



January 2011

Factor XIII Patient Story

Steve's* first indication that something was wrong was an intense headache. Over-the-counter pain medication did not help, so he saw his primary doctor, who could not find anything wrong with him other than the headache. The next day he was in such searing pain he could not get out of bed. His wife became alarmed and rushed him to the hospital where he was diagnosed with bleeding within the skull (an intracranial hemorrhage).

Intracranial hemorrhages are serious medical emergencies that can crush the brain and cause temporary or permanent brain damage. Steve's hemorrhage and surgery to repair the damage left him unconscious for a month. Afterwards he needed three months of rehabilitation to help him overcome problems from the bleed, including memory loss. As his memory slowly came back, he did return to work, but he had difficulty remembering his co-workers' names. After his return to work his doctor called him and explained that his head bleed was caused by a very rare clotting factor deficiency, Factor XIII. The only approved treatments for this condition in the US are two blood derived products, cryoprecipitate or fresh frozen plasma. Steve was initially treated with one of these and later was able to use a plasma-derived, pasteurized study medication, which has successfully prevented further bleeds. He needs infusions of this drug once a month.

Today, Steve lives in another state with his wife and two sons. He travels to Wisconsin monthly for his infusion. He is also on anti-seizure medication to prevent seizures associated with his head bleed. He says that he feels very well, and that he doesn't feel his condition really hurts his life. He accepts that he will need monthly infusions and is willing to travel quite a distance to get them. He feels more confidence now that he is getting the regular infusions and feels that the positives of his situation outweigh the negatives.

Steve's message to others diagnosed with rare bleeding disorders is to take your medication. "Family is the most precious thing; you need to be around to see them grow." He says he has gone through a lot in his life, but he is not afraid of being poked by a needle (to get his infusion) and is not afraid of being in a hospital. He willingly plans everything around his monthly infusion. Steve's positive outlook has been very helpful in his adjustment to living with this rare disorder.

*The patient's name has been changed.

JOIN US IN WELCOMING DR. THOMAS ABSHIRE

Thomas C. Abshire M.D. joined BloodCenter of Wisconsin in November 2009 as Senior Vice President – Medical Services and Medical Sciences Institute and Chief Medical Officer. Dr. Abshire provides leadership for all medical programs and medical practice at BloodCenter of Wisconsin (BCW). He also directs the newly-formed Medical Sciences Institute at BCW, bringing together education, clinical care and clinical research at the center.

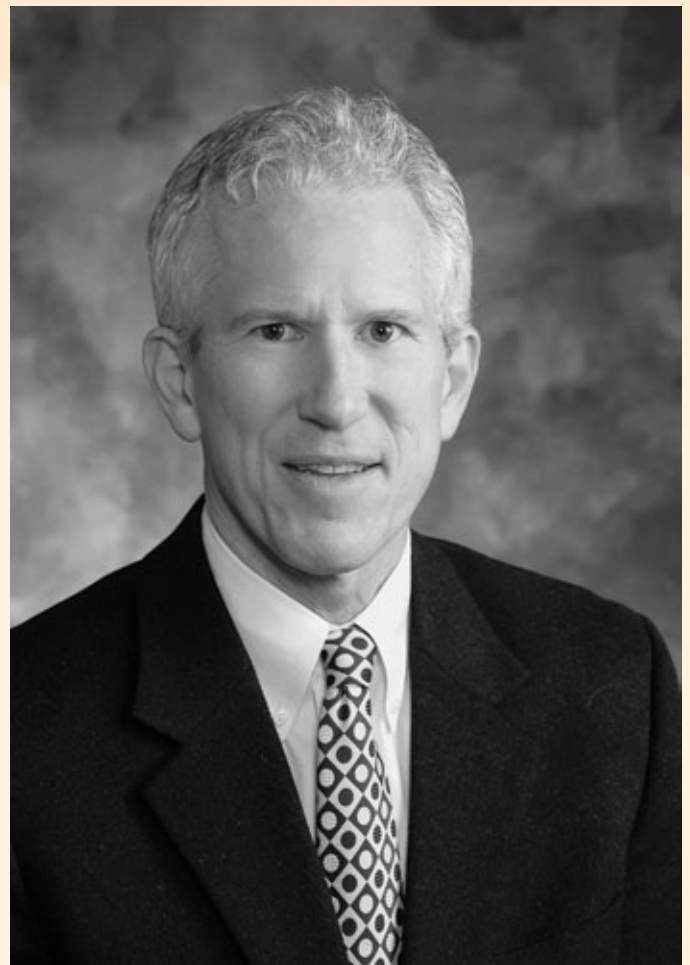
Dr. Abshire comes to BloodCenter of Wisconsin from Emory University School of Medicine and Children’s Healthcare of Atlanta where he was Director of the Comprehensive Hemostasis Program and Professor of Pediatrics. He held the Hemophilia of Georgia, Inc. Director’s Chair in Hemostasis and served as Principal Investigator for the Uniform Data Collection (UDC) of the CDC for Hemophilia Region IVS. Dr. Abshire also served for 13 years as Director of the Pediatric Hematology/Oncology Fellowship Program at Emory and Children’s.

Dr. Abshire is a distinguished graduate of the US Air Force Academy. He attended medical school at Tulane University, fulfilled his pediatric residency training at David Grant USAF Medical Center and completed pediatric hematology/oncology fellowship training at the University of Colorado Health Science Center.

During his 20+ years as a practicing pediatric hematologist/oncologist, Dr. Abshire has maintained a steady involvement with clinical trials and new product development in hemostasis and thrombosis, including laboratory evaluation of mild bleeding disorders and therapeutic intervention in hemophilia, von Willebrand disease, and thrombosis.

Dr. Abshire is past President, Hemophilia & Thrombosis Research Society (HTRS) as well as past Chair of both the ASPHO Training Committee and Pediatric Hematology/Oncology Fellowship Program Directors. He continues with an educational emphasis as member: Council of Pediatric Specialties, ASH Committee on Training and

Section of Hematology/Oncology, American Academy of Pediatrics (AAP). He also serves as co-Chair of the SSC Scientific Subcommittee of the ISTH on von Willebrand Factor, is a member, Medical and Scientific Advisory Council (MASAC) of the National Hemophilia Foundation (NHF) and Chair, American Thrombosis and Hemostasis Network (ATHN).



WELCOME NEW CCBD STAFF

Hello, I am **Corbett Reinbold** a new Nurse Coordinator at the CCBD. I will be working with

families and patients with clotting disorders and those having hemophilia. I am very excited about meeting all the families we care for. I also look forward to helping your families in achieving their goals for their loved ones with bleeding disorders. My history with BloodCenter of Wisconsin began ten years when



I was hired as a laboratory technician after graduating from UW-Milwaukee in Microbiology. Working at BRI provided many opportunities to work with BloodCenter's world renowned research staff. Still wanting more from a career, I decided to return to school and change my career path to nursing. At which time, I attended the Columbia College of Nursing through Mount Mary College and completed my BSN in 2009. I currently live in Milwaukee and enjoy spending time with my wife Natalie and two children, Hamilton age 6 and Siri age 3.

school I have worked in a sub acute rehab facility and performed home care services within Milwaukee and the surrounding counties. I have always enjoyed working closely with my patients providing the best care possible. When I'm not at work I enjoy spending time with my 8-year-old daughter Taylor. Thank you for allowing me to introduce myself.

My name is **Karen Weigman**, the newest CCBD Clinical Services Specialist. I am excited to be part of the team the supports the CCBD mission. My past work experience includes 30 years at Columbia St. Mary's and two years at Froedtert Hospital. When not at work, I am enjoying spending time with my husband of 23 years and three children. I am pleased to be part of the team at BloodCenter of Wisconsin and hope to make a difference.



Hello, my name is **Tiffni Boardman** and I am a new Nurse Coordinator at CCBD. I am very happy to

have become part of such a great team. I will be working mainly with patients with clotting disorders as well as providing support to our hemophilia nurses. I am eager to expand my knowledge and begin working with patients and their families who are affected by these disorders. Since graduating from nursing



CCBD HOME CARE PROGRAM

CCBD's HomeCare Program launched in July 2009 with Dr. Sheryl Moss as Outreach and HomeCare Coordinator. The HomeCare Program offers in-home education and medical/nursing care to CCBD patients and their families, with a focus on prevention as well as treatment.

