

Summer 2008

A Funny Thing Happened On The Way To The Delivery Room....My Bleeding Got Better

By Bonnie Hall

Pregnancy and childbirth conjures up images of glowing mothers-to-be with expanding bellies, and tiny infants with pink cheeks and perfect fingers and toes; it can also evoke new concerns and insecurities, particularly when a chronic illness or condition is present. I am a mother of five children ranging from 2-17 years old. I have experienced an unplanned home birth, an emergency frank breech birth, long and difficult labors, and record-breaking quick deliveries. I am also a woman with Type 1 vonWillebrand Disease and Impaired Platelet Aggregation.



The diagnosis of a bleeding disorder was not made until after the birth of my first two children. As is common in woman with vonWillebrand Disease, my bleeding disorder was present during childhood, but not understood. My bruising was explained away by my clumsiness, my bleeding gums were blamed on my aggressive brushing, and my excessive menstruation was just part of becoming a woman in my family of bleeders. My birthing and postpartum hemorrhages were thought to be caused by my being so young or because I was trying to do too much too soon or because it was a difficult delivery.

When I was finally diagnosed with a bleeding disorder it was such a relief. I finally had an explanation for my unmanageable bleeding. It wasn't caused by my behavior or other circumstances, and there were ways of managing it aside from hoping and praying the bleeding would end.

Pregnancy was a favored time for me, because bleeding was almost a non-issue. My hematologist and obstetrician had clear, written plans should an emergency or unexpected bleed occur. Still, aside from the aches and pains most woman feel when pregnant,

I felt great. In many ways, I felt better than I ever had. There was no monthly bleeding to make me anemic and fatigued, and the pregnancy raised my factor levels enough that I could wear summer shorts and shirts without the shame of bruised limbs. I often would joke that I kept getting pregnant so I wouldn't bruise or bleed.

Ironically, it was after pregnancy and birth, when I was in my own comfortable home that bleeding became a problem. It was explained to me that the hormones that that kept me 'normal' and bleed free would ultimately return to pre-pregnancy levels and I would be

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From The President

Dear NEHA Member,
“There is a difference between interest and commitment. When you are interested in doing something, you do it only when circumstance permits. When you are committed to something, you accept no excuses, only results.” - *Unknown*

Well, I do wish I could locate the originator of this quote – you may have heard it here first, but it is certainly not original. What does it mean to you?

After returning from the NHF Leadership Weekend recently, I spent a few moment reflecting on our discussions and to think about why (this year) it felt so dramatically different – refreshing, hopeful, even exciting. Regardless of how I sliced and diced my interpretation of the weekend, I realized that we are now embarking on a journey of true, mutual commitment at both the local and national level.

The NHF has recently taken a very bold step with the decision to hire Val Bias as their Chief Executive Officer. A former Executive Director, Board President, and NHF Board Chair, Val brings grass-roots leadership, years of experience in the community, and a sense of unprecedented commitment to the NHF. We have already seen Val exemplify solid leadership skills at the NHF level, while maintaining an appropriate degree of sensitivity at the chapter level. Over the years Val has been able to demonstrate his trust in the community, and himself has been a trusted, reliable source for many of our chapters and the NHF as well. Like NEHA, many chapters have recently made a solid commitment to participate in strengthening our national organization so that we can continue to advocate for all community members smarter, louder, and with greater impact.

The outstanding level of commitment of our own staff, volunteers, and board members at NEHA is also something that should not go unnoticed. Our organization continues to prosper with renewed commitment, enhancements to our leadership, and the cultivation of our emerging leaders of tomorrow.

We have seen many wonderful results from NEHA, and we are continuing to see changes at the NHF level that are truly inspiring.

As we continue in our personal endeavors, let us take pause and ponder the provocative differences between interest and commitment – the results could be delightfully surprising.

Best wishes to all, for a healthy, happy summer season.

Warmest Regards,

Patrick Mancini, NEHA President

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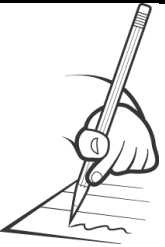
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My Story . . .

(My Story is a regularly appearing column, written by NEHA members. Got a story to tell? Send it to info@newenglandhemophilia.org)

Devin & Morgan's Story

Chris B.—

This spring our family had the opportunity to attend our first NEHA SpringFest. Our five-year-old son Devin has moderate Factor IX deficiency, and we thought it would be a good chance for him to get to know some of the other children. On the ride home I asked Devin, "So, did you have fun playing with the other boys with hemophilia?" "You know Mom, girls can have hemophilia too. Like Morgan," he responded. Over the next couple of days, the one name that kept popping up when Devin talked about SpringFest was Morgan, an eight-year-old *girl* with hemophilia. I was so glad that he'd made a connection and found someone that he liked that could be a friend as they grow up together, seeing each other at camps holiday parties, and meetings.



A few days later, Devin had his annual comprehensive appointment at Children's Hospital Boston. As we were leaving the exam room, we ran into Morgan and her mom Destinee. Both kids would need a blood draw in the phlebotomy lab downstairs and Devin was already feeling anxious about it. He wanted some time for his EMLA to sink in before the needle poke, so we went for a bite to eat and then over to the courtyard playground while the kids waited for their turn. They had a blast playing together, so much so that we asked the kids if they wanted to have their

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Val Bias: New CEO of the National Hemophilia Foundation

By Jane Cavanaugh Smith

This article originally appeared in the May/June 2008 issue of CLOT, a newsletter published by Hemophilia Innovation LLC.

Phone lines were buzzing and emails were flying around New England on Monday, April 14th, as we heard the exciting news: Val Bias will be the new Chief Executive Officer of the National Hemophilia Foundation. The response from our community? A resounding.....*YES!* At a time when we need strong leadership and guidance on the national level, NHF found someone uniquely qualified. Val's long history of hard work on behalf of our community has earned him admiration and respect from consumers, NHF and chapter staff, medical professionals, industry, other national organizations, and federal agencies such as the CDC, NIH, and FDA. Val has invaluable experience and insight that will help him maintain effective working relationships with all of these groups. Here's what some New Englanders had to say about Val's appointment:



Barbara Gordon, Vice President of New England Hemophilia Association, told us that, "Val is thoughtful and reasonable. He is a great listener and there is calmness in how he handles challenges. He knows our community, warts and all; he knows our many strengths and also how we sometimes get in our own way. I believe that he will keep people focused on the issues rather than let emotions distract us. His is a voice that people trust."

John Rider, HIV/AIDS/HCV National Advocate for the Committee of Ten Thousand (COTT), said. "The nice thing about having Val as the new CEO of NHF is that I see him as a potential bridge-builder between generations. Val brings important wisdom on blood safety issues and will build upon the good work of people like Paul Haas with regard to the concerns of the older gen-

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Leading Edge Program for Teens

By Kevin Sorge

What better way to see teenagers doing a flying squirrel than by attending May's Leading Edge program? Held at Project Adventure, the program was attended by 14 teens and sponsored by Wyeth Pharmaceuticals. Pat "Big Dog" Torrey hosted the program, which stretched the teenagers' minds while challenging their bodies. Designed to encourage teamwork and develop leadership skills, this two-day workshop took our group out of their home environment and put them in the woods in beautiful Beverly. After introductions and some self-reflection, the teens were putting on climbing harnesses and swinging from the trees!



The flying squirrel maneuver has one participant fastened to a rope tethered high in the trees. One end of the rope is connected to their harness, the middle wrapped around a pulley high on a tree, and the other end is managed by the hauling team. At the 'squirrel's' direction and command, the hauling team pulls strongly on their end, thereby launching the squirrel high into the air! Bravely tried by almost everyone, the activity challenged their creativity, physical ability, decision-making skills and the ability to following directions and commands.

Another activity encouraged the group to work together as a team, by transporting each other on a

LEADING EDGE: Exploring the Outer Limits

(Many thanks to Pat Torrey of Physis, Inc., and sponsor Wyeth Pharmaceuticals for providing this outstanding program!)

My Perspective by Matt LaRovere

I had a great experience at the Leading Edge Program. One main memory from this experience was breaking me out of my shell. After this program I was able to talk in front of people better because it was necessary to communicate in the activities. The activities also taught teamwork. I learned to take some risks that will help me, but risks that are not so risky that they might become dangerous. Overall at the Leading Edge program I was able to better myself for everyday skills like communication and teamwork.

My Perspective by Nick LaRovere

The Leading Edge showed me and helped me gain multiple life and leadership skills. One is stepping up to the challenge, and facing your fears. This was evident through the multiple rope courses that looked dangerous to try. After each rope course, I was always proud of myself for stepping up, and facing the challenge head on. The second skill I learned was to be patient, and to trust in others. We had multiple challenges that involved teamwork, and trusting the others on our team. If we got frustrated and rushed the challenge by ourselves, we surely would fail. In conclusion, these skills helped me to grow in my abilities as a leader.

rope sled across a river of unknown barriers. The teens had to create tools for the exercise, develop a priority order of crossing based on need, leverage the resources they had, and ultimately get everyone

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Q&A on Pregnancy and Bleeding Disorders

By Molly Polen

(This article appeared in the May/June 2008 issue of Hemaware. It has been edited for space.)

For women with bleeding disorders (including carriers), pregnancy can be a time of heightened worry and confusion. In this issue of *Hemaware*, we conducted e-mail interviews of two experts in the field and members of the National Hemophilia Foundation's Medical and Scientific Advisory Council; Andra James, MD, co-director of Duke University's Comprehensive Thrombosis and Hemostasis Center, and Amy Shapiro, MD, director of the Indiana Hemophilia and Thrombosis Center. We discussed some of the issues that most concern pregnant women with bleeding disorders.

All women with a known diagnosis should have contact with their hemophilia treatment center (HTC) during pregnancy to ensure coordinated prenatal and postpartum care.

Are there any blood products or medications taken during pregnancy that might pose a risk to the baby's health?

Dr. Andra James: von Willebrand factor concentrates are derived from purified human plasma and carry the risk of virus transmission. While a small risk of virus transmission exists, no transmission of human immunodeficiency virus (HIV), hepatitis B or hepatitis C has occurred with any von Willebrand factor concentrates currently marketed in the United States. Parvovirus B19, however, is very difficult to eradicate despite the purification process. Parvovirus B19 can cause a mild disease (fever, rash, aches and pains) in adults, but can cause severe, life-threatening anemia in unborn babies. There is a risk that this virus could be transmitted with purified factor products and potentially harm an unborn baby. There are, however, no reports of this actually happening.

Blood products such as fresh frozen plasma and cryoprecipitate are tested for known viruses, but are not purified, and may allow unknown, but potentially harmful viruses to be transmitted.

DDAVP, a synthetic version of the hormone vasopressin, if required prior to a procedure, is generally thought to be safe for mother and fetus. Tranexamic acid (cyklokaptron) crosses the placenta, but has been used to treat bleeding during pregnancy in a limited number of cases without adverse fetal effects. There are limited data about aminocaproic acid (Amicar) in preg-

nancy, but it was not found to cause birth defects in rabbits. In one case of its use during pregnancy, there were no adverse fetal effects.

Dr. Amy Shapiro: Since the data are so limited, Amicar should only be used in circumstances in which it is thought essential, and any issues should be reported to widen our knowledge base.

Women with von Willebrand disease (VWD) have a tenfold greater risk of antipartum bleeding (bleeding during pregnancy). What can be done to decrease this risk?

