



August, 2007

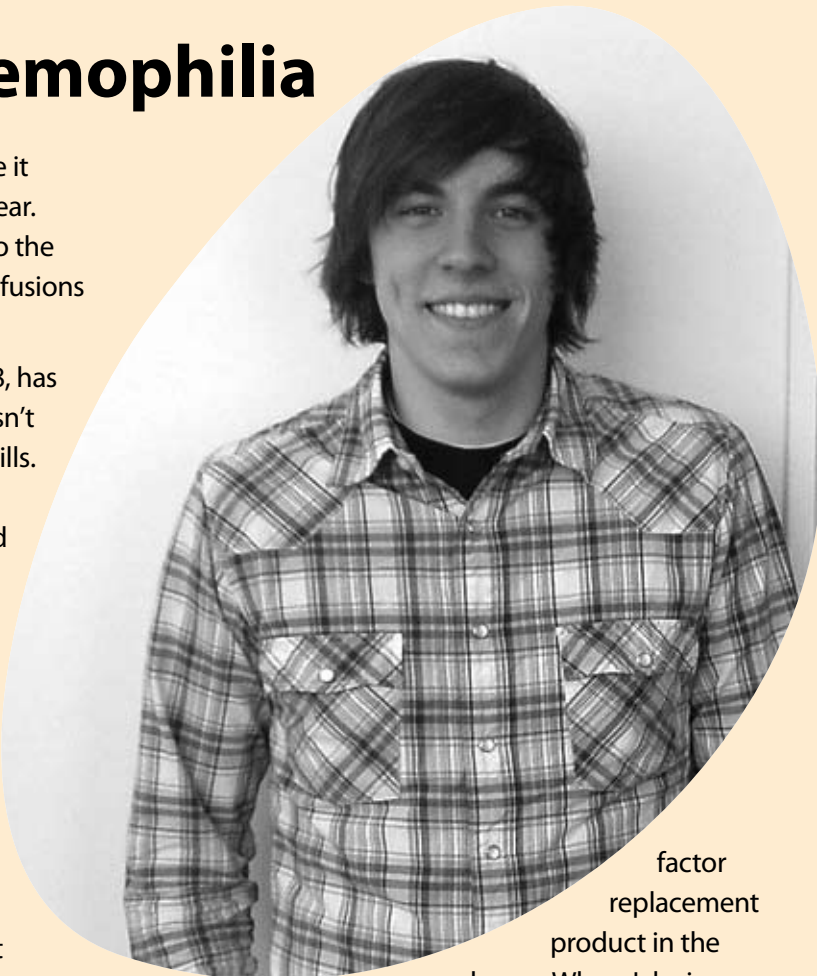
## Living with Mild Hemophilia

Jake really enjoys skateboarding, but decided to give it up after falls resulted in two big bleeds within one year. He says he stopped because of the hassle of going to the hospital three times a week for several months for infusions of factor replacement product to treat the bleeds.

Like almost all mild hemophilia patients, Jake, age 18, has not been trained in home infusions because he doesn't have bleeds often enough to keep up his infusion skills. And, like many other mild hemophilia patients, he finds determining when he is actually having a bleed that requires treatment difficult, simply because his bleeds are relatively rare.

Jake is an excellent student who will graduate this spring from Wisconsin Lutheran High School. In the fall he will attend UW-Madison, majoring in business. A National Honor Society member, he has a GPA of 3.8 and enjoys many extracurricular activities, including basketball and playing guitar to accompany the school choir. He also finds time to play guitar in two bands: Liv Kid (a rock band) that has performed at the Milwaukee Miramar Theater several times, and Shoot Down the Moon, a more "mellow" band that has done some recording.

Having hemophilia has not slowed Jake down, but it has certainly had an impact on his life. He finds it difficult to know when he is having a bleed that will require treatment, and delaying treatment often means a longer bleed that will require more time and product (and therefore cost) than a bleed that gets immediate treatment. Patients with a severe form of hemophilia generally know when they are having a bleed, and are able to start the treatment process immediately since most are trained to self-infuse and have



factor  
replacement  
product in the  
home. When Jake is

injured, he or one of his parents calls CCBD for treatment recommendations. In addition to factor replacement product, he can also use Stimate and DDAVP for some bleeds (see accompanying article).

Jake has a very positive attitude about having mild hemophilia, but feels that he has fewer options than other young people his age because of his diagnosis. Obviously there are some sports and activities he cannot participate in. Because of the necessity of maintaining insurance (see accompanying insurance article), he cannot take "off" for

*Continued on pg.3*

# When to Call Your Treatment Center

## for Patients with Mild Hemophilia

Patients with mild hemophilia are more likely to have bleeding in soft tissue and muscle rather than in their joints. It is often difficult to recognize bleeding events that need treatment and to know when to call the Hemophilia Treatment Center. Below is a summary of the symptoms associated with different bleeds and tips on when to call your treatment center.

### Recognizing a Bleed

- **HEAD/INTRACRANIAL:** Signs of an intracranial bleed include nausea, projectile vomiting, lethargy, loss of appetite, and change in behavior. Call your treatment center IMMEDIATELY as you may need to be transported to the closest ER for FACTOR INFUSION FIRST, and evaluation.
- **ABDOMINAL:** A large amount of blood can accumulate in the abdominal space, and this can be a life-threatening emergency. Some signs of an abdominal bleed include abdominal pain, inability to stand up straight, and paleness due to blood going from the vascular system into the abdominal cavity. Call your treatment center IMMEDIATELY as you may need to be transported to the closest ER for FACTOR INFUSION FIRST, and evaluation if an abdominal bleed is suspected.
- **MOUTH/GI:** Mouth bleeds can start and stop, due to the saliva breaking down the clot that is trying to form in the injured area. Mouth/GI bleeds may need a factor infusion or DDAVP/Stimate first, then several days of Amicar treatment. It is also important to avoid hard or sharp foods if there is an area of injury in the mouth, until it is completely healed.
- **MUSCLE:** Muscle bleeds are often painful. Signs of a muscle bleed include pain, firmness when feeling the muscle, refusing to use or move the muscle, redness, warmth, and swelling.

- **SOFT TISSUE:** Soft tissue bleeds can consist of bruises and also hematomas (bruises with a bump). Hematomas can cause discomfort. Minor soft tissue bleeds can also cause redness and warmth.
- **JOINT:** Bleeding into a joint causes significant pain, refusal to move the joint, redness, warmth, and swelling. Blood in joint spaces causes damage to the synovium (joint lining). Repeated joint bleeds can cause serious joint destruction, ultimately leading to arthritic changes. Joint bleeds should be treated as soon as possible in order to minimize damage to the synovium.

### Reasons to Call Your Treatment Center

- You suspect a head, abdominal, joint, or muscle bleed
- Bleeding that won't stop with pressure and routine first aid
- Surgery or dental procedures (other than routine cleanings)
- Broken bones or other fractures
- Sprains
- Bruises that have lumps underneath (hematomas) that limit range of motion or cause significant pain
- Significant swelling
- Decreased range of motion or significant pain after trauma (especially if it does not respond to cold compresses and/or Tylenol)
- Anytime you have questions, concerns, or think you might be having a bleed.

## *Jake (Continued from cover)*

a year to travel as some of his friends can. He has to stay in school to keep insurance through his parents, and then he will have to find employment with a company large enough to provide him with adequate health insurance. Being a self-employed rock musician is probably not a realistic option for him.

Fortunately, Jake is a bright, motivated young man who has accepted the realities of his diagnosis and is moving on with his life. We'll check back with him in a few years to see what direction his life has taken.

## ***School Days! School Days!***

*Yes, school will be back in session all too soon. A school or day care in-service is important for our patients with severe or moderate bleeding disorders. These in-services (or education sessions) are for teachers, school nurses, and office administrators. We cover your child's bleeding problem, what to do in case of an emergency, and also basic first aid techniques. A folder with information specific to your child will stay at the school and serve as a reference guide for all staff who may be working with your child.*

*Please contact us as soon as possible so that we may begin to arrange for an in-service at your child's school before the school year actually begins. It is important to have at least one parent and the child (if they are old enough to comprehend the in-service) present at the in-service. The typical in-service will take an hour to complete. Call (414) 257-2424 and ask to speak with a nurse coordinator if you would like an in-service at your child's school.*

## ***Great Lakes Hemophilia Foundation: Upcoming Programs in 2007***

August 18, Saturday, from 12:00pm – 3:00pm  
Couples Get Together \* Charcoal Grill  
15375 West Greenfield Avenue, New Berlin.