Services available through the HomeCare Program include customized training in self-infusion, coaching for central to peripheral access skills and infusions of factor replacement product for patients unable to infuse themselves or an affected family member.

Providing these services to patients in their own homes reduces anxiety and decreases problems associated with scheduling, transportation, travel costs and insurance coverage. It supports CCBD's vision of appropriate care and maintenance of central lines, encourages an earlier transition to peripheral access and independence in patients, and less reliance on contracted nursing services who may be inexperienced in the specialized care of patients with hemophilia and other bleeding disorders.

ON THE WEB

The CCBD webpage is hosted on the BloodCenter of Wisconsin site: 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 visit www.bcw.edu/ccbd

ASK CCBD

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

Everyday Steps to Reduce Overall and Out-of-Pocket Medical Costs

Health care costs are on the rise. What can you do to help to reduce these rising costs? The following list offers a few ideas. Some of the ideas offer a quick start, while others take more time to plan and organize. Your health is an important investment at any time, but you will find many of these ideas make even more sense in today's uncertain economic environment.

Eat Healthy – a preventative measure to help decrease the chances of getting health conditions such as heart disease, obesity and diabetes.

Exercise – helps to combat obesity as well as helps to build strong bones and muscles.

Washing your Hands – helps to prevent illness. Germs are often on your hands and then passed to your mouth or eyes causing illness.

Wear your Seatbelt – in the event of an accident this can prevent some serious injuries.

Floss Daily – healthier teeth means fewer and lower dental bills and better overall physical health.

Get Regular Check Ups – routine doctor visits can help identify health problems that are treatable before they become more serious.

Quit Smoking – not only is it good for your health but it saves money as well.

Avoid Excessive Alcohol Use – too much alcohol leads to health problems and can become costly.

Brown Bag Lunch – pack a lunch instead of eating out or in the work cafeteria; it saves money and is often healthier.

Use Generic Medication if Available – generic medications have lower co-pays.

Use Emergency Room only in Emergencies – a call to your primary care doctor can save unnecessary trips to the ER. These visits have higher co-pays.

Review your Medical Bills - know what you were charged for, what your insurance covered and what you are responsible for. Billing errors can and do happen.

Use In-network Providers – using providers contracted with your insurance means greater coverage by the insurance and less out-of-pocket expense to you.

Stay Insured - plan ahead for insurance changes.

Know Your Health Insurance Policy – knowing your deductibles, co-pays, co-insurance and authorization processes can help you plan ahead and ensure medical expenses are covered.

Consider a Flexible Spending Account (FSA) - if available through your employer, an FSA allows you to set aside pre-tax dollars for medical, dental, vision expenses and even over-the-counter items for that year.

This is just a small list of ways to save on overall and out-of-pocket medical costs. As the financial counselor for CCBD, I am available to help you with your insurance needs. Please contact me with any questions or concerns: Sheri Robbins, (414) 937-6574.

School In-services

The beginning of a new year is a great time to review CCBD's guidelines for school in-services. If your child has a severe or moderate bleeding disorder and will be attending a new school or day care this year, it's not too early to start scheduling educational in-services. These in-services, or education sessions, are for teachers, school nurses, office administrators and daycare staff, including family members who provide daycare. If possible, we also like to include gym teachers, playground or recess supervisors and teacher aides. Some schools use the 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 as well as basic first aid techniques. A folder with information specific to your child will stay at school and serve as a reference for staff working with your child.

Please contact us as soon as possible to arrange for an in-service at your child's school or daycare before he/she begins attending. Contacting us early allows us to arrange a time that is most convenient for you and the school or daycare. 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 takes less than one hour to complete. Call (414) 257-2424 and ask to speak with a nurse coordinator if you would like us to schedule an in-service at your child's school.

If your child has a mild bleeding disorder (platelet function defect or mild von Willebrand disease) we can prepare a First Aid Care Plan for your school or daycare 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.

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: _____

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.***
