

HACA News

June 2006
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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.*

Hemophilia Association of
the Capital Area
10560 Main Street
Suite 604
Fairfax, Virginia
22030-7182
(703) 352-7641
Fax (703) 352-2145
E-mail: hacacares@aol.com
www.hacacares.org
CFC #6022

Golf Tournament Update

133 golfers enjoyed a surprisingly beautiful day of golf at the Heritage Hunt Golf Club on Monday, May 15th. The day was off to a very rainy beginning, but the golfers enjoyed a window of sunshine and cool temperatures during the tournament. We're grateful to Cliff Krug, Jr. and his great golf committee—Kathy Krug, Chris and Eileen Prohett, Sean and Kristi Quill, Tim and Meredith Holland, John and Jay Kittelberger, Mike Gray, Howard Robertson, Mike Rutherford, and Kirk Taylor—for the many hours they spent recruiting golfers and soliciting items for our live and silent auctions.

Thanks to our generous sponsors—Wyeth, Novo Nordisk, the J. Willard and Alice S. Marriott Foundation, ZLB Behring, Baxter BioScience, The Irus Group, Bayer Healthcare, Kearney & Company, Johnson & Johnson*Merck, Factor Support Network Pharmacy, Hemophilia Health Services, Attitude, Skills & Knowledge, Inc., Kittelberger Plumbing, Southern's Automotive, Data Solutions, AHF, Inc., Building Resources, Inc. and Regency Moving & Storage—for ensuring the financial success of this event.

Thanks to our hole sponsors—Akad, Inc., Chris & Marilyn Brennan, The Bray Team, Capitol Securities, Carpex Construction, Cypress Contracting, Farrish Dealership, Factor Health Management, The O'Brien Family, Potomac Bank, Springfield Auto Care, Dr. Gary Weiss, and Whisenhut Title. If you have any reason to be in any of the listed company outlets, please be sure to thank them for sponsoring our tournament.

Thanks to all our golfers who generously supported our tournament and who purchased items at the live and silent auctions. Thanks to all the golf courses, restaurants, and individuals who donated items for the live and silent auctions. Last, but not least, thanks to all the volunteers who gave up time to be the Heritage Hunt for the day to help things go smoothly during the tournament.

Art Auction Re-Scheduled

We have re-scheduled our Art Auction with Ross Galleries for Saturday, July 22, 2006. The Auction will be held at the Old Town Hall in Fairfax City. The art preview will begin at 6:30 and the auction is scheduled for 7:30. Please plan to join us as we come together to celebrate and support our chapter. The proceeds of this new fundraising event will assist the chapter to continue the advocacy, education, and family support services that are so important to the bleeding disorders community.

Ross Galleries from Holbrook NY will provide the art and a professional auctioneer who will keep the event lively and fun! There will be a wide array of art to purchase guaranteed to satisfy your personal decorating style! On every ticket the purchaser has an opportunity to mark what type/style of art they would be interested in.

Here is how you can help!

- Join us! Tickets to the event are \$10 each or \$15 per couple.
- Help with ticket sales. Ask your friends or co-workers to come and sell them tickets!! This is a great opportunity to purchase art for home or office. Let your human resources department know about it so they can tell employees. Posters and flyers are available from the HACA office
- Program Advertising. Know of a business who would like to promote their products or services to our attendees? Very reasonable ads are available. Call the HACA office for a price list.
- Be a volunteer. We need help during the event, so roll up your sleeves and get ready to have some fun while helping YOUR chapter!
- Dessert or fruit and cheese donation. We will be serving desserts, fruit and cheese, and wine at the pre-show at 6:30. Please call the HACA office at 703-352-7641 if you are willing to donate a dessert or a fruit and cheese platter.

The success of this event depends on you! Everyone can make a difference, so choose which way you can help make this inaugural event a great success! It will be a wonderful way to spend a beautiful summer evening.

**Chapter News
continued**

And They're Off

16 campers will depart on June 9th for 6 days of fun at Hole in the Wall Gang Camp in Ashford, Connecticut. We extend a special thanks to Deb DeArmon for chaperoning our campers during their time at camp. We also thank Harvey Gates, Sr. and Paul Brayshaw for flying with the campers to Hartford and from Hartford.

