Results of 2009 Patient Satisfaction Survey

Over the past year, CCBD social workers Jane Volkmann and Sheