



Seeking Independence

By: Ann L. Schrader

I recently attended the Regional Hemophilia Treatment Center Conference and the National Hemophilia Foundation Spring Summit, which focused on health, transitions, and emergency preparedness.

Many RMHBDA members are pre-teens and adolescents, which is a specific developmental stage where these individuals seek independence as they separate from their parents and family. Friends, social networking, and music become important—reflecting a sense of self and identity. This life stage is an exciting time for everyone. Parents see the results of their care and parenting efforts take shape, helping their children move toward total self-care.

Recently, I watched a Robin bird build her nest on top of our satellite dish—a very savvy move—well protected from the weather, under the house’s eye and in a place where no cat, fox or other birds could get to her eggs or young chicks.

As time passed, I saw her sit on the eggs, warning me if I came too close. Then the eggs hatched and both mother and father birds took turns guarding the nest, finding worms, and feeding the chicks. One day I could easily see the chick heads, open beaks, and new feathers.

Finally, one young robin flew out of the nest, landing on our deck. Eventually, my husband had to help it back into the nest it flew too soon. Two of the three birds flew to a nearby tree. Mama bird sat next to them for quite a while, and then they flew to the ground. One bird remained in the nest and was finally pushed out by his mom—and off they all went. Mother Nature is so amazing.

I tell this story because it reminded me of raising my two children. It’s a process, and the teen stage is comparable to when chicks grow quickly, crowding

the parents out of the nest. The mother bird, who still tries to keep them warm, feed and protect them, knows they need to fly on their own soon!

For teens with a bleeding or clotting disorder, this can be a challenging time (as well for their parents). They don’t want to be defined by their illness and they’re right. They are so much more and have hopes and dreams for a bright future. Parents and other adults need to support their positive outlook.

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RMHBDA Has a New Web Site!

By: Eve Armour

It’s official! RMHBDA has a new web site at rockymountainhemophilia.org. It is refreshed with lots of updated information and an online form that allows you to register for the upcoming Family Camp in August, as well as a Patient Assistance Form. The web site also has an updated calendar, links to relevant resources and programs, and a listing of industry representatives. You can even download the current RMHBDA newsletter, submit comments or requests, and find driving directions to our office in Bozeman.

Please visit the new web site and let us know your first impressions. We hope you’ll find the site clean, informative, and easy to use. But please let us know if you spot any bugs or something doesn’t work the way you expect. There is always room for growth and we are committed to providing a web site that serves you and the bleeding disorders community.

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Thank You Members!

Many thanks to our new and renewing members. We appreciate you immensely! If you know anyone who may want to join RMHBDA, please use the enclosed membership form.

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Bleeding Disorders in Women

By: Krista Conger, PhD; Science Writer for Stanford University Medical School

Because bleeding from the reproductive tract is a naturally occurring event during menstruation and childbirth, women who exhibit menorrhagia, or excessive bleeding after their menstrual cycle, may have underlying diseases that are underdiagnosed. In order to address important issues related to the diagnosis and management of reproductive tract bleeding in women with bleeding disorders, a consensus conference was convened. Results are published in the July 2009 issue of the American Journal of Obstetrics & Gynecology.

The goals of the consensus conference were to highlight the problems these women experience and to provide clinical information and recommend strategies to guide practicing obstetricians and gynecologists. Where the international panel of experts in obstetrics, gynecology and hematology reached consensus, recommendations were made.

Von Willebrand Disease (VWD) is the most common inherited bleeding disorder. VWD results from a deficiency in, or a dysfunction of, von Willebrand factor (VWF), a protein necessary for normal platelet

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adhesion and protection of factor VIII (FVIII) from proteolysis in the circulation. The prevalence of menorrhagia in women with VWD is 74–92%.

Although the majority of women who present with menorrhagia do not have a bleeding disorder, the conference participants identified more than a dozen symptoms that suggest further evaluation, including menorrhagia since puberty, a family history of a bleeding disorder, and personal history of one, but usually several, of the following symptoms: nosebleeds (generally bilateral for more than 10 minutes), more than once in the past year; notable bruising without injury (and with bruises >2 cm in diameter); minor wound bleeding from trivial cuts lasting for more than 5 minutes; or prolonged or excessive bleeding following dental extraction.

A hematologic evaluation of the patient's platelet number and function and her coagulation factor profile should be assessed in collaboration with a hematologist. Meeting participants also agreed that hematologic evaluations should be repeated to confirm the diagnosis of a bleeding disorder.

