



June 2009

## Transitions

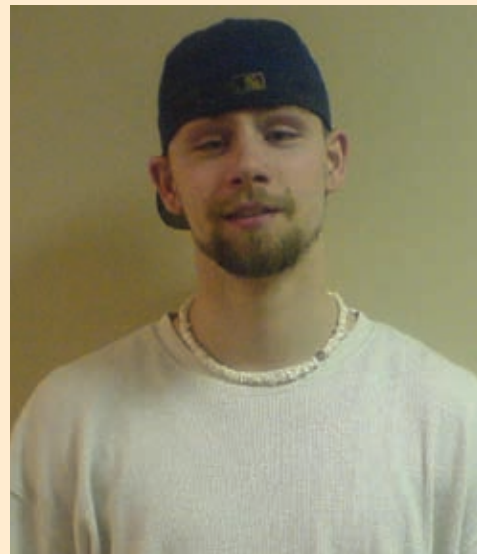
The transition to full adulthood is difficult for many young people. But for those with a bleeding disorder, this normal rite of passage is even more challenging, and the stakes are much higher. Young people with bleeding disorders need to be knowledgeable about their medical care, their finances, and about complicated insurance issues. Fortunately, there are many paths to successful independence, as demonstrated by our two featured patients.

### *JD Emmerich*

J.D. Emmerich did not know he had an aptitude for accounting until he aced a required accounting class (an 8:00 AM class with a “difficult-to-understand” instructor). J.D., who is 22 years old and has severe hemophilia, admits that he did not particularly apply himself in high school. He was more focused on sports than academics. He wanted to play football or be a hockey goalie, but eventually accepted that, due to his hemophilia, he needed to find other ways to be active. Last summer he married his girlfriend of five years, Crystal. The two of them are working hard and attending college. J.D. is a teller at a bank, works in a restaurant on the weekends, and attends UW Whitewater with a double major in accounting and human resources. Crystal, who also works and attends college at UW Whitewater, is majoring in education. The couple hopes to buy a home in the near future.

As a young boy, J.D. recalls getting painful bleeds, being unable to move a joint, and then getting infusions. He was aware that he was somehow “different”, but was glad his parents were not over protective. Indeed, his advice for parents of children with bleeding disorders is to let them live as normal a life as is possible. He feels it is very important for children to learn from their experiences.

J.D. commends his parents and CCBD staff for helping him make good decisions as he moved out on his own. He readily admits that insurance is confusing, but he is working closely with CCBD’s financial and insurance counselors to make sure that he maintains adequate coverage. J.D. is focused on getting a degree and then his CPA certification. His goal is to provide a good living for himself, for Crystal, and for their future family.



*Continued on page 3.*

## Health Insurance and Young Adults

David Linney, Financial Project Coordinator: Great Lakes Hemophilia Foundation

For young adults with bleeding disorders, the subject of health insurance is not very exciting, but it is important.

- Everyone needs health insurance.
- Individuals with expensive medical conditions like hemophilia and other bleeding disorders must have reliable health insurance.
- Health insurance with very good coverage is necessary to avoid having to pay large out-of-pocket costs.
- Most young adults will need to secure their own health insurance.
- Health insurance is often very expensive but should always be maintained, because the cost of caring for a bleeding disorder usually far exceeds the cost of an insurance premium.

### ***When Do I Need to Get Health Insurance?***

You will need to secure your own health insurance when current insurance coverage ends. Coverage usually ends due to a “personal change” involving age, dependent status, student status, work, marriage, or disability status. Some examples follow:

- Many employer health plans will end dependent coverage when a young adult turns 19 (if not attending school full time); graduates from a post secondary school (up to age 25); stops going to school full time; or gets married. (Actual coverage

will vary from plan to plan.)

- Medicaid through BadgerCare Plus for children will end when you turn 19.
- Medicaid through Supplemental Security Income (SSI) will end if you fail to meet disability, income, or asset requirements. (Otherwise benefits will continue.)

### ***Insurance Options***

- COBRA (insurance continuation up to 36 months for dependents through the group policy of a parent who works for an employer with 20 or more employees).
- Employer insurance.
- Spousal health insurance (if you get married).
- The Wisconsin Health Insurance Risk Sharing Plan (HIRSP).
- Special Medicaid programs for individuals who work despite their disability; and,
- In the near future, the possibility of an approved Medicaid/Wisconsin BadgerCare Plus Core Plan for low income, childless adults.

### ***Health Insurance Planning***

Plan ahead. Start planning at ages 16, 17 and 18. Review your educational and vocational goals. Understand when you will need to get insurance on your own.

Work with your parents and CCBD’s Financial Counselor, Sheri Robbins, to develop a plan. Give Sheri a call at (414) 257-2424.

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### **Ben Wagner**

People who receive personal banking services from Ben Wagner might be surprised to learn that this very fit 26 year old has a serious medical disorder. Ben was diagnosed with severe hemophilia A when he was about eight months old. He says he remembers being aware at a young age, perhaps eight, that he had joint bleeds that were treated with infusions. His sister, who is three years older, did not get infusions or bleeds, so he knew his situation was unusual. As he grew, he gradually became aware that his diagnosis would to some extent limit his career choices. David Linney, CCBD Financial Counselor, educated Ben and his family about the need for good insurance coverage during Ben's transition to adulthood. Ben understood that he needed to work for a large company to have insurance to cover his factor infusions.

Even though he knew about the cost of insurance, when he was living on his own and first saw the bills for his factor product he was shocked by the amount. The cost of factor replacement product for a typical severe hemophilia A adult is about \$150,000 per year, more than most young adults are able to earn.



Fortunately, Ben made wise decisions regarding his future. He attended college and graduated from UW Oshkosh in 2006 with a BS in Finance. Since his graduation he has held three jobs, all in the financial services

field. He enjoys the security and flexibility that comes with his degree. Since his strong interest was mathematics, this career is a great fit for him.

Ben's advice for young people with similar disorders is to make sure to participate in education through CCBD so that you know what to expect when you are out on your own. He recommends utilizing CCBD financial and insurance counseling services, since these are some of the most difficult aspects of handling a severe bleeding disorder on your own.

## *You're 18 – Now What? Managing Your Bleeding Disorder as a Young adult*

All of us face new challenges as we enter adulthood. But young people with bleeding or clotting disorders have an additional responsibility—to manage their ongoing healthcare. As you celebrate this milestone birthday, consider the following points to ensure uninterrupted medical attention for your condition:

1. Establish a relationship with an adult hematologist. Pediatricians are trained to care for children and are experts on diseases specific to that population. As you age, your disease risk changes. Family practice physicians or internists are better suited to monitor your condition as you get older. If you decide to move or go away to college, be sure to establish care with an adult hematologist. Contact CCBD to locate a treatment center near your new residence, or visit <http://www.wfh.org> and look under “Resources” to view a directory of treatment centers. Once you select a new hematologist, contact CCBD to forward your medical records. If you plan to continue receiving care at CCBD, make sure to follow up as recommended. Keep in mind that CCBD policy states that recommendations for surgery or pregnancy may not be given without a recent evaluation. Also, please contact us with any insurance or demographic changes, and to update permission for CCBD staff to discuss your condition or treatment plan with your parents.
2. Be your own best advocate. Make sure you understand your diagnosis, treatment plan, and when to call for help. The following situations usually require treatment: persistent nose bleeds, heavy menstrual bleeding, surgeries (including dental extractions), significant injuries, and pregnancy. Remember that CCBD can provide you with ER cards, first aid plans, or travel letters upon request. These items can give you peace of mind as you go about your busy life.
3. Maintain insurance coverage. If you are a student, your insurance options may differ. As you plan for college and a future career, make sure you have access to adequate health insurance to cover the expense of managing your bleeding or clotting disorder.
4. Informed family planning. Bleeding and clotting disorders are often inherited and can be passed on to your children. Be aware of the likelihood that a child will be affected with your disorder. The odds of having an affected child vary dependent on the diagnosis.

If you have questions or need educational materials, please contact CCBD at 414-257-2424.

## THE CCBD LIBRARY

CCBD has a large library of information available regarding bleeding and clotting diagnoses, general health issues, medications and treatments and parenting information. If you are interested in obtaining information on a specific topic, please call the CCBD Clinical Services Specialist at (414) 257-2424 or toll free at (888) 312 -2223.