We express our thanks to the sponsors who made the trip possible—The Leonard A. Wenzel Family Fund, Factor Support Network Pharmacy, Caremark, Camp Superfly, Critical Care Systems, ZLB Behring, Baxter BioScience, and Bayer Healthcare.

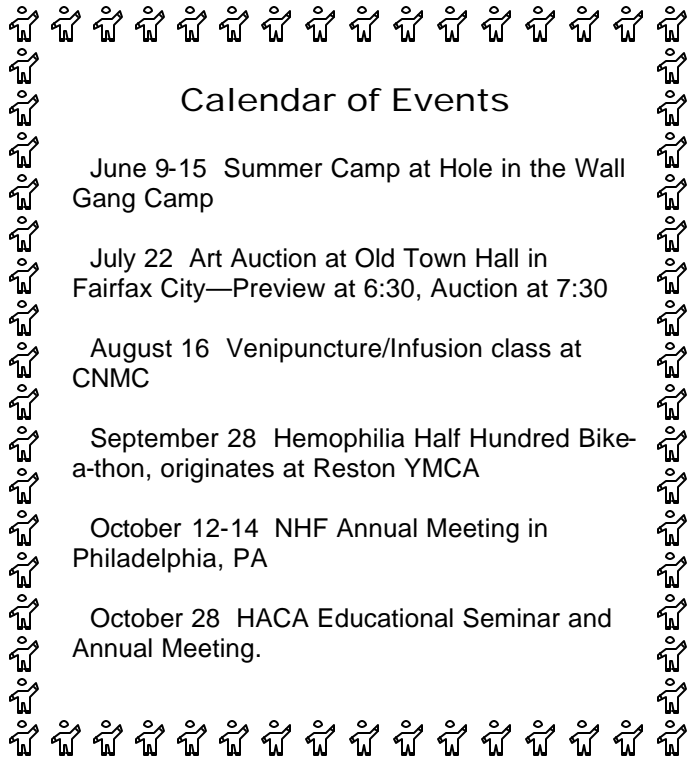
Chapter "Soccer Mom" or "Soccer Dad" Needed

HACA has been invited to take part in a fund-raising project with the World Federation of Hemophilia (WFH). We need someone to coordinate the project—to contact area soccer teams and get them to participate in fundraisers to benefit WFH and HACA. The grand prize winners of the soccer raffle will be invited to a DC United game and honored there. The soccer team in the United States that raises the most money will win a trip to DC for a DC United Soccer game (if a team in our area wins, the site of the trip may be changed) and a training session with Freddy Adu, the youngest member of the DC United Team. Freddy started playing professional soccer when he was only 16 years old. If you are interested in learning more about this project or in volunteering to head it up on behalf of HACA, please contact the HACA office at 703-352-7641.

**2006 Board of Directors
Meetings**

General Board Meeting
June 12, 2006
September 11, 2006

General Board meetings begin at 7:00 p.m. and are open to all interested HACA members. Please notify the HACA office that you will be attending. Directions and site will be shared with you at that time.



Calendar of Events

- June 9-15 Summer Camp at Hole in the Wall Gang Camp
- July 22 Art Auction at Old Town Hall in Fairfax City—Preview at 6:30, Auction at 7:30
- August 16 Venipuncture/Infusion class at CNMC
- September 28 Hemophilia Half Hundred Bike-a-thon, originates at Reston YMCA
- October 12-14 NHF Annual Meeting in Philadelphia, PA
- October 28 HACA Educational Seminar and Annual Meeting.

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A Great Opportunity for Inhibitor Patients to Listen, Learn, & be Heard

When it comes to living with inhibitors, there's a lot to learn—which makes it surprising that there haven't been specific educational opportunities for patients with inhibitors and their families. That is, until now.

This year, patients from this unique community will get a chance to unite and learn at one of four Inhibitor Patient Education Summits being held around the US.

The Summits are learning and networking opportunities focused exclusively on topics of interest to the inhibitor community. Speaker selection and agenda development for these meetings have been directed by a steering committee of national and local hemophilia leaders, including physicians, nurses, advocates, patients, and representatives from physical therapy and social work. So all topics are sure to be relevant and timely. The Summits are sponsored by Novo Nordisk Inc.

The very first Summit, held last fall in Philadelphia, was a great success. More than 50 families came together with hemophilia leaders for a weekend of learning, sharing, and networking experience. Those who attended the meeting gained much more than new insights into treating and living with an inhibitor—they created personal and professional connections that will continue to teach, support, and inspire.