September 29, Saturday  
Walk with the Animals at the Milwaukee County Zoo \*  
Walk through the zoo and learn ways to live a healthy lifestyle.  
Specific details to follow.

\* You must register for these programs. To register for programs or for more information, please call 414-257-0200 or 888-797-4543

# Insurance Issues and Mild Bleeding Disorders

David Linney

Individuals with mild hemophilia and Type I or II von Willebrand disease sometimes have problems knowing how to use their insurance when they need care related to bleeding disorders. This happens because these needs are usually very infrequent. Crisis insurance situations for individuals with mild bleeding disorders can be avoided. The key is to understand insurance coverage and know how to use it before you need it.

## **First determine what care you need or may need; then understand your insurance coverage**

### **“REGULAR” CARE**

#### ***Bleeding Disorder Evaluations***

- Obtain any required HMO authorizations before the evaluation.

#### ***Prescriptions for Stimate, DDAVP, Amicar or Factor Product***

- Verify specific prescription coverage through your drug plan or health plan in advance of when you need a prescription filled. Find out if you are required to use a specific pharmacy.
- Know how long it takes to fill a prescription. Many pharmacies do not stock Stimate or Amicar and require 24 hours (or more) to fill an order.
- Many drug and health plans must pre-authorize coverage for a prescription of Stimate or Amicar. A bleeding disorder diagnosis usually needs to be confirmed.
- Don't run out of your prescriptions or let your prescriptions expire before getting a refill.

### **SPECIALTY CARE**

#### ***Bleeding Episodes that Require Care in the Emergency Room or Infusion Clinic***

- Understand your health plan coverage for emergencies. Talk to CCBD and your health plan. Find out if you need to go to a specific hospital. Understand any reporting responsibilities you have.
- If you have an HMO, discuss the management of emergency bleeding disorder care with your HMO primary care physician beforehand.

- Never delay treatment because of insurance. Go straight to the hospital emergency room.
- After your emergency treatment, call your HMO (or managed care health plan) as soon as possible to ask about reporting or authorization requirements.
- If you need additional treatments after your Emergency Room visit, call your HMO (or managed care health plan) about the need for a new authorization.

#### ***Bleeding Disorder Care for Dental Surgeries/Procedures***

- Fill prescriptions in advance.
- Health insurance and dental insurance are separate and don't coordinate benefits. Dental insurance is responsible for most traditional dental care (that is not accident related). Health insurance will usually pay for bleeding disorder treatments for dental procedures, so long as billing for such services lists a bleeding disorder diagnosis.

#### ***Bleeding Disorder Care for Medical Surgeries/Procedures***

- Fill prescriptions in advance of a surgery or medical procedure.
- If you need factor product administered at home by a home care agency nurse after surgery, note that factor product is often supplied by a provider other than the home care nursing agency. So coverage for factor product and home care nursing would both need to be verified and coordinated. Note that hospitals have discharge planners that help with this coordination. Also, if you have an HMO, the HMO typically will need to authorize these services.

For questions, please call CCBD at (414) 257-2424 or toll free at (888) 312-2223.

## CCBD Doctors Listed Among Best in Nation

We are proud to announce that CCBD physicians **Dr. Joan Cox Gill** and **Dr. Kenneth D. Friedman** have been listed among the *Best Doctors*® in America for 2006.

Each year, Best Doctors, Inc. surveys thousands of physicians to identify the most skilled and respected specialists in the nation. The result is a list of doctors selected by their peers as the very best at treating complex medical conditions. The individuals on the *Best Doctors*® List represent the top 5-percent of the country's practicing Board-certified physicians.