- A Guide for Women and Girls with Bleeding Disorders
- A Guide to Living with Von Willebrand Disease
- Acquired Thrombophilia (CCBD)
- Alexis, The Prince Who Had Hemophilia – English and Spanish
- Blood Clots and Strokes
- Caring For Your Child With Hemophilia – English and Spanish
- Clotting Newsletter (CCBD)
- Coping with Nosebleeds (CCBD)
- Dental Care for Adolescents with Bleeding Disorders: Ages 11 to 18
- Dental Care for Adults with Bleeding Disorders
- Dental Care for Children with Bleeding Disorders: Ages 5 to 10
- Dental Care for Infants, Toddlers, and Preschoolers with Bleeding Disorders
- Dental Management article
- Diane Dino's Dilemma
- Drug Interactions with Coumadin
- DVT
- EMLA
- Factor Fun
- First Aide Plans (CCBD)
- Fun and Facts About Inhibitors
- Genetic Counseling in Hemophilia
- Hemophilia Logic
- Hemophilia, It's Logical
- Hemophilia: The Young Adult Years (11-18)
- Hepatitis Brochures (CDC)
- Hereditary Thrombophilia (CCBD)
- Immune Tolerance Therapy
- Inheritance of Hemophilia (NHF)
- Inherited Bleeding Disorders and Child Abuse Investigations (NHF)
- Inhibitors to Factor VIII and IX (Novo Nordisk)
- Joshua Knight of the Red Snake
- Living with Hemophilia and Inhibitors (Novo Nordisk) – English and Spanish
- Must You Always Be A Boy
- My Blood Doesn't Have Muscles – English and Spanish
- My Journal
- Newsletter on Hemophilia (CCBD)
- NHF Brochure
- Obtaining Factor Product (NHF)
- Pain Management Book
- Patient's Guide to Using Coumadin
- Physical Therapy with Bleeding Disorders
- Platelet Disorders (Novo Nordisk)
- Platelet Function Defect (CCBD)
- Practical Advice for Parents (CHW)
- Practical Advice for Parents of Teens (CHW)
- Prophylaxis (NHF) – English and Spanish
- Questions Concerning Excessive Menstrual Bleeding
- Radiosynovectomy
- Rafting Rescue
- Raising a Child with Hemophilia
- Rare Bleeding Disorders (Novo Nordisk)
- Role of Vitamin K in Coumadin Use
- Sports Activities (NHF)
- Stimate
- Taking Charge: Living with Chronic Hepatitis
- Tell Them the Facts (age 11-16)
- They Will Probably Ask- What is Hemophilia? – English and Spanish
- Thrombophilia (CCBD)
- Treatment of Hemophilia: Orthopedic Management
- Understanding Von Willebrand Disease (Montgomery) – English and Spanish
- Von Willebrand Disease in Women
- Von Willebrand Disease: A Patient's Guide to Understanding (do not reorder)
- Von Willebrand Disease: Just the FAQs – English and Spanish
- VWD Newsletter (CCBD)
- Your Child's hemophilia: What to expect during infancy
- Your Child's Hemophilia: What to expect during the school- age years (5-10)

## SCHOOL IN-SERVICES

If your child has a severe or moderate bleeding disorder and will be attending a new school or day care, it's time to start scheduling late summer to fall in-services. These in-services, or education sessions, are for teachers, school nurses, and office administrators. If possible, we also like to include gym teachers, playground or recess supervisors, and teacher aides. Some schools use in-services as health education for teachers and require all teachers to attend. At the in-service, we will discuss your child's bleeding problem, recommended activities and sports, signs and symptoms of a bleed, 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 next school year actually begins. Contacting us early allows us to arrange a time that is most convenient for you and the school. Some schools prefer that in-services are completed before the fall semester begins (usually late August). It is important to have at least one parent, if possible, and the child (if they are old enough to comprehend the in-service) present at the in-service. The typical in-service will take less than 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.

If your child has a mild bleeding disorder (for example, platelet function defect or mild von Willebrand Disease) we can prepare a First Aid Care Plan for your child's school or day care which explains how to handle injuries, provides basic first aid for mild bleeding disorders, and gives important contact information. Please call CCBD to request a written plan of care.

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## ON THE WEB

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

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.)

## 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: \_\_\_\_\_

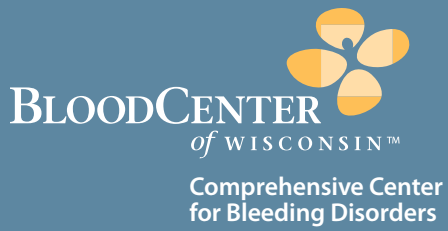
Patient Signature: \_\_\_\_\_

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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