Keep Moving: Sports & Activities for Patients with Bleeding Disorders

Feedback from the 2010 Patient Survey (see accompanying article on page 3) indicates that many patients aged 12 to 22 feel that their bleeding disorder restricts their ability to participate in sports and other physical activities. Some believe that the only safe exercise for patients with bleeding disorders is swimming. While swimming is an excellent activity for many of our patients, it is not the only option. The following article lists popular activities and sports, from those recommended for individuals with bleeding disorders to those that should be avoided.

The many benefits of exercise include strengthening bones and muscles to stabilize joints and help lower the frequency and severity of joint bleeds, maintaining a healthy weight, improving balance, reflex and coordination and improving overall fitness.

There are also psychological and social benefits to regular exercise. Exercise can increase relaxation, improve self esteem and may increase feelings of social acceptance and inclusion. In addition, participating in recommended activities and sports is fun!

The challenge for patients with hemophilia or other bleeding disorders (or patients who have a clotting disorder that requires anti coagulation medication) is to find activities that provide both physical and psychological benefits without risk of serious bleeding episodes. High contact sports (Category 3) increase the risk of the following injuries: joint bleeds, muscle bleeds, joint damage (in “target” joints already affected by repeated bleeds) and body collision or contact injuries ranging from minor and serious bruising (hematomas) to life threatening bleeds involving the head, neck, chest or abdomen.

For many children and young people, being excluded from high risk sports such as football can be very discouraging. Because of the significant risks associated with the decision to play some sports, we encourage you to discuss this issue with us by calling CCBD or mentioning exercise at your next clinic visit. We can help you find healthy exercise options customized for your unique situation. We want all of our patients to be active and fit. Please contact us with any questions you have about making healthy exercise choices.

Sports Activities: See page 2.
Sports Activities

Risk of injury with sporting activities should be taken into consideration if you or your child has one of the following:

- A mild, moderate or severe bleeding disorder
- A clotting disorder that requires anticoagulation (aspirin, coumadin, lovenox)

Some of the more popular sporting activities have been divided into three categories so that you are able to identify which activities are most appropriate to participate in.

Category 1
Most individuals with either a bleeding disorder or a clotting disorder that requires anticoagulation can participate safely in these activities.

- Bicycling
- Frisbee
- Hiking
- Swimming
- Fishing
- Golf
- Tai Chi
- Walking

Category 2
The physical, social and psychological benefits often outweigh the risks. The majority of sports fall into this category. If you have moderate or severe hemophilia, or moderate or severe von Willebrand disease, consider prophylaxis prior to participating in these activities.

- Baseball
- Bowling
- Gymnastics
- Ice skating
- Mountain biking
- Roller blading
- Rowing
- Skateboarding
- Skiing (cross country)
- Soccer
- Track and field
- Water skiing
- Basketball
- Diving (recreational)
- Horseback riding
- Karate/Kung Fu Tae Kwon Do
- River rafting
- Roller skating
- Running/Jogging
- Skiing (downhill)
- Snowboarding
- Tennis
- Volleyball
- Weight lifting

Category 3
The risks outweigh the benefits. The nature of these activities makes them dangerous, even for those without a bleeding disorder.

- Boxing
- Football (tackle)
- Lacrosse
- Racquetball
- Rugby
- Diving (Competitive)
- Hockey (field, ice, street)
- Motorcycling/Dirt Biking
- Rock climbing
- Wrestling

Please remember that participating in some of these activities, even the safer ones, requires protective gear such as helmets, wrist pads, elbow pads, kneepads, etc. Participate in sporting activities safely!
We would like to thank all of you who participated in the 2010 Patient Questionnaire through interviews with our CCBD social workers. Your answers give us important information about ways we can improve both your medical care and your access to medical care. Based on the comments of the 244 new patients and the 165 previously diagnosed patients who participated in the 2010 survey, we are making changes to our processes to better meet your needs. Below are some of the findings from the 2010 survey responses:

- Of the 165 previously diagnosed individuals (or their parents) who participated in the questionnaire, 163 (99%) reported that they were very satisfied with the medical care they were receiving through CCBD for their bleeding or clotting disorder (the remaining two individuals reported moderate satisfaction). However, in addition to being quite satisfied with their medical care, a number of patients had very useful suggestions about changes we might make to improve our services. Some of the suggestions were: speed up the clinic process (this was the most popular suggestion) and have more hours, days of the week and locations available for clinics. One mother suggested that we have a place for parents with children with hemophilia to meet to socialize during the clinic. Currently, we do not have enough staff or enough rooms/times available at Children’s Hospital of Wisconsin to make these changes. However, we will keep these concerns in mind as we plan for the future. There were also a couple of concerns about staff turnover and delays in reporting back patient lab values. We hope we have resolved these, but please contact us if you have further concerns in these areas. The questions about suggestions for improvement also elicited a lot of comments about positive changes at CCBD, including the addition of a Home Care Program which, under the direction of Dr. Moss, provides inhome education and training on infusions of factor product and also provides some infusions for patients not able to self infuse. “Dr. Moss was very helpful.” Other positive comments included: “level of care is extremely high”, “wonderful clinic”, “far exceeds expectations” etc.

- Most (159 or 96%) of the 165 previously diagnosed patients or parents felt they had received enough information regarding their diagnosis. The six respondents who didn’t were provided with more information.

- The next two charts represent the percentage of patients from different age groups and parents of patients reporting the amount of physical impact and emotional impact the bleeding disorder has on daily activities.

**Impact of Disorder**

The impact that a serious bleeding disorder has on the daily activities of the individual patient (over the age of 12) or the family of a patient up to age 12 does not vary much by age. For the total group, 56% (85 out of 153 responding) reported almost no physical impact, 37% (57) reported some physical impact and 7% (11) reported a lot of impact. The percentage reporting a lot of impact has decreased over the years. For example, in 2009, 19% of patients over the age of 23 reported a lot of physical impact. It may be that our efforts to help patients successfully manage their own hemophilia care have helped to contribute to this decrease in the reported physical impact of the disorder.
**Emotional Impact of Disorder**

For all age groups, 7% of patients reported that the emotional impact of their disorder was positive. A slightly larger group (14%) reported a negative emotional impact, usually related to bleeds and/or infusions. The majority (79%) indicated no emotional impact. Compared to previous years, patients this past year indicated comparatively less negative and more positive emotional impact. In 2009, an average of 28% of patients indicated a negative impact and 6% a positive impact. Again, we can only speculate why there has been a general improvement in the emotional status of our patients; but perhaps the emotional weight of HIV concerns have diminished somewhat. It is also possible that patients, with the assistance of CCBD staff, have come to anticipate a more normal life and lifespan.

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<th>Impact</th>
<th>Ages 23+</th>
<th>Ages 12-22</th>
<th>Parents</th>
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**Sports and Activities for Patients with Bleeding Disorders**

A new question this year was directed to the 12-22 age group. The question asked if there were certain sports that the patient felt he or she could not play because of their diagnosis. Most of the 43 respondents (77%) felt that there were sports that they could not play, such as contact sports in general: football, boxing, wrestling, hockey, soccer, basketball and/or baseball. Four patients indicated that they felt that swimming was the only permissible activity (see article on front page).