Dr. Cox Gill has served as the treatment center's Medical Director since 1984. She has been listed among the Best Doctors in America every year since 1996. Dr. Friedman has been the Medical Director of the Hemostasis Reference Laboratory since 1997. Also making the list for 2006 was Dr. Gilbert



Case White, II, Executive Vice President and Research Director for the BloodCenter's Blood Research Institute.

For more on the nation's Best Doctors, visit [froedtert.com/bestdoctors](http://froedtert.com/bestdoctors).

### SATURDAY SEMINAR – Fall 2007

**PORTS & PROPHYLAXIS – have your questions about prophylaxis and the use of ports answered and watch a live demonstration**

**Presented by Joan Gill, M.D.  
Director of the Comprehensive Center  
for Bleeding Disorders**

Date: TBA  
9:00-11:30 a.m.  
Blood Research Institute  
8739 Watertown Plank Road, Milwaukee

9:00-9:30 Registration & Refreshments  
9:30-10:30 Presentation  
10:30-11:30 Questions

To pre-register or to get additional information about the seminar, please call Jane Volkmann at (414) 937-6575 or toll free at (888) 312-2223.

We look forward to seeing you there!  
Refreshments will be provided courtesy of Great Lakes Hemophilia Foundation.

### ON THE WEB

The CCBD webpage is hosted on the BloodCenter of Wisconsin site: [www.bcw.edu](http://www.bcw.edu).

You can go to the main page and follow the tabs for : **BLOOD PRODUCTS & MEDICAL SERVICES** and then **COMPREHENSIVE CENTER FOR BLEEDING DISORDERS**.

(Or you can type "**CCBD**" in the search field at the top right corner.)

## **Blood Research Institute/ CCBD/Wauwatosa Donor Center Grand Opening**

*On Monday, September 17, the 60th birthday of the organization, BloodCenter of Wisconsin will hold a grand opening celebration for its newly remodeled and expanded facility on the grounds of the Milwaukee Regional Medical Center. The facility, located on the corner of 87th and Watertown Plank Road houses the Blood Research Institute, the Comprehensive Center for Bleeding Disorders (CCBD) and the Wauwatosa Donor Center. The renovation included the addition of 36,000 square feet of new research space, new office space for CCBD staff and allows the donor center to address increased capacity needs.*

*Patients and families of the CCBD are invited to attend the event which includes a ribbon cutting ceremony at 11:30 a.m. and an Open House with guided tours and refreshments from 11:45 to 2 p.m. If you would like to attend please RSVP with Jane Volkmann at 937-6575.*

### **Ask CCBD**

*Do you have a general question that you would like to address to a member of the CCBD staff, including one of the hematologists who works with our patients? To have your question considered, please visit our page on the BloodCenter of Wisconsin website ([www.bcw.edu](http://www.bcw.edu)) and click on "Ask CCBD." We will pick at least one question to answer in every issue of CCBD Connections.*

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### **WE'VE MOVED!**

*The Comprehensive Center for Bleeding Disorders offices are in the Blood Research Institute (BRI) of BloodCenter of Wisconsin, located on the Milwaukee Regional Medical Center campus. Due to construction on campus, parking is limited. CCBD has moved to our new space inside the BRI. If you have any reason to visit our office, please call ahead (414) 257-2424.*

*We see patients at Children's Hospital of Wisconsin in semi-weekly clinics. These clinics are held on the second floor of the hospital. If you have an appointment in either our Monday or Thursday clinics, please look for specific directions in your appointment letter. These will include directions to the campus, the current parking situations, and the easiest way to get to our clinic once you are inside the hospital.*

## 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

Patient Name: \_\_\_\_\_

DOB: \_\_\_\_\_

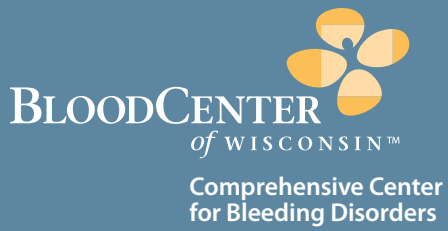
Patient Signature \_\_\_\_\_

Date: \_\_\_\_\_

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## 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.*



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***BloodCenter of Wisconsin advances patient care  
by providing life-saving solutions grounded in  
unparalleled medical and scientific expertise.***

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