

# CCBD Connection



BLOODCENTER  
of WISCONSIN™

*Doing more good  
than you know®*

February 2006

## Living with a Clotting Disorder: A teen's perspective

Brianna is an attractive and lively fourteen year old who works out in the fitness room after school. When she was eleven years old she had a scary episode where her leg became swollen, purple and painful after she returned from a long trip. Her family doctor suspected that she had a blood clot in her leg and referred her to CCBD. After testing (during hospitalization at Children's Hospital of Wisconsin) she was diagnosed with a deep vein thrombosis (DVT) and two inherited clotting disorders, deficiencies of protein C and antithrombin III (ATIII).

Brianna has had several recurrences of blood clots and was just recently in clinic for a follow up visit. She consented to be interviewed by the CCBD social worker regarding her experience being a teenager and having a significant clotting disorder.

Brianna reported that she was so young at the time of her initial clot and diagnosis that she really did not understand how serious it was. She said she was about twelve when she began to understand her diagnosis and its severity. She feels it is difficult to be a

teenager and have a clotting disorder because it limits what she can do (she needs to take care not to have periods of prolonged immobility such as the trip that may have initiated her original DVT), and she also has the responsibility of taking daily doses of anticoagulant medication as well as regular lab work to monitor her medication levels.

Teenagers are naturally resistant to the routine of daily medications, so Brianna was asked how she has been able to remind herself to take her medications. She did say she has not always been totally compliant, but she has gotten better. Her mother purchased a weekly pill box (with compartments for each day of the week; these are readily available at drugstores) and they keep it on the kitchen table where they both can see if she has taken her pill for the day. She also has become more aware of the consequences of skipped medication; she can easily develop another clot. The clots are potentially life-threatening at worst, are generally painful and debilitating, and necessitate a hospital stay.

We are grateful that Brianna is doing well and that she was willing to share her story. There are a number of young people who have clotting disorders and/or have experienced a DVT or PE (pulmonary embolism, a clot in the lungs), but few have a chance to meet with another young person with a similar experience. If you have questions about clotting disorders or this article, please contact CCBD (414-257-2424).



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**SATURDAY SEMINAR CORNER – MAY 6, 2006**  
**VON WILLEBRAND DISEASE, PLATELET FUNCTION  
DEFECT, AND OTHER BLEEDING DISORDERS**

*Presented by Dr. Joan Gill*

*Details on page 3*

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## **Construction Update**

As many of you may already know, the Medical Campus where CCBD is located is undergoing an extreme makeover. In addition to the Blood Research Institute expanding its building, Children's Hospital and the Medical College of Wisconsin are also undergoing construction. The construction in the area affects us all. We appreciate your patience during this transition. Hopefully the following information will make your travel to clinic a little easier.

The front entrance of Children's Hospital will be closed until 2008 when the construction project is complete. Before coming to CCBD's comprehensive or coagulation clinic, located on the 8th floor of the hospital, you may want to consult the Children's Hospital website ([www.chw.org](http://www.chw.org)) for the latest construction updates. The hospital's current parking hints include:

- Free parking is available for patients and families in the visitor's parking structure.
- Several parking spaces in the parking structure, including Level 2, have been reserved for families.
- The easiest access to the hospital and clinics building during construction is through the skywalk.
- The skywalk is located on Level 2 in the southeast corner of the visitor's parking structure. Continue to the East Tower elevators to get to the 8th floor.

If you have any questions, including information on traveling by public transportation, feel free to call CCBD at 414-257-2424. We will assist you in making your trip to clinic appointments as easy as possible.

## **CCBD Nursing Staff**

In December, 2005, CCBD's hemophilia nurse coordinator, Nicole Kimmes, R.N., resigned her position. All of us wish Nicole continued success as she begins a challenging new calling.

We are pleased to announce that CCBD's new hemophilia nurse coordinator is not "new" at all. Andrea Dopke, R.N., B.S.N., has been with CCBD for almost 9 years. During this time, she previously served as hemophilia nurse coordinator, and later as coagulation nurse coordinator. More recently, Andrea has focused on education and surgery coordination. She looks forward to again working with our severe bleeding population, which includes not only hemophilia but also von Willebrand disease types 2 and 3, as well as other more rare bleeding disorders.

Jodi Haar, R.N., will continue as the CCBD coagulation nurse coordinator, which she has been doing for more than a year. Her main duties will remain working with the diagnostic clinics held each week at Children's Hospital of Wisconsin, as well as assisting our patients with clotting disorders and less severe bleeding disorders.

As of this writing, CCBD's Medical Director, Dr. Joan Gill, and the CCBD staff are in the process of interviewing for the newly created position of triage nurse coordinator. This person will be responsible for triaging telephone calls, and also for coordinating surgical and dental procedures for all of our patients with bleeding and clotting disorders.

