening to the mother and father. This will show the child they can be trusted and dissuade them from feeling needy.

When to Intervene

A parent needs to be acutely aware of warning signs that there may be a need to address certain issues. Signs that intervention may be needed are when an adolescent seems overwhelmed with emotional

issues, displays a pattern of non-compliance, shows disturbing rebellion or he/she has shown a developmental regression augmented by overly-dependent activities and withdrawal. Aside from the normal emotional swings some adolescents are prone to (which are perfectly normal for the most part), there is a certain amount of self-pity and anger that is normal in an adolescent with a chronic illness. When parents see this behavior, they should avoid the inclination to put further restrictions on the child to reign in his/her behavior, as most likely, this tactic will backfire. This may be the time in which a parent needs to back off (if the child is unresponsive to them) and enlist the help of an outside party.

If there is a trusted physician or a favorite teacher, perhaps he/she could serve as a mentor. If the parent thinks the child may respond better to someone closer to his/her own age, an organization specific to the child's disorder will most certainly provide mentors who have learned successful coping skill via their own experiences

Taking Charge of Medical Care

Parents need to be aware of subtle (and not so subtle) clues an adolescent may give out that he/she is ready for the management of his/her illness. These cues can range from increased questions about treatments to a sense that the youth is beginning to show independence in other areas of his/her life. At this point, a parent can serve as a coach while allowing the adolescent to take the lead. The adolescent should begin to make his/her own appointments for doctor visits and should be given literature concerning his/her condition. Suggestions, such as relaxation techniques before some treatments, may be made by parents, but not insisted upon.

Self Image

The adolescent years are a time when young people discover a greater sense of self. They become acutely, almost obsessively, aware of how others view them and they are desperate to fit in. For young people with a chronic illness, this may cause unique psychological stresses. Firstly, there is the primal

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sense of loss an adolescent will experience over the healthy life they expected. The feelings of invincibility most adolescents have are not present for a teen who has spent a good deal of time or with a strict adherence to a medical regimen.

Another difficulty may be linked to the fact that, "adolescents tend to feel that everyone is watching them, and ill adolescents who receive a great deal of medical attention may find that scrutiny overbearing."¹ The overwhelming nature of some of the health care concerns adolescents deal with, coupled with the predominant feeling that they are different, may cause them to burn out. They become, in essence, sick of being sick. They feel identified by their illness and, consequently, trapped by it.

The key to overcoming all the potential downfalls and rising above them may lie in an acceptance of the illness by the adolescent, coupled with the ability to move past all the pitfalls concerning the stigma

and perceived limitations. It is each individual's choice whether one decides to define oneself by the illness, or despite the illness. The future of the bleeding disorders community, if it can be gleaned from the comments of the young people who are taking leadership roles, is that the community is only as empowered as each member sees himself.

Despite the many challenges that adolescents with chronic illnesses face during this transitional time of their lives, there are many ways to boost self-esteem and make this period one of growth and awareness. Whether it is through community, family ties or an inner feeling of strength, the adolescent must find a path that raises him up to his true potential.

¹ Boice M. *Chronic Illness in Adolescence*. *Adolescence*. Winter 1998; 179-190.

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Should I Apply for Supplemental Security Income for My Child with a Bleeding Disorder?

SSI usually reviews disability status every two to three years. If the number of "spontaneous" bleeds your son or daughter has decreases to a less than significant number, SSI may determine that he or she no longer meets disability requirements.

- Check to see if SSI automatically generates Medicaid eligibility in your state or if you must apply Medicaid through another state agency. (A common agency is the local Department of Health and Social Services.)
- Contact Social Security for more information about applying for SSI for your child through its toll-free number (800-772-1213), Web site (www.ssa.gov) or local office. When you make contact, ask about income and asset requirements (pertaining to your family size), disability requirements and the SSI application process.

For further assistance, contact the social worker at your hemophilia treatment center, your local NHF chapter or NHF's HANDI at 800-42-HANDI.

HemAware, Volume 6, Issue 2, July/August 2001

Do the 5:

- 1) Get an annual comprehensive checkup at a hemophilia treatment center.**
- 2) Get vaccinated – Hepatitis A and B are preventable.**
- 3) Treat bleeds early and adequately.**
- 4) Exercise to protect your joints.**
- 5) Get tested regularly for blood-borne infections.**

NHF NATIONAL PREVENTION PROGRAM

Key steps today for giant strides tomorrow.

HACA News

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