Dr. Shapiro: We usually ask patients to maintain careful observation and provide us with early notification of bleeding. In cases where there have been previous problems, or in specific types of VWD, some form of treatment may be considered.

Should a woman with a bleeding disorder assume that her baby will also have a bleeding disorder? If so, what precautions should be taken during delivery?

Dr. Shapiro: The inheritance of bleeding disorders depends on the specific disorder with which the woman is

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Read NEHA NEWS in .PDF Format!

Starting with this issue, readers may request to have an electronic version of the NEHA News sent to your email address. Later this year, NEHA plans to add electronic (.PDF) versions on our Website for viewing and downloading.



If you wish to receive an electronic version of NEHA News, please send a short message to: info@newenglandhemophilia.org requesting your copy.

NEHA Lauds Passage of Genetic Information Non-discrimination Act (GINA)

The New England Hemophilia Association lauds the passage of the landmark Genetic Information Nondiscrimination Act of 2008. The law protects individuals from discrimination in health insurance policies and employment on the basis of their genetic information. State laws, to date, have not adequately protected an individual's genetic information from misuse by health insurance companies and in employment. There had been no federal protection prior to the passage of this bill. Prior to its passage genetic information could be used to deny, limit or cancel health insurance, or to deny employment or promotions at work.

This protection will go a long way to eliminate concerns about the potential for discrimination in hiring and in availability and costs of health insurance, and encourages individuals to take advantage of genetic testing, new technologies and therapies, and participate in genetic research.

The New England Hemophilia Association would like to thank members of Congress and the Executive Branch for their careful consideration and thoughtful support of this measure. Its passage reflects an understanding that medical privacy is a paramount concern in this information age. Attempts like this to safeguard medical privacy reaffirm our belief that medical decision-making should involve patients, their doctors and their families with an eye towards securing the best, most appropriate care without obstacle.

What enactment of the Genetic Information Nondiscrimination Act of 2008 means:

Health Insurance

Amends the Employee Retirement Income Security Act of 1974 (ERISA) and the Public Health Services Act (PHSA) by prohibiting health insurance issuers from:

- Adjusting premiums on the basis of genetic information;
- Requesting or requiring an individual or a family member of an individual to undergo a genetic test;
- Using or disclosing genetic information for purposes of underwriting or determining enrollment eligibility.

This would apply to employer-sponsored group health plans, health insurance issuers, Medigap, and state and local non-federal governmental plans as well as others.

Protection under this law applies to everyone regardless of whether a person is currently sick, disabled or currently healthy. If found in violation of this law, fines would range from \$2,500 - \$500,000 and up to ten years in prison depending on the severity of the violation.

Employment

The second part of the legislation protects employees from having genetic information used against them by:

- Prohibiting employers, including employment agencies and labor organizations, from requesting or requiring genetic testing of an individual or his family;
- Prohibiting employers from using genetic information to make hiring or promotional decisions, or when determining eligibility for training programs.

Employers are prohibited from requesting, requiring, or purchasing genetic information about an employee or family member, except for the following legitimate reasons:

- For genetic monitoring of biological effects of toxic substances in the workplace;

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Be A NEHA Member— Join Now!

Our Membership Drive is Now Open for our 2009 fiscal year! It's time once again to show your support and sign up for membership in NEHA. If you're currently a member for 2008, thank you for being part of our organization, and please renew for 2009. If you're not yet a member, please consider joining us and supporting all the wonderful programs and events throughout the year. Family memberships are also now available.

To benefit our membership, this year we have added a two-tier fee structure for all NEHA-subsidized events. All current NEHA members may continue to attend events either free or with a small nominal fee, while non-members may attend for a higher fee. Your NEHA membership not only saves you money, but also supports our organization so we may continue offering new and innovative programming.

Our Annual Membership Drive ends October 1, 2008. Join us today and support the only NHF Chapter in New England serving our community. Sign up now for the upcoming program year, and show your support!