The 2006 Summits are planned for: Anaheim (July 28–29), Dallas (August 4–5), Baltimore (September 22–23), and Chicago (October 27–28). Topics will include Basics Behind Inhibitors, Treatment Strategies, Immune Tolerance Therapy (ITT), Insurance: Changes and Challenges, Exercise and Sports, Psychosocial Issues, Joint Health, Surgical Considerations, and Pain Management. All meetings will take place at handicap-accessible facilities. On-site childcare will be provided.

Travel grants will be available to eligible individuals and administered by NHF and HFA chapters. To register or learn more about attending a meeting, please call 1-888-706-6867 or visit www.inhibitorsummits.org. HACA also has booklets that have been provided by Novo Nordisk that give more information about the summits and answer some frequently asked questions. For your copy, contact the HACA office at 703-352-7641.

Save the Date

Our annual educational seminar is being planned for October 28, 2006. Please put this date on your calendar today and set aside the time to learn more about your bleeding disorder, to renew old friendships, and make new friendships.

NHF Annual Meeting Scholarships

The NHF Annual Meeting will be held in Philadelphia, PA, October 12-14, 2006. HACA will once again be able to offer small stipends to help interested people travel to the meeting. Please contact the HACA office at 703-352-7641 for an application form. The deadline for applying for this stipend is September 1, 2006. Preference will be given to individuals who have never attended an NHF meeting.

S1955 Stalls Out

A great big thank you to everyone who responded to our call to action regarding Senate Bill 1955—The Enzi Bill. This was the bill that would have allowed insurance companies to sidestep state mandates and would also have allowed them to increase the cost of insurance for “sick” people with no oversight or limits on those increases. On Thursday, the 11th of May, the Senate was unable to garner 60 votes to bring the bill to “cloture” which would have meant that the debate on the bill would have been given only 30 hours more and then there would have been a vote on whether the bill would become law or not. When the votes were tallied, there were only 55 votes for cloture and 43 votes against.

This effectively stopped the debate and the bill has now been put on the “back burner”. Most people feel sure that it will come back in yet another form. Hopefully, the next time around, it will be much more favorable for people with bleeding disorders.

Again, thanks to everyone of you who responded to our urgent messages and contacted your Senators. Along with many others, we definitely made our voices heard!!

New Super-High Potency of FEIBA VAH Available for Patients with Inhibitors

Baxter is proud to announce the launch of a new 2500 Super-High potency of FEIBA-VH for the treatment of inhibitors. The new Super-High potency of FEIBA-VH has a six-month room temperature storage (up to 77 degrees F, not to exceed the expiration date), a two-year shelf life if refrigerated (35 degrees-46 degrees F., Not to exceed printed expiration date), and the BAXJECT needle-less Transfer Device.

In addition, to make it easier to distinguish between the three potencies of FEIBA-VH, Baxter has added color-coding to the packaging of all three potencies.

Ultra-High Dosage Strength for ADVATE

Baxter has also announced the launch of its new Ultra-High dosage strength for ADVATE (Antihemophilic Factor (Recombinant) Plasma/Albumin Free Method rAHF-PFM). The Ultra-High vials contain 2000 IU/vial.

You Can't Have Hemophilia—You're a Woman!

By Patricia Stewart

The term *carrier* has traditionally meant a woman who inherited the gene that causes hemophilia and who could then pass it on to her son who would have hemophilia. The common belief was that these women did not have hemophilia: they only “carried” the defective gene. These days more and more carriers are coming forward and seeking treatment for problems related to bleeding. Unfortunately, these women don't always find a receptive ear, even at Hemophilia Treatment Centres (HTCs). This can be a frustrating and frightening experience with serious repercussions.

The average age for a woman to be diagnosed with a bleeding disorder is 27. At this point, she has probably dealt with menorrhagia (excessive menstrual bleeding), among other things, for many years. Studies show that approximately 25% to 30% of female carriers—as opposed to men with hemophilia who are also technically carriers—are symptomatic. Some women have factor levels that in males are automatically diagnosed as mild hemophilia, but in females, simply give them the label of carriers. When asked why they took so long to seek medical help, women stated they were usually told: “That's what it's like to be a carrier,” or “It isn't possible for a woman to have a bleeding disorder.” Some were told that their levels weren't low enough to cause a bleeding problem. One woman, when the pain and exhaustion due to bleeding continued, was asked, “Are you sure it's not psychological?” Years later she was diagnosed with hemophilia. Many women don't see their situation as a problem, but as normal, especially when specialists have told them this repeatedly.