- Most patients or parents of patients (92%) were aware that CCBD should be contacted if the patient goes to an emergency room. This is to make sure that a CCBD hematologist is immediately involved in the treatment plan. Most patients also indicated that their primary medical doctor and dentist had sufficient knowledge about their disorder. If you feel that your doctor or dentist does not have enough information, please contact CCBD for assistance.
- Given the severity of their disorder, it is important to note that only 21% of patients 23 and older report being unemployed (mostly due to disability). Fifty-one percent are employed full time, 11% part time, and 17% are retired.
- A major barrier to access to medical care is inadequate health insurance. Although 92% of our patients indicate that they have adequate insurance, they are still concerned about maintaining their insurance and about high out-of-pocket costs, including large co-pays for costly factor product and other medications, physician visits and clinic appointments. We do know that a small percentage of CCBD patients do not attend clinic regularly and/or do not follow treatment recommendations because of cost concerns. If you share these concerns, we urge you to contact the CCBD Financial Counselor at 414-257-2424 for assistance with these issues.
- Seventy-eight percent of the 12-22 age group reported weekly exercise: 57% said they exercised 4-7 times per week, 22% 1-3 times per week and 22% not at all. For the 23 and up age group, 72% reported exercising, up from 49% in 2007. Of those reporting exercise, 37% exercised 4-7 times per week and 35% said they exercised 1-3 times per week, while 28% did not exercise. The respondents again reported a wide range of activities: walking, swimming, lifting weights, working out at a gym, basketball, biking, tennis, volleyball, racquetball, gardening, using an elliptical machine, water aerobics, yoga, Pilates, soccer, etc.
- An important issue for young people with bleeding disorders is choosing an occupation that will both provide adequate insurance to cover the very expensive factor products used to treat many of the disorders and also not be too demanding physically. This year when the 12-22 year olds were asked about their career plans, more than half had already chosen a career. Some of the choices mentioned this year were: medicine/hematology/radiology/phlebotomy, forensic scientist, music, trucking, welding, PE teacher, criminal justice, real estate, printing, manufacturing, sports trainee, lawyer, IT, business manager and architect.
- Because of the unique career challenges facing young people with bleeding disorders, one of the questions asked this past year addressed how much young people understood about the challenges and whether or not parents were discussing those challenges. In the 12-22 age group, 35% knew that both insurance issues and the physical demands of a career need to be considered; 26% did not know about either concern and the rest knew about only one of the issues. In the group of parents, only 22% had begun to discuss these issues with their children. Some of the children were clearly too young for this discussion, but at about age
We’d Like to See You When You Turn 18

Turning 18 marks an exciting time in your life. You may be graduating from high school and looking forward to college, technical school or a new job. You may be moving into your own apartment, ready to begin your life as an independent adult.

It is also time to take ownership of your health and learn to manage responsibilities that were previously handled by your parents. One of those responsibilities is managing your bleeding or clotting disorder.

Now that you are an adult, we would like to see you in clinic to make sure you have all the information you need to take good care of yourself through the coming years. For patients who have hemophilia or type 2 or 3 von Willebrand Disease, we will automatically schedule a clinic visit for you. For patients with other bleeding or clotting diagnoses who are age 18 or older and have not yet scheduled a clinic visit, please call us at (414) 257-2424 so that we can set up a visit at a time that is convenient for you.

6 parents can begin to help direct their children toward appropriate careers. The CCBD social workers are available to help with this discussion.

• In the 12-22 age group, 59% are doing their own infusions after certification by CCBD (17 of the 29 young people with a severe or moderate diagnosis) and 48% are completing the required calendar documentation of their bleeds and infusions.

• We also asked families with young children with bleeding disorders if they felt they had sufficient contact with other families in the bleeding disorder community. Thirty-eight percent indicated sufficient contact (up from 14% in 2007), 8% would like more, and 43% did not have much contact but were fine with that. For those families seeking more contact, we provided mentoring families if they chose as well as information about Great Lakes Hemophilia Foundation, the support and advocacy organization for people with bleeding disorders.

• Our survey again included patients with clotting disorders as well as carriers. Their satisfaction responses are included with the bleeding disorder patients.

• Of the 244 new patients surveyed, 96 (39%) were referred by a specialist (41 by an ENT specialist, 12 by a neurologist, 8 by an OB/GYN specialist, 5 by other hematologists, 3 by a cardiologist, 7 by a GI specialist, 4 by adolescent medicine specialists, 3 were referred by the preoperative clinic at Children’s Hospital of Wisconsin, and 7 were social services referrals. The orthopedic, dental, renal, transplant, pulmonology, cranio-facial, migraine and pathology departments each referred one or two patients to us. Seventy-eight (32%) of patients were referred to us by their primary medical provider, and 20 (8%) came to us because of a family member, usually a family member who had previously been diagnosed by us.

The information we gather from the patient survey is essential in helping us structure our clinic and other processes to best meet the needs of our patients. For this coming year we will be giving patients an opportunity to respond anonymously to questions about barriers to attending comprehensive clinic, as well as satisfaction feedback and suggestions for improvement. We really appreciate the time and thought you put into answering our questions this past year. Your suggestions for improvements and any other feedback about our services are always welcome. You can call Jane Volkman or Sheri Robbins at 414257-2424 or toll free at 888-312-2223 anytime throughout the year with additional comments or with questions about the survey.
**BMI: What is Your Quetelet Ratio?**

Body mass index, or BMI, is a simple tool used to estimate body fat, based on a person’s height and weight. It is calculated by dividing your weight in kilograms by the square of your height in meters. Originally developed in the mid-nineteenth century by Belgian Adolphe Quetelet to study the average body fat of a large population, it is currently used to calculate if an individual’s weight is under or over the healthy normal range.