Note: By now, you should have received your membership application in the mail. Please contact NEHA if you haven't received it yet.

NEHA Board Seeks Members

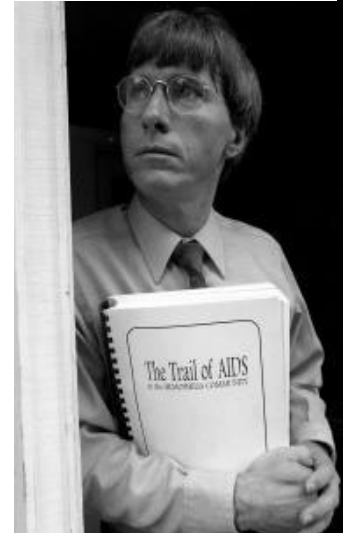
The NEHA Board of Directors has announced an open application period for individuals interested in applying for a seat on the Board. Call Kevin Sorge at the NEHA office at 781-326-7645 for more details and an application. The deadline to apply for consideration is September 10, 2008.

COTT Co-founder Dies at 62

Reprinted from NHF

Jonathan Wadleigh, a co-founder of the Committee of Ten Thousand (COTT), died on Wednesday, June 4, 2008, at Beth Israel Deaconess Medical Center in Boston, of liver cancer. He was 62 years old.

Wadleigh, along with Tom Fahey, founded COTT in 1989. Both men had severe hemophilia, and contracted HIV and hepatitis C from blood products. Wadleigh served as president until 1996. The grassroots organization was established to be the voice of the growing number of people with hemophilia who contracted HIV/AIDS through contaminated blood products.



"We shall never forget the tireless work he did to get a settlement for those impacted by HIV," said Gregory McClure, LSW, Rush Hemophilia and Thrombophilia Treatment Center in Chicago, IL. Wadleigh's experience as a political activist set the stage for his role as the lead plaintiff in a class action lawsuit that garnered a multimillion dollar settlement from the drug companies that had provided the contaminated products.

"I extend my heartfelt condolences to Jonathan's family and friends," said Val Bias, NHF CEO. "Jonathan was one of many men with hemophilia who took his infection as a call to action on behalf of the bleeding disorders community. He shall always be remembered as a leader and advocate for those infected with HIV."

Wadleigh had taken classes at the University of Massachusetts and Boston University. He worked in computer programming and marketing at several companies, hospitals and nonprofit organizations in the Boston area. He was a Brookline Town Meeting Member and served as president of the Boston Philatelic Society.

A memorial service was held for Jonathan Wadleigh on Saturday, June 14, 2008, at First Parish in Brookline. He is survived by his wife, Joanne Womboldt.

NEHA FAMILY WEEKEND at THE HOLE IN THE WALL GANG CAMP

Ashford, CT
October 17—18, 2008

Children ages 5-14 years who have hemophilia or type 3 vonWillebrands are invited to come with their families* and experience the magic of The Hole in the Wall Gang Camp.

(* - siblings of affected children may be any age)

This weekend is intended as an introduction to the Camp's summer program; admission criteria have been set by The Hole in the Wall Gang Camp, not NEHA.

Space is limited. Preference will be given to children who have not attended Hole in the Wall Gang's summer program before.

~ Watch your mail for a flyer with more info and RSVP deadline ~

Scholarships Available to NHF Annual Meeting

NEHA is pleased to announce that we will provide two scholarships to the NHF's 60th Annual Meeting to be held **November 13 – 15, 2008, in Denver, Colorado**. One scholarship will be awarded to a family living with hemophilia, the second will be awarded to a family living with vonWillebrand's disease.

Each scholarship will pay travel expenses (airfare and transportation to and from the airport), as well as one hotel room and meeting registration fees for two family members. Families are responsible for all additional expenses; however, most meals during the meeting are available free of charge.

ELIGIBILITY: this opportunity is available to families currently living in New England. Families whom NEHA has previously sponsored will not be eligible.

EXPECTATIONS: NEHA sponsored attendees are expected to attend educational and support sessions throughout the two-day meeting and will be asked to write about their experience for our chapter newsletter, NEHA News.

If you have questions or would like to apply for one of these scholarships, please call the office at 781-326-7645 or email info@newenglandhemophilia.org. Please indicate if your family member has hemophilia or vonWillebrand's disease. **The deadline to submit your name is Monday, August 11, 2008**. Winners will be drawn by lottery on August 12th and notified that day.

For more information on NHF's 60th Annual Meeting, please visit their website at www.hemophilia.org.

Q & A (Continued from page 5)

affected. Based upon the specific diagnosis and the mode of inheritance, the risk to the fetus can be predicted. These issues are best addressed by a knowledgeable genetic counselor (associated with some HTC's or hospitals).

Are there any concerns about using epidural anesthesia?

Dr. James: An epidural anesthetic provides pain relief during labor. To administer this medication, a catheter (thin tube) is placed into the epidural space, which is just outside the dura, or wrapping, around the spinal cord; repeated or continuous doses of a local anesthetic or narcotic pain reliever are then delivered through this catheter. In contrast, a spinal anesthetic provides anesthesia for cesarean delivery. Its administration involves a single injection of a local anesthetic into the spinal fluid, which is located beneath the dura and surrounds the spinal cord. Because bleeding in the epidural space or spinal fluid could compress the spine and cause paralysis, anesthesiologists usually refrain from giving a patient with a bleeding disorder an epidural or spinal anesthetic unless her factor levels are continuously higher than 50 IU/dL. If a woman needs pain relief while in labor and does not have levels that are continuously higher than 50IU/dL, narcotic pain relievers can be used instead of an epidural. If she requires a cesarean delivery, a general anesthetic can be used instead of a spinal.

Is there a risk for head bleeds in newborns? Is that risk increased if the baby has certain factor deficiencies? What can be done to decrease this risk?


Dr. Shapiro: There is a risk with hemophilia A and B that is increased in infants who are born to women who are unaware of their carrier status, or when delivery requires use of instrumentation (like forceps) or vacuum extraction. There are specific disorders in which intracranial hemorrhage (head bleeds) risk is increased, but these disorders are ones in which the mother is not affected, such as factor XIII deficiency.

Bleeding disorders affecting women, such as VWD type 1, are not associated with a significant rate of intracranial bleeding in newborns, but this information is largely based upon general information rather than prospectively gathered study data. Having a premature baby is associated with an increased risk of intracranial hemorrhage – the more premature the baby, the higher the risk of head bleeds. Regular prenatal care and avoidance of risk factors known to be associated with prematurity are especially important for pregnant women with bleeding disorders and for women who will deliver an infant with a bleeding disorder.

Women with VWD are five times more likely to have postpartum hemorrhage (excessive bleeding in the mother after delivery). How would a woman recognize her postpartum bleeding as abnormal? What can she do to try to decrease the risks?

Dr. James: “Abnormal” bleeding is soaking through a pad in an hour and continuing for more than an hour. During pregnancy, a woman’s von Willebrand factor levels increase. Women with mild type 1 may achieve levels above 50 IU/dL, the lower limit of the normal range outside of pregnancy, and may be able to be safely managed by their obstetrician / gynecologist at their local hospital. Women with type 3 VWD, type 2 VWD, type 1 VWD with factor levels less than 50 IU/dL or a history of severe bleeding should be referred for prenatal care and delivery to a center where, in addition to access to specialists in high-risk obstetrics, there also in an HTC or a hematologist with expertise in VWD. Laboratory, pharmacy and blood bank support is essential. The most important thing women can do to try to decrease the risks of postpartum hemorrhage is to make sure they have the right doctors and the right hospital. Most postpartum hemorrhage is caused by failure of the uterus to


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contract or tighten after delivery.