Lack of proper diagnosis can have a serious effect on a woman's life. One such case is that of a woman who, as a 13-year-old suffering from menorrhagia, was given the pill (hormone therapy). Despite this, she soaked her pad every hour, couldn't take part in gym classes, and missed a week of school each month. It wasn't until her son was diagnosed with mild hemophilia A (14% factor VIII levels) that she was tested. At this point, her sisters also tested positive, as well as her father, who was 54. He had never had any problems, nor had her sisters, nor their sons who also have mild hemophilia. Both she and her son, however, have bleeding problems. Despite constant menorrhagia and anemia, and the knowledge of her carrier status, she never spoke about her own problems.

She underwent a hysterectomy at the age of 27, when she began fainting after three consecutive months of menstrual bleeding. When at the age of 37, she finally mentioned her own problems to her son's hematologist, he quickly ordered tests. She was diagnosed with mild hemophilia. Her levels were 49% while on the pill, which

are known to raise factor VIII levels. The years of bleeding problems now make sense to her. It took years of anemia, missed school and social events, visits to family doctors and gynecologists and a hysterectomy before she was finally properly diagnosed.

Unfortunately, just because a woman seeks treatment at hemophilia treatment centre doesn't mean that she'll get it, even if she's aware of her carrier status. Another woman had problems with bleeding since her youth, including epistaxis (excessive nosebleeds), bleeding after tooth extractions, bruising and menorrhagia. After her son's diagnosis with severe factor VIII deficiency, her factor levels were measured at 70-80%. Because of menorrhagia, she sometimes needed DDAVP to be able to continue working or attend family gatherings, but eventually had to have a uterine ablation. A few years later, she injured herself in a fall and realized that she was experiencing the exact symptoms in her joint she had told her son to tell her about—tingling inside, hot and boggy. She called to get an appointment with her HTC, but was refused. She was told that “by definition, you cannot be bleeding.”

The bleeding continued, and she consulted an orthopedic surgeon who said it was normal and would settle down in 8 to 12 weeks. She returned to a job requiring her to work on her feet all day. This provoked more bleeding and she rested on the weekend, but the cycle began again on Monday. This continued for a year. The joint continued to be painful and swollen. After one year, a second orthopedic surgeon told her she had stage-4 arthritis, and would need a knee replacement! She told him of her bleeding history before having arthroscopic surgery. Despite bleeding through dressings afterwards, she was told it was “normal” by the orthopedic resident and the ER staff, who refused to consult hematology.

Six weeks after the procedure, her surgeon showed her pictures from the scope, pointing out the blood in the joint, saying she'd bled so much during surgery that she was given DDAVP. She was not told this at the time. When she called the HTC, she was again told it was not related to low factor level. Clearly they weren't interested. She contacted another hematology specialist who explained that because the body can only produce a limited amount of factor at a time, her body couldn't keep up to meet her needs over this long period and her reserves were being depleted. During the 6-week post-procedure recovery time, she was off work and able to RICE (rest, ice, compress, elevate) her knee, hence the bleeding finally stopped and her factor levels were restored to normal. However, she is now anxious that if she ever needs it,

she won't be able to get proper treatment since the local treatment centre refuses to acknowledge her bleeding problem.

These are only a handful of experiences to illustrate the lack of recognition that women can have hemophilia. Often, because they don't present to the doctors with a problem, the doctors don't see the situation their patient is in, nor do they see the scope of the problems experienced by girls and women who are carriers.

One woman stated, "Not only is this sad for the women individually, but it means we are sentencing our daughters to a lifetime of living with problems that shouldn't be tolerated."

The Female Factor, Hemophilia Today, Spring 2006

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You say...How to Talk to Teenagers So They Will Listen

By Nancy Samalin, MS

Teenagers have never been easy on their parents. On the road to becoming adults, teens are naturally inclined to take risks, and experiment and discover for themselves what life is all about. This process of separation creates a great deal of frustration and anxiety for parents.

A common refrain among parents is, "I must have told you a thousand times not to do that." Just saying the words doesn't necessarily mean teens listen to what parents say.