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Writing in the article with her co-authors, Andra H. James, MD, Women's Hemostasis and Thrombosis Clinic, Duke University Medical Center, Durham, NC, states, "Obstetricians and gynecologists should be aware of bleeding disorders such as VWD, rare bleeding disorders and platelet disorders, which remain underdiagnosed in women with menorrhagia and potentially in other cases of abnormal bleeding such as postpartum hemorrhage. Clues, including a family or personal history of bleeding events, should provoke suspicion of an underlying bleeding disorder. Responding to these clues facilitates collaboration among obstetrician–gynecologists and hematologists that could lead to a decrease in the diagnosis of "idiopathic" menorrhagia and allow more effective management of bleeding events."

Obesity and Bleeding Disorders

By: Ann L. Schrader

Did you know that in 2000, 15 to 20% of Montana and Wyoming residents were obese? Today, 20-24% of adults in these states are obese. This article will briefly examine ways we can reverse this trend for both ourselves and our children.

At the NHF Spring Summit, we focused on how obesity affects children and youth with hemophilia and bleeding disorders. In a 2008 study conducted by the Center for Disease Control, 17.4% of this age group is obese—1.1% more than the rest of the population.

For people with hemophilia and bleeding disorders, reasons to maintain a healthy weight include:

- decreases amount of factor needed;
- lessens long-term joint disease;
- reduces stress on joints;
- lowers health care costs.

The keys to maintain a healthy weight include:

- Be active at least two times a week; 150 minutes of moderate exercise and 75 minutes of rigorous muscle strengthening.
- Choose healthy foods and be watchful of your calorie needs: fruits, vegetables, whole grains, fat-free dairy, lean meats, poultry, and fresh eggs and nuts.
- Stay away from saturated fats, trans-fats, cholesterol, added salt and sugar.

See: "Obesity and Bleeding Disorders" on page 8



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Eating Right

By: Ann L. Schrader

At the NHF Spring Summit conference, I was shocked to learn that obese children and adolescents are more than five times more likely to have a poorer health-related quality of life (QOL) than healthy children. In fact, their risk for a lower QOL is about equal to that of children undergoing chemotherapy for cancer, according to the results of a new study.

As parents, we are responsible to help our children (and ourselves) eat nutritiously, participate in regular physical activity, and maintain a healthy weight.

Avoiding health problems are an excellent reason to choose healthy foods. There are many contributing factors to obesity, but some are in our control:

- The best predictor of a child being obese is having a television in the bedroom—so keep the TVs out of everyone's bedrooms!
- Limit screen time (i.e., inactive DVD watching, texting, etc.). Two hours a day should be the maximum amount allowed.

- Increase physical activity, reduce portion size, and avoid power struggles over food.

Parents are in control of purchasing food, planning meals and snacks, and providing food. Kids get to choose from the food provided what and if they eat and how much. Remember, normal eating is flexible and should only be in response to real hunger.

Most importantly, keep loving your children and eating together as a family—without the TV on! For more information, visit our web site and www.rockymountainhemophilia.org/resources. Additional resources include:

- KidsHealth (<http://kidshealth.org/parent/emotions/feelings/bullies.html>)
- My Pyramid (www.mypyramid.gov)
- Ellen Satter Associates (www.ellynsatter.com/)
- The Body Positive (www.thebodypositive.org/)



RMHBDA Calendar

- **July 13:** Board Meeting Teleconference
- **July 19-24:** Hemophilia & Thrombosis Center University of Colorado Denver Summer Camp Rocky Mountain Easter Seals Camp facility
- **August 7-9:** Family Camp at Luccock Park Camp, MT.
- **August 8:** Board Meeting at Luccock Park Camp
- **September:** Emergency Preparedness Month
- **October 29-31:** NHF Annual Meeting in San Francisco
- **November 11:** Board meeting Teleconference

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Hemophiliac Happy to Live on the Active Edge

By: Gail Johnson; Health Features writer for Straight.com

Justin Tanguay works hard and plays hard. At 29, the former RCMP computer programmer is a heli-ski guide who also works on avalanche control. When he's not cruising down steep grades or mountain biking down equally treacherous terrain, he works as a contractor in the Kootenays, where he's building dozens of homes.

With his penchant for rough-and-tumble activities, the Ontario native might seem like any other hard-core outdoorsy type. But what's staggering about Tanguay's ability to conquer mountains—and his desire to live on the edge—is that he has hemophilia.

Contrary to popular thinking, people with the hereditary condition do not bleed more profusely than others. However, they lack certain proteins (called factors) that are necessary for clotting blood. So what would be a minor injury to anyone else could cause a hemophiliac to experience serious, even life-threatening, internal bleeding in the joints, muscles, tissues, and organs.

Among the symptoms in a baby is bleeding in the gums and tongue during teething. In older kids and adults, some of the signs are bleeding in the mouth after losing a tooth or biting the tongue, and blood in the urine.

