

CCBD Connection



BLOODCENTER
of WISCONSIN™

*Doing more good
than you know.*

November, 2007

Cycling: A Great Way To Get Fit

Two years ago, Cody, an engaging 21 year old with severe Hemophilia B, was a self-described couch potato who weighed 195 pounds and did not participate in any sports, other than a little golf. Today, as you can see from his picture, he is fit and well muscled at 170 pounds and now bikes 2,000 to 3,000 miles per year, including racing in 12 hour races.

Cody is currently attending Waukesha County Technical College and is majoring in general business management. For the past several years he has worked for his family's business in promotional products, screen printing, and embroidery. He travels for the business and puts in about 30 hours per week in the summers and about 10 during the school year. He spends his free time on one of his five bikes. He is active in five cycling disciplines: road, cross, track, sprint/marathon mountain biking, and endurance mountain biking. He races frequently and travels to races across Wisconsin and upper Illinois.

His cycling adventures started in June 2005 when he began riding his bike as a way to get out of the house, get a little fresh air, and find a positive social outlet. Cody is very knowledgeable about his diagnosis and knew he needed to find an activity that was relatively low impact. He began by slowly increasing his cycling



and at the same time made some changes to his diet such as eliminating simple sugars and increasing his protein. He has probably lost significantly more fat than the 25 pound loss that shows up on his scale. His muscle mass, which is heavier than fat, has increased with all his activity and displaced the fat.

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An Invitation to Better Health

Virtually all of us in this country are struggling with how to keep our weight down and get more exercise. Children and adults with hemophilia or other bleeding disorder diagnoses (and also many clotting disorder patients) have additional concerns related to overweight. Extra weight can put additional stress on joints, while strong muscles gained through exercise can help prevent bleeds. Since making changes in eating and exercising patterns is difficult, this article will discuss simple steps families and individuals can make to start the process toward better health.

The food changes that we all need to make include eating more fruits, vegetables and whole grains, and less processed foods that are high in sugar or fat. Smaller portion sizes are also important.

Activity changes that would help most of us would be to limit leisure time sedentary activities (such as TV watching, computer usage or video games) to no more than 1-2 hours per day (and much less for small children). Gradually increase the amount of time involved in physical activity, such as walking, to about 30 minutes five

days a week for adults (if you have any medical conditions check with your doctor before beginning an exercise program). Children should be getting at least an hour a day of physical activity.

Some behavior changes that may help are: 1) do not use food as a reward, 2) if you are part of a family, eat meals together as much as possible, 3) do not eat in front of the TV, 4) find family activities that are physically active, like walking in a local park, and 5) try out new fruits and vegetables or new recipes incorporating whole grains. Get children involved in picking out fruits, vegetables, or healthy recipes.

If you would like more assistance or information in making changes in your diet or exercise routine, please contact CCBD at (414) 257-2424. Some websites you may find useful are www.health.gov/dietaryguidelines and www.nhlbi.nih.gov/health/public/heart/obesity/lose_wt/ control. The last site has great suggestions for making healthy changes, a BMI (Body Mass Index) calculator and recipes for healthy ethnic cooking.

WEIGHT LOSS CAN MEAN FACTOR PRODUCT COST SAVINGS

David Linney

This issue of the CCBD Connection primarily focuses on the health benefits of weight loss for those individuals with bleeding disorders who are overweight. One additional benefit is the cost savings in factor product that you will be able to realize through appropriate weight loss.

Less weight will mean less prescribed factor product for each treatment and maybe even fewer treatments overall. This can result in out-of-pocket cost savings. It can also lessen the dollars used toward your lifetime insurance limit.

To estimate basic savings, determine your percentage of weight loss. For example, if you weighed 200 pounds and now weigh 180, you've lost 20 pounds or 10% of your original body weight. (20 pounds divided by 200 pounds equals 10%.) Your savings estimate would be 10% of your former factor bill.

So losing excess weight can be a good thing not just for your medical health, but for your financial health as well.

Cody (Continued from cover)

The physical changes in Cody were accompanied by improvements in his bleeding patterns. Although he does occasionally get a bleed from the activity (for example from spending too much time in one day biking), overall his total number of bleeds has decreased, probably due to improved muscle strength. He now also requires slightly less product because of his weight loss (see accompanying article about the potential for reduced medical costs associated with weight loss).

Cody feels that his increased fitness gives him more energy, more interest in social activities, and allows him to be more outgoing. Cody's story is inspiring to all of us. He did not have a particularly athletic background and he has a serious bleeding disorder, yet he found a way to exercise that he is really passionate about and one that has led to better health.



Great Lakes Hemophilia Foundation: Poinsettia Sale

It's beginning to look a lot like Christmas!