As always, our focus at BloodCenter's Comprehensive Center for Bleeding Disorders is on you, our patients. If you have any questions about your diagnosis or our practice – or any suggestions about how we may serve you better – please call us at 888-312-CCBD.

## **SATURDAY SEMINAR CORNER – MAY 6, 2006**

### **VON WILLEBRAND DISEASE, PLATELET FUNCTION DEFECT, AND OTHER BLEEDING DISORDERS**

*Presented by Dr. Joan Gill*

*Director of the Comprehensive Center for Bleeding Disorders*

*All seminars will be held from 9:00 - 11:30 AM in the*

*Blood Research Institute Building, 8739 Watertown Plank Road*

*9:00 - 9:30 Snacks and Socializing*

*9:30 - 10:30 Presentation*

*10:30 - 11:30 Questions & Socializing*

*Refreshments will be provided courtesy of GLHF.*

*Day care will not be provided.*

**REGISTRATION IS REQUIRED:** *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!*

## **CCBD Welcomes Samantha Rice**

The staff at CCBD welcomes Samantha Rice, who is the new Patient Services Coordinator for the BloodCenter factor product program.

Samantha works under the direction of the BloodCenter Therapeutic Products manager. However, she is located in the CCBD office and works closely with the medical staff when factor product is ordered. Also, she attends the Monday Comprehensive Clinics to meet with patients who receive product through

BloodCenter of Wisconsin, and answer questions for patients interested in using BloodCenter of Wisconsin as their factor product provider.

In addition to her position at BloodCenter of Wisconsin, Samantha divides her time working as a Military Police Officer with the U.S. Army Reserve and bartending at the Charcoal Grill.

If you have any questions, please call her at 414-937-6579.



## **PDA Research Study Completed**

In addition to directly caring for patients, CCBD is also involved in several research projects. Most recently, Medical Director Dr. Joan Gill and Research Coordinator Katie Westover completed a study which could improve and simplify the care of patients with severe or moderate hemophilia.

Hemophilia is considered "severe" when a person's blood has <1% factor 8 or factor 9. (The normal range is about 100%) Patients with

this condition may infuse factor product prophylactically (preventatively). In order to properly oversee the treatment, the medical staff requires a careful record be kept of how much factor product was used, when and why.

In the past, this was done by writing the information on paper calendars. Through this research study, several CCBD patients have had the opportunity to try out using a personal-data-assistant (PDA) to electronically record this data

and transmit it directly to the medical staff via a phone line.

The study compared a group using the PDA to a control group using paper and found that communication with CCBD occurred significantly more often with the patients using the PDA (every 10 days) compared to paper (every 67.8 days). The data was also more complete in the PDA group.

After six months, the paper group was switched to PDA. This resulted in more

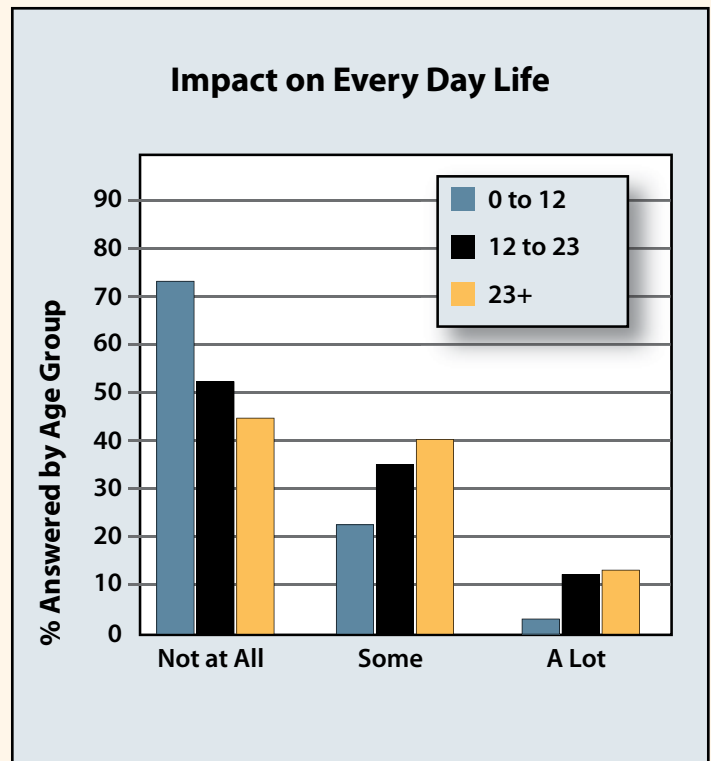
frequent communication with CCBD and a trend toward improved compliance with recommended number of treatments/infusions. Although, there were no differences in Quality of Life measurements, nor in the rate of break-through bleeds in the two groups over time, a larger study over a longer period of time may be required to see such differences.