Nancy Samalin, MS, is the Director of Parent Guidance Workshop and the author of several popular books on parenting and communication. Samalin offers some helpful strategies to keep the lines of communication open with teens.

Talk about values. Passing along a strong sense of values is one of the fundamental tasks of being a parent. No matter how uncomfortable it may be, parents need to talk to their children about difficult social issues. Teenagers are likely to be more receptive, if, instead of sitting them down and saying, "We need to have a talk," you bring up these issues casually. A good time for these discussions is while you are driving with your teen in the car. Not only do you have a captive audience, you also avoid the need for eye contact. Another part of transmitting values is to let teens know that they can turn to you as a resource if they ever need help.

Example: If you're ever at a party and something happens that you're uncomfortable with, call us and we'll come pick you up—no questions asked.

Use "What if" questions. By posing "What if" questions, parents can help teens consider various scenarios that will help them formulate effective ways of dealing with different eventualities.

Example: What if your peers dare you to perform an activity? What will you do? What will you say?

Focus on what is important. Most teens feel compelled to try out different roles. As painful as it may be to watch, it's one way that teens learn to function on their own without having to consult their parents about every decision. Rule of thumb: Don't make a fuss about issues that are reversible or don't directly threaten your child's or another person's safety. Reversible topics include messy rooms, torn jeans or other normal, if annoying, teenage habits. Save your thunder for more important concerns. Safety rules need to be stated clearly and enforced consistently.

Example: Drinking is not acceptable. If you have a party here, no beer or hard liquor is allowed...and an adult must be present at any party you attend.

Don't give hasty answers. The best and sometimes hardest way to respond is by being non-committal. You don't owe a response or a long-winded explanation to everything they ask.

Example: I have to think about that.

Example: I need more information.

Be willing to be unpopular. Accept that there will be times when your children won't like what you say or will act as though they don't like you. Being your child's friend should not be your primary role during this time of their lives.

Example: You teen responds to your decision by saying, "You don't understand, I'm the only one who has to..." or "I'll die if you don't let me." They're trying to get you to relent and say yes when you want to say no. Hold your ground—and try not to take it personally.

Help teens learn from experience. No matter how hard we try to teach good judgment and supervise their important decisions, teens may still act in ways that frighten us. Sometimes dealing with the consequences of their own actions inspires sensible behavior more effectively than any lecture or discussion.

Example: A mother went away for the weekend and, without permission, the daughter invited a few friends in for a party—no adults present. Some other teens crashed the party, drank heavily and threatened to get violent. The girl felt she had lost control in her own house. She realized her mother was right in insisting that adults be there.

Be respectful. We get offended when our children treat us discourteously. But we often fail to recognize when we're doing the same to them.

Example: A parent who enters a teenager's room without first being invited is showing disrespect. Of course, respect works both ways. Teens owe us the courtesy of letting us know where they are and how we can reach them.

Try to avoid arguing. Arguing only fuels hostility and it doesn't get you heard. Here are some principles to follow:

(Continued on page 8)

Risky Behavior

By Lydia Dixon Harden

During her years of working with teens and their parents as a clinical psychiatrist and psychoanalyst, Lynn E. Ponton, M.D., has come to two conclusions about adolescents: they are going to take risks, and most of their parent are terrified of this.

"Parents who believe that they just barely survived their own adolescence may be frightened to death that their teenager will not," tells Ponton in her book *The Romance of Risk: Why Teenagers Do the Things They Do.* "No matter how big a risk-taker the parent was, he or she is scared by the new risk behaviors available to their child's generation."

Some of those risky behaviors include: reckless driving; use of legal and illegal drugs; sexual activity without protection; drinking; smoking; body mutilation (cutting, piercing); withdrawal from school; eating disorders; free running (jumping from rooftop to rooftop between buildings); car surfing (riding on top of a moving car); choking games; extreme sports; playing with firearms; and skitching (hanging on to a car while riding a skate board or rollerblades)

Ponton offers that our culture has come to believe the adolescence is naturally a tumultuous time. This belief, in turn, has blurred the line between behavior that is normal and exploratory and behavior that is dangerous. Compounding this myth are others: the perception that adolescents don't want to be guided; teens' perception that risky behavior is sexy and exciting as reinforced by advertising, movies or videos; or the idea of the generation gap, where parent and teenagers are destined to never understand each other.