Has the Holiday season arrived in your home? Well now's the time! Decorate for a cause with GLHF's Annual Poinsettia and Wreath sale!!

Order before Monday, November 12, 2007. You can order these gorgeous poinsettias, wreaths, and lovely stationery by phone 414-257-0200 or online at www.glhf.org.

Cheerful volunteers will deliver orders of \$300 or more to your home. Or you can choose between 3 pick up options: Friday, November 30th at BloodCenter of Wisconsin (18th & Wisconsin Ave) or Friday, November 30th or Saturday, December 1st in Brookfield, WI.

For an order phone or if you would like to volunteer for this festive fun call or visit our website!

Get Moving!

It's easy enough to tell someone they need to get more exercise, but it's hard for most of us to fit it into our busy schedules. And even harder for someone who has a bleeding disorder (or is on anticoagulants), since some activities, such as football and wrestling, are dangerous and may lead to major injuries.

So first: **why exercise?**

- Everyone needs exercise to keep fit, maintain strong muscles and bones, maintain a healthy weight and, current research suggests, help maintain your brain power as you age.
- If you do have a bleeding disorder, exercise that keeps your muscles well conditioned and your joints mobile can help prevent bleeds!
- For children, physical activity helps increase self esteem, builds skills including social skills and helps "normalize" childhood experience for children who have bleeding disorders.

Second: **what activities are best?**

- Walking, swimming, bicycling (with a helmet of course) and golfing are some of the best activities for everyone, including someone who has a bleeding disorder.

- Weightlifting, baseball, basketball and running may be good exercises for someone with a bleeding disorder. If you want to participate in one of these, call CCBD for more information on how appropriate these exercises are for you given your diagnosis. Your nurse or the CCBD physical therapist will be able to give you safety guidelines for these activities.
- Riding ATVs, diving, playing football, hockey and wrestling are too dangerous for an individual who has a bleeding disorder (and can be dangerous for individuals without a bleeding disorder).

Third: **How can I or my child get started?**

- Call CCBD for tips on how to begin exercising safely, resources for programs and a complete list of recommended sports activities.
- Begin exercising as a family, with friends, with your dog or a borrowed one.
- Have fun!

SATURDAY SEMINAR – Spring 2008

Von Willebrand Disease, Platelet Function Defect and Other Bleeding Disorders

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.

Holiday Product Delivery Schedule

Since the holidays are fast approaching it seems like a good time to address product delivery from BloodCenter of Wisconsin.

Please be aware of your inventories (product and supplies) at all times, and double check them on a weekly basis to assure proper inventories. You should never have less than 2-3 doses on hand at any time.

Place your order at least 2 days prior to the desired delivery date – taking in consideration any upcoming holiday or weekend. There is a lot of background information needed to process your order and waiting until the last minute may delay your delivery. (Although BloodCenter of Wisconsin drivers can make next day or same day deliveries in emergency/ life threatening occurrences, this service should never be used as a convenience!)

Keep in mind there are no deliveries on the holidays or on weekends. Additionally, CCBBD is closed on the following days and therefore there will be no staff available to take any orders:

- Thanksgiving and the day after (November 22 & 23)
- Monday the 24th and Tuesday the 25th of December
- Tuesday the 1st of January, 2008

Finally, please let us know of any changes in your insurance as soon as they occur. If you have any questions please call your nurse coordinator at 414-257-2424.

ON THE WEB

The CCBBD 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 type “**CCBD**” in the search field at the top right corner.)

Hello, my name is **Jennifer Bruette** and I am happy to be a part of the CCBD team. I will be working as the new **Clinical Services Specialist**. I am looking forward to working with Charles and Cathy to support the medical staff, coordinate clinics, and interface with other departments in BloodCenter and the hospitals. I am very excited about beginning this new phase of my life and I look forward to meeting patients and staff.

The previous 5 years I have worked in both the banking and real estate industries. In my spare time I enjoy spending time with my beautiful 9 year old daughter Victoria. Thank you for the opportunity to introduce myself.



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) and click on "Ask CCBD." We will pick at least one question to answer in every issue of CCBD Connections.

BLOODCENTER OF WISCONSIN NOW SMOKE FREE

To ensure the healthiest possible environment for employees and the donors we serve, all BloodCenter of Wisconsin properties will be tobacco-free and smoke-free starting November 16, 2007. After implementation of the policy, there will be no smoking or use of tobacco products on any property owned or leased by BCW.

BCW is working with Froedtert Hospital, Medical College of Wisconsin, Curative Care Network, Children's Hospital of Wisconsin and the Behavioral Health Division of Milwaukee County to provide a tobacco/smoke free environment. We are optimistic that collaboration will only help us to create a cleaner and safer environment for all.

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: _____

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.***