# Results of 2005 Patient Questionnaire

Virtually all patients who are seen at either of the two weekly CCBD clinics held at Children’s Hospital take part in a short patient satisfaction survey administered by the CCBD social worker, Jane Volkmann. Your responses provide us with valuable information to help us better serve you. We make continuous improvements to our processes throughout the year based on this feedback. One example is our automated phone message, new this past year, which several of you said was too long and confusing. So we simplified and consolidated the phone messages and options. The revised message and system has been favorably received. Below are some other highlights from the survey responses:

- Of the 24 families (with children ages 0-12 who have significant bleeding disorders) who responded to the question about whether or not they have enough contact with other families in the bleeding disorders community, 14 (58%) indicated that they have sufficient contact already, four (16%) said they did not have much contact but that was acceptable to them and six (25%) indicated that they would like more contact with other families. We did pair up two families from this group for a mentoring type relationship. We also informed all the families about the services of Great Lakes Hemophilia Foundation (GLHF), the support and advocacy organization for individuals with bleeding disorders (and their families). The patient survey next year will include questions regarding patients’ knowledge of and interest in GLHF services.
- Of the 330 new patients surveyed, 32 (10%) were referred by a friend, family member, or acquaintance, 130 (39%) by a specialist (e.g. obstetrician), and the rest by the individual’s primary medical doctor.
- All but one of the 100 previously diagnosed patients who answered the question “How satisfied are you with the medical care you are receiving for your bleeding/clotting disorder?” indicated that they were very satisfied. That one patient indicated moderate satisfaction with our services. However, a number of patients did offer some suggestions for improvements (see below).
- In answer to the question “What can we do to improve your satisfaction with our services?” 54 (76%) of the 71 patients responding to this question either had positive comments regarding changes we have made or indicated that they experienced no problems with our clinics. Some of the positive comments included praise for a more timely and organized clinic process, satisfaction with our new

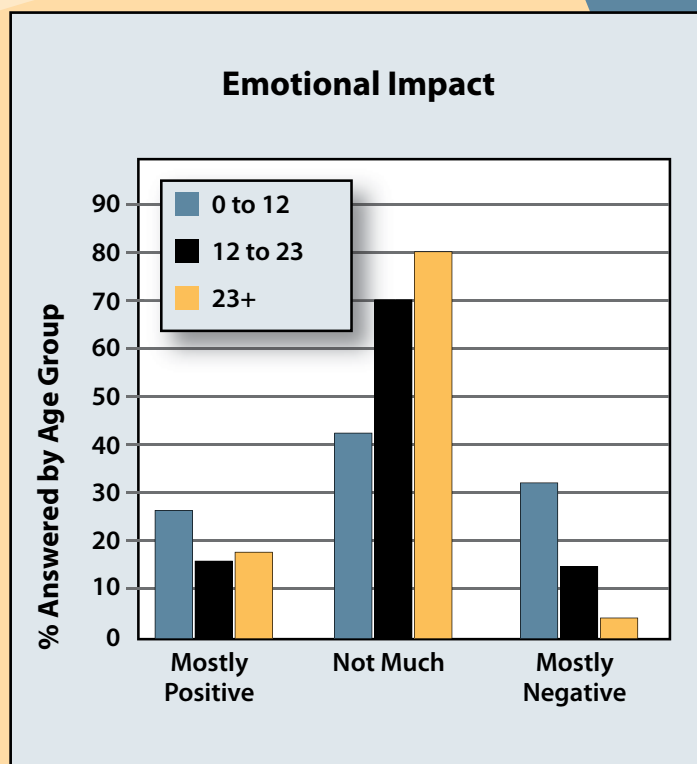
scheduling process which allows patients more flexibility with scheduling appointments, including scheduling their next appointment during their clinic visit, as well as gratitude for support during surgeries. Many of the suggestions patients made for improving our processes continue to focus on the length of clinic; with six individuals (8%) saying it was still too long. Other suggestions include utilizing electronic records for calendars of infusions (an excellent suggestion and one we hope to implement) and establishing an outreach clinic in the northern region of the state. Several patients brought communication issues to our attention, and we will continue to work on improvements in this area. Some additional suggestions involved hospital processes which are not under our direct control, but we have passed on these concerns to the appropriate hospital departments and will monitor progress in these areas.