Being overweight can increase risk for certain health problems such as heart disease, type 2 diabetes, high cholesterol, certain cancers, high blood pressure, sleep apnea, stroke and joint arthritis. For a patient with a bleeding disorder, being overweight or obese can aggravate the frequency and severity of joint bleeds in knees, ankles and hips, leading to increased pain, increased medication and factor use, and more recovery time. Extra weight puts more pressure on the joint, so those patients with existing joint arthropathy may suffer more frequent and intense pain.

There are several places online to calculate your BMI (and even a mobile phone app). While it is a helpful tool to assess your weight appropriateness, remember that it is not a diagnostic tool. For example, it is possible to have a BMI result in the “overweight” category but also to have an acceptable amount of body fat because muscle mass is denser than fat tissue (this is typically only seen in athletes). It is also important to note that children should use a BMI chart for children only. We recommend that patients discuss their weight with their primary care physicians to plan a healthy weight loss and exercise program.

For more information, you can visit the website for the Center for Disease Control: [www.cdc.gov/healthyweight/assessing/BMI](http://www.cdc.gov/healthyweight/assessing/BMI)

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**TIME FOR CAMP**

There are three summer camps located close enough to Wisconsin for CCBD patients to attend:

- Camp Warren Jyrch, Illinois
- Camp Courage South, Minnesota
- Camp Bold Eagle or Eagle Outpost, Michigan.

These camps offer fun and educational experiences for young patients (ages 6 to 17) living with a serious bleeding disorder. Camps can also help young patients learn to self infuse. Seeing their peers perform successful self infusions at camp seems to really help young patients, reducing their anxiety and improving self-sufficiency.

Great Lakes Hemophilia Foundation provides “camperships” (camp scholarships) for any patients who request help paying for camp. If you think your child would benefit from a week at camp, please call the CCBD social worker, Jane Volkmann, at (414) 937-6575 for assistance in registering your child at an appropriate camp.

Please note that application deadline for camperships is rapidly approaching on May 20, 2011. New to this year’s campership application is a section the child must answer about what they hope to get out of camp. Applications are available on GLHF’s website, www.glhf.org or by contacting CCBD.
HAVE YOU MOVED?
Please complete the form below and return to us at the Comprehensive Center for Bleeding Disorders, PO Box 2178, Milwaukee, WI 53201-2178. It is important that we keep our mailing lists current so that you can be sure to receive current medical information along with announcements regarding our special medical programs.

Patient Name: ____________________________

DOB: ____________________________

New Address: ____________________________

City, State, Zip Code: ____________________________

New Phone Number: ____________________________

New Dentist or Primary Doctor: ____________________________

Office Phone Number: ____________________________

Is this the address of patient’s:
MOTHER    FATHER    BOTH

HAVE YOU RECENTLY TURNED 18 YEARS OLD?
Check the appropriate boxes telling us how we may contact you and who we may speak with regarding your medical care and return it to us at the Comprehensive Center for Bleeding Disorders, PO Box 2178, Milwaukee, WI 53201-2178. Because you are legally an adult, CCBD cannot speak to anyone but you regarding your medical care without your authorization.

I authorize CCBD staff to:

☐ Contact me at my work phone number:

(Detailed messages will not be left)

☐ Leave a detailed message on my home phone/voicemail:

☐ I authorize CCBD staff to speak or leave information with person(s) in my home as follows:

Name / Relationship to Patient

Name / Relationship to Patient

WE WOULD LIKE YOUR INPUT

Remember, this is your newsletter. We welcome any requests you might have for future articles. Just give us a call and let us know of your ideas or suggestions. Or, just give us a call and let us know if you feel we are providing you with an informative newsletter.
BloodCenter of Wisconsin advances patient care by providing life-saving solutions grounded in unparalleled medical and scientific expertise.