Women with bleeding disorders are particularly vulnerable to delayed postpartum hemorrhage, the type that occurs more than 24 hours after childbirth. This type of hemorrhage occurs in less than 1% of deliveries, but occurs in up to 25% of women with bleeding disorders. Normal blood clotting appears to be necessary to prevent delayed postpartum hemorrhage.

If a woman is being seen by a knowledgeable physician or hematologist, every effort will be made to assure that factor levels are sufficient to prevent bleeding from tears and incisions, and to prevent delayed postpartum hemorrhage.

If hemorrhage occurs, how should it be treated? Are there differences for the different types of VWD?

Dr. James: Factor levels should have been corrected before delivery, so the treatment of postpartum hemorrhage should be the same as for any woman with postpartum hemorrhage. The first response is stimulating

the uterus to contract. The next response is the administration of additional medications to cause the uterus to contract. In some cases, emergency surgery may be necessary to scrape the uterus (curettage), physically compress the uterus or ligate (tie off) blood vessels.

Hysterectomy is a last resort and is only necessary after one in 1,000 deliveries. In the case of massive hemorrhage, treatment with blood products may be necessary. Ideally, planning for pregnancy begins before conception. Women contemplating a pregnancy should be aware that they may be at an increased risk of bleeding complications. They should be aware of their own health status before getting pregnant. Prior to conception or during pregnancy, women may want to speak with a genetic counselor regarding the inheritance of VWD and with a pediatric hematologist regarding the evaluation of the infant after delivery.

Because of the possible need for transfusion during delivery, women who have not already been vaccinated should be immunized against hepatitis A and B.



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GINA (Continued from page 6)

- If the employer provides genetic services such as through a wellness program, with the employee's prior consent;
- For compliance with the Family and Medical Leave Act
- The purchase of commercially and publicly available documents or inadvertently requesting or requiring family medical history would not violate this title.

However, under each of the above exceptions a person's genetic information still could not be used or disclosed.

Privacy

Privacy protections currently established in the 1996 Health Insurance Portability and Accountability Act (HIPAA), Americans with Disabilities Act and the Civil Rights Act only touch on the issues raised by the misuse of genetic information. The Genetic Information Nondiscrimination legislation provides comprehensive and consistent protections against a person's genetic information from employers and insurers.

Val Bias (Continued from page 3)

eration. I have great confidence that the work between our two organizations will continue in a positive direction under Val's leadership."

Ann Forsberg, Region I administrator, has worked with the hemophilia community for over 25 years. She commented, "I have had the honor of knowing Val Bias for many years and am thrilled. Val has been a strong advocate for the bleeding disorder community both as a volunteer on local and national boards, committees, and as a professional lobbyist for quality treatment. I have witnessed his talent for fostering partnerships between the consumer organizations, the providers at the HTC's and governmental agencies, and removing barriers to successful collaboration. His years of experience and strong commitment will be a tremendous asset to the National Hemophilia Foundation."

Kate Muir, Board Member of the New England Hemophilia Association and Chair of our Advocacy Committee, notes how Val's efforts on that front have inspired so many of us. "Val's skills as a public speaker, a careful listener, and charismatic leader led him to Washington D.C. Val was both effective and unyielding in delivering a clear message to the FDA, CDC, and halls of Congress; a tragedy of the magnitude of the contamination of the blood supply must never happen again. Working closely with other national organizations including COTT and HFA, Val was part of the pivotal team of community leaders who were able to secure the passage of the Ricky Ray Hemophilia Relief Fund Act. His vigilance, personal story, and wonderful grin are ingrained in many people's minds."

As NEHA's Program Director, I appreciate how Val believes in the leadership capacity of youth. Val's commitment to uniting adults and youth in shared leadership will build a stronger community for all. I am also struck by how he has touched so many of us individually. Val is never too busy to answer a question or brainstorm an idea. He is approachable and generous with his time. As the mother of a teenager who has severe hemophilia, I have also learned from Val's positive approach to living his life to the fullest. He taught me to accept hemophilia, to deal with it, put it in its place, and get on with your life. How inspiring!

We are all looking forward to great things ahead of us and thank Val for his continued dedication to our community. Welcome to the Northeast, Val and Robin. Just one question from the New England contingent.....Red Sox or Yankees?

**NEHA's 18th Annual
Golf Tournament
& Auction**

September 8, 2008

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P.O. Box 985, Enfield, CT 06083
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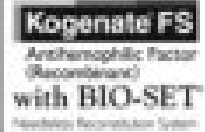




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For more information, please contact your local Bayer HealthCare Account Executive, Janice Yorke, at (203) 641-1455, or by e-mail at janice.yorke@bayer.com.



When you need us, Baxter will be there.

Through Therapies

Providing innovative recombinant factor, plasma-derived, and inhibitor management therapies highlights our commitment to choice and illuminates our investment in research and development.

Through Participation

Offering initiatives for patients, families, physicians, and nurses and supporting local and national organizations and community events, in addition to volunteering.

Through Progress

Improving current therapies and developing new and better ways to manage hemophilia A—innovations inspired by listening to you.

For more information on Baxter programs and services, visit www.thereforyou.com.



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Delivery Room (Continued from page 1)

right back to my same 'ol bleeding-disordered self. As predicted, this would occur within a week or two of delivery and would result in postpartum hemorrhaging.

Once I had a proper diagnosis, I was much better prepared for these bleeds. I learned some things I could do to have some control over my bleeding. For starters, I choose to breastfeed. Breastfeeding causes the uterus to contract, which slows bleeding. I also learned to limit my activities. Instead of trying to be supermom by making sure the house was spotless, laundry done, and the kids had neatly combed hair; I learned to let some things go. Curled up on my bed with a stack of children's books and puzzles and surrounded by smiling little faces meant far more than a clean house. It also meant a quicker recovery because it could help avoid major bleeding. Although these changes did help, my hematologist also prescribed Stimate for the postpartum bleeding. I do tend to get terrible headaches from this medication but it did curb my bleeding episodes.

As a mother of multiple children I would advise that every pregnancy and birth is different, just as every child is different. As a woman with a bleeding disorder, I advise you to be encouraged... Bleeding can be managed with frequent and consistent communication with your hematologist and good self-care.

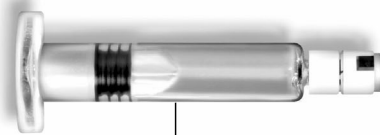
Leading Edge (Continued from page 4)

standing on a 4-foot by 4-foot platform high over the river (actually only one foot off the ground). They were doing great until the final sled ride bowled into them, and knocked everyone off the platform. The most amazing part of this was seeing the intense teamwork, sharing of ideas, and joining of resources that it took to make this happen. Leadership skills were evident throughout the exercise.



During a weekend full of activities and with lots of time to reflect, the group was challenged to think differently, to work together, to help one another, and to know when to ask for help. All in all, the NEHA teen group did themselves proud! Not only did they conquer every challenge, but they did so with style. They proved that together there is nothing that they can't accomplish.

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NEHA Annual Golf Tourney & Auction: *September 8, 2008.*
Cyprian Keyes Golf Club, Boylston, MA

Family Weekend at The Hole in the Wall Gang Camp: *October 17-19, 2008.*
Ashford, CT

National Hemophilia Foundation's 60th Annual Meeting: *November 13-15, 2008.*
Denver, CO

Annual Holiday Party: *December 7, 2008.*
The Village Club, Needham, MA

Maine Consumer Advisory Board: *Meets the second Thursday of every month.*
For more info, call Vicki Jacobs-Pratt at 207-786-5924.

NEHA Membership Drive: *July 1, 2008—October 31, 2008*
Call the office if a membership form is needed.