- Patients gave very interesting responses to two questions regarding how much their bleeding disorder affected their everyday life (the physical impact) and the emotional impact of their bleeding disorder. (See accompanying graphs). As patients grew older, the physical impact of their disorder

was more significant (probably due to increased joint disease as well as, in some cases, coinfections) but, their perception of emotional distress connected to their disorder appeared to decrease (this may reflect improved coping skills and maturity).

- A new question this year assessed how satisfied patients who are on homecare are with the customer service of their product vendor. Twenty two individuals answered this question; twenty of them are BloodCenter customers. Nineteen of the twenty indicated that they were very satisfied (95%). The other two individuals who purchase their product from an outside vendor also indicated that they were satisfied.
- This past year for the first time we started using a questionnaire developed specifically for carriers (women who carry a gene for hemophilia which they can pass on to their children and who may also have some bleeding symptoms themselves). Three women who are carriers participated this year. One of them indicated a need for more information about family planning as it relates to the genetics of hemophilia. We hope to interview more carriers next year to determine if their unique needs are being met through our clinics.
- We also interviewed five patients who have a significant clotting disorder and regularly attend our clinic. All indicated satisfaction with their medical care and our services, and one individual indicated that his clotting disorder interfered with his daily activities, while the rest indicated that there was no impact on their daily life.
- Because exercise is so important for the health of all our patients, for the past few years we have also been asking patients about their level of exercise and what type of exercise they engage in. For the twenty-five 12 to 23-year olds who answered the question about exercise, all twenty-five indicated that they did exercise regularly. Seven (28%) said they exercised 1-3 times per week and eighteen (72%) said they exercised 4-7 times per week. Preferred forms of exercise were lifting weights, playing basketball, baseball, soccer, golf and tennis, as well as walking, bike riding and swimming. For the thirty-one patients over age 23 who answered this question, two (6%) indicated that they did not get any regular exercise, eight (26%) said they exercised 1-3 times a week and twenty-one (68%) said they exercised 4-7 times a week. For this age group the overwhelming preferred form of exercise was walking, with a few individuals indicating other activities such as swimming or playing golf.



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. We really appreciate the time and thought you put into answering these questions. Your suggestions for improvements and any other feedback about our services are always welcome. You can call Jane Volkmann at 414 937-6575 or toll free at 888 312-2223 anytime throughout the year with additional comments or with questions about the survey.

## BloodCenter of Wisconsin Volunteers

Four times a year, CCBD sends out 3500 copies of CCBD Connections. This monumental task would be impossible if it weren't for the efforts of BloodCenter of Wisconsin's volunteers who fold and address this newsletter so it can arrive in your mailbox.

The BloodCenter volunteers also play an important role in patient care by providing a priceless link between BloodCenter of Wisconsin and those who donate the gift of life to patients.

Our thanks go out to our volunteers. If you would like more information on this group, or would like to volunteer your time, please contact Maria, Volunteer Coordinator, at 414-937-6364 or 1-877-232-4376, ext. 6364. Volunteers must be 17+ years old, have exceptional customer service skills, and enjoy being with people.

When you volunteer for BloodCenter of Wisconsin, every effort will be made to place you in an area where your abilities and creative talents shine. Volunteer opportunities include (but are not limited to):

- Greeting donors
- Calling donors with appointment reminders or just to say "thanks" for donating
- Serving refreshments to donors
- Assisting Marrow Donor Program staff at marrow drives
- Assisting donors attending media drives
- Performing clerical tasks

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*"Our world is saved one or two people at a time." Andre Gide*

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## **GREAT LAKES HEMOPHILIA FOUNDATION 2006 BENEFACTOR'S BALL**

Dr. Joan Gill, the Medical Director of the Comprehensive Center for Bleeding Disorders, will be the Guest of Honor at the 2006 GLHF Benefactor's Ball, to be held March 25, 2006 at Milwaukee Hilton's Crystal Ballroom.

The evening will feature dinner and dancing and other entertainment, including a silent auction and, new this year, an on-line auction prior to the ball. The organizers are still looking for donations for the auctions (categories include Children/Family, For Him, For Her, The Arts, Experiences to Remember) as well as a donor and/or ideas and for a Signature Drink that will compliment the theme "*Sunset In Tuscany.*"

For more information, or to offer a donation, please call Nancy Johns 414-937-6780.

**Theme:** Sunset In Tuscany

**Date:** March 25, 2006

**Place:** Milwaukee Hilton's Crystal Ballroom

**Table Prices:** \$1500 table of 8  
\$1800 table of 10

**Individuals:** \$100 per person

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

Is this the address of patient's:

MOTHER

FATHER

BOTH

## HAVE YOU RECENTLY TURNED 18 YEARS OLD?

Check the appropriate boxes telling 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/voice mail:

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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