"Many parents accept chaos and dangerous behavior as part of adolescence," Ponton says. "Therefore, many adults assume that little can be done to interfere with this tumultuous time and to help a child practice positive risk-taking."

Not all risk is bad.

Wait a minute, you ask. There's positive risk-taking? Yes, according to Ponton. "When we assume that all risk-taking is dangerous, we betray our teenagers. Positive risk-taking includes participating in sports, developing artistic and creative abilities, going on a date, traveling, applying for college, volunteer activities, and making new friends. All of these activities involve uncertain outcomes and some level of risk. Adolescence is a time when, quite literally, young people are learning how to think and how

to act," says Ponton. "More than any other age group, adolescents are attempting new things for the first time."

Dr Charles Irwin of the University of California San Francisco Adolescent Medicine Clinical is also a pediatrician who has specialized in adolescent risk-taking. He describes risk-taking among adolescents as young people who have limited experience engaging in potential destructive behaviors without understanding the consequences of their actions. It is difficult and frightening for parents to recognize that most risk-taking is a normal, developmentally appropriate part of adolescence because the more negative and dangerous risk behaviors overshadow normal adolescent risk-taking. There is a difference, Irwin states, between turbulence and danger.

Teens often view the world differently than adults. The ability to evaluate risk seems to be skewed in many teenagers, says Irwin in a study published in the *Journal of Pediatrics*. "For instance, when teens were asked to anticipate what risks become more or less dangerous over time, they saw addiction from drug use and pregnancy from unprotected intercourse as becoming less rather than more likely."

Taking Action

If the risk-taking becomes dangerous, then, of course parents must act, says Ponton. The key for all parents in preventing negative risk-taking is to understand adolescent behavior, Ponton emphasizes. She offers 10 observations:

- All teenagers are going to take risks as a normal part of growing up. It is the tool an adolescent uses to define and develop his or her identity.
- Inherent in risk-taking is the possibility of failure. Parents must recognize and support children with this.
- Negative risk-taking is a category of behaviors that can be dangerous for adolescents, including drinking, smoking, drug use, gang activity and others.
- Unhealthy risk-taking may appear to be an angry gesture specifically directed at parents, often understood as "adolescent rebellion." However, whether healthy or unhealthy, it is part of a teen's struggle to test out an identity.

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(Continued from page 7)

- Some adolescent behaviors are deceptive—a teen may genuinely be trying to take a healthy risk that evolves into more dangerous behavior.
- Red flags that help identify dangerous adolescent risk-taking or the increased potential for it to occur, include psychological problems such as persistent anxiety or depression, problems at school, engaging in illegal behaviors, and clusters of unhealthy risk-taking.
- Because adolescents need and should take risks, parents need to help them find healthy opportunities to do so.
- Although adolescents do not usually talk directly with parents about their negative risk-taking activities, they often offer subtle clues about their behavior. Parents need to share their own histories of risk-taking in order to be effective role models.
- Adolescents do look to their parent for advice and modeling about how to access risks. Parents need to help their teen learn how to evaluate risks, anticipate the consequences of their choices, and come up with strategies to divert their energy into healthier activities when necessary.
- Parents need to pay attention to their own current patterns of risk-taking. Teenagers are watching and imitating, whether they acknowledge this or not.

Parents need to be aware of how and where they can intervene. It's not an easy process, Ponton acknowledges. "Adolescents fight with their parents. This is only natural.

Parents need to know that they cannot simply throw in the towel when the conflict starts. Adults need to develop a comfort level for talking with teens about these matters. Many parents shy away from it, but it is an absolutely imperative step in helping young people develop in healthy ways."

Different parenting skills are required to care for adolescents than for younger children. Being able to change those skills is a special task for parents of adolescents, and it is not easy, Ponton points out. Learning new skills when you feel like you're under attack is difficult.

When teens fight, it is not meant as a personal attack on the parents. Parents have to understand this and respond rather than react. This fighting signals a desire for greater independence, but not total autonomy. "Adolescents want to be treated with respect, want their new maturity recognized, and want to be seen as separate people. They need to be left alone to make certain choices for themselves and try new experiences. They need to know that their parents are available to offer opinions when asked. They need to know that there are certain limits, and they are not allowed to do anything and everything they want," says Ponton. "Parents still need to fill the presence of supporting, guiding adults who can accept the changing roles in the family."