Tanguay's mom is a carrier of the genetic disease, which is more common in men than women, so she knew there was a 50-50 chance her first son would acquire it. (Tanguay's younger brother doesn't have it.) But she wasn't about to let the diagnosis deprive her little boy of a fun-filled childhood.

"The doctor didn't encourage me to do any physical activity, not even ride a bike," Tanguay says on his cellphone. "My mom basically flipped him the bird and said I was going to do whatever all the other kids were doing. It was as if I should have been on a leash tied to my mom to make sure I wouldn't get hurt."

Tanguay got onto a bike and into ski boots at an early age, even going along with his elementary-school class for its weekly trips to the slopes. His parents were often by his side, teaching him to play it safe—but to still play.

"It was, 'Mountain biking is okay, but maybe it's not okay to jump six feet in the air off the deck,'" Tanguay explains. "It was about knowing my limitations and my capabilities. All my friends and coworkers knew about my hemophilia, so nobody ever egged me on to do something I didn't want to do. If I was mountain biking and there was an area where I could crash and get seriously hurt, I just wouldn't do that part.

"If I hit a tree with my knee, it would hurt just as much as the other guy; we'd both get internal bleeding, but mine isn't going to stop and his is."

There are two types of hemophilia—A, which is more common, and B (which Tanguay has)—and the condition as a whole is classified as mild, moderate, or severe. The extreme forms affect mostly men.

According to the Canadian Hemophilia Society, there are about 2,500 with hemophilia A and roughly 500 with type B.

Tanguay's active lifestyle hasn't been without mishaps. As a child, he regularly had to go for three-day stays at the hospital, where he'd receive blood transfusions.

But treatment has come a long way since he was a kid. What used to take 72 hours in hospital now can be done in 15 minutes in his own home, Tanguay says, referring to the freeze-dried concentrates of clotting factors that he can administer himself intravenously. He's usually back up and at 'em within a day.

Tanguay—who says he skis about 150 days a year and has guided snowcat-skiing expeditions in the Selkirk Mountains and led three-week-long ski trips in Alaska—says that what hasn't changed much is so many misconceptions about the condition.



See: "Active Life" on page 8

From: "Active Life" on page 7

As a result, he doesn't tell most people right away that he has hemophilia.

"There were times when I'd go for a job on a construction site and they'd say, 'Here's a mop.' I'd restrain myself from telling people until they could see what I could do.

"As hemophiliacs, we're big bleeders, but we know how to handle our situations, and as adults we know our capabilities," says Tanguay, who was declared a "hemophilia hero" by the World Federation of Hemophilia on last month's World Hemophilia Day. "I still try to push the limits within a safe realm.... When people meet people with hemophilia, they instantly judge them. Ask them about it instead. Really talk to them and ask about their situation and their case."

In the late '70s and early '80s, Tanguay says, hemophilia was often hush-hushed because of the tainted-blood scandal, in which viruses like HIV and hepatitis were spread through blood products.

Hemophilia "was a bad word", Tanguay says, quickly adding that he feels completely safe using the blood products available today. In the early 1990s, safer concentrates were developed; they're either purified with monoclonal antibodies or genetically engineered.

The Canadian Hemophilia Society encourages hemophiliacs to get regular exercise. Physical activity helps keep the bones and joints strong, and being in good shape can help diminish the number of bleeding episodes.

The Society categorizes different sports according to their risk factors on its Web site. Golf, tennis, and swimming are low-risk, for instance, while

hockey, in-line skating, and alpine skiing fall in the high-risk zone.

For Tanguay, it could all be condensed into the words of that B.C. Lottery Corporation motto: "Know your limit; play within it." He plans to keep on skiing, within bounds, of course—the mountains' and his own.

From: "Obesity and Bleeding Disorders" on page 3

According to the CDC, "When it comes to weight loss, there's no lack of fad diets promising fast results. But such diets limit your nutritional intake, can be unhealthy, and tend to fail in the long run. The key to achieving and maintaining a healthy weight isn't about short-term dietary changes. It's about a lifestyle that includes healthy eating, regular physical activity, and balancing the number of calories you consume with the number of calories your body uses."

Staying in control of your weight contributes to good health now and as you age. See <http://www.cdc.gov/healthyweight/index.html> for further information about maintaining a healthy weight and to use the BMI calculator

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As parents, we know the dangers that lurk...our job becomes one of asking open-ended questions of our teens, helping them own their disorder, while becoming independent. I know, much easier said than done, but we have lots of great role models!

Visit our website at www.rockymountainhemophilia.org/Programs/Transitions for more information on transition steps toward independence.