By learning how to assess risks and make reasonable choices, young people begin to learn just how powerful they can be, how much control they have over their own lives, and what promise their futures hold, says Ponton. Risk-taking becomes more than romance then, it becomes a vital tool that adolescents can use to shape their lives.

Bloodstone Magazine, Spring 2006

How to Talk to Teenagers (Continued from page 6)

- Don't judge everything your teen says. Remember that what they say isn't necessarily what they'll do.
- Never try to reason with someone who is upset—it is futile. Wait until tempers have cooled off before trying to sort out a disagreement.
- Agree to disagree. Teen's sometimes outlandish opinions are healthy proof that they are becoming their own person.
- Don't try to talk teens out of their feelings. They have the right to be hurt, angry, disappointed—just as you do. You can acknowledge someone's reaction with condoning it. This type of response often defuses anger.

Sources: Nancy Samalin, *Parent Guidance Workshop, Bottom Line Personal, October 1, 1994, Volume 15, Number 19. Hemalog, January, 1997. Bloodstone Magazine, Spring 2006.*

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YOUNG PEOPLE'S PAGE

Volume 3, Issue 3

The 'US' in Famous People

History shows us that anyone (that means any of us) can have an impact on those around us and the world whether we end up in the history books or not. The most important part about being you and part of the US in famoUS, is believing in yourself and feeling good in your own "skin". So let's look at some examples of individuals who have had an impact on those around them, despite their medical challenge.

Is your passion investigating and questioning? Do you think like a scientist? Then maybe a good example of determination and perseverance for you is Sir Isaac Newton. Sir Isaac Newton had epilepsy which periodically impacted his life. However, he continued to work on his scientific ideas although few people supported him. Many European scientists, after reading his publications, objected and made long speeches of disapproval. Despite this lack of support, Newton believed in himself and persevered. Here are some other scientists you might recognize who also had to persevere despite medical difficulties:

- Stephen Hawking: Lou Gehrig's Disease
- Alexander Graham Bell: Learning Disability
- Leonardo Da Vinci: Dyslexia
- Pythagoras: Epilepsy

Are you more of an artist than a scientist? There are many artists who also succeeded despite medical difficulties.

Claude Monet was a painter who had a visual impairment. When Monet was alive, he was part of a new style of painting called Impressionism. It took a lot of guts to be part of something new, when many people didn't understand his style of painting. Ludwig Van Beethoven was deaf and had asthma, but he still composed some of the greatest pieces of music that will ever be written. Just think, he never heard some of the pieces he wrote himself. Here is a short list of other artists who persevered with a medical condition:

- Pierre-Augustine Renoir: Rheumatoid Arthritis, used a wheelchair
- Edgar Allen Poe & Charles Dickens: Epilepsy

Not into science or art? Do you dream of running the country? If you are into politics read further! President John F. Kennedy had attention deficit disorder and a chronic back problem. Despite this he was able to focus on America. His confidence in himself allowed him to be a successful president who changed America forever. Here are other politicians who succeeded despite medical difficulties:

- Franklin D. Roosevelt: Polio
- Julius Caesar: Epilepsy
- Bob Dole: One functioning arm

Do you think athletes are immune? Think again! And what about entertainers? Check out these well-known athletes and celebrities:

- Magic Johnson: AIDS
- Jim Abbot: One hand
- Nolan Ryan: Dyslexia
- Christopher Reed: Paralysis
- Michael J. Fox: Parkinson's Disease

So, what does this mean for you? Well, you probably will not end up in the history books. However, you do belong to a community just as the scientists, artists, government leaders and entertainers do. You also have potential! So join "US", the every day people in the bleeding disorder community striving to do their best despite whatever obstacles we face. Remember when we choose to believe in ourselves, our energy becomes the power that makes the difference. Become that "famous" person called "you". Never underestimate the impact that you have. John Schaar probably said it best:

The future is not someplace we are going, but one we are creating.

The paths to it are not found, but made, and the activity of making them changes

Both the maker and the destination.

-Adapted from an article, "The 'US' in Famous People", *Teen Talk*, Volume 1, Issue 3, Great Lakes Hemophilia Foundation

HAPPY MAY/JUNE BIRTHDAY TO:

Isiah M. May 3
 John Taylor N. May 4
 Colin W. May 8
 Will H. May 10



Taylor L. May 12
 Eric G. May 28
 Tony J. June 2
 Michael S. June 10
 Gerald H. June 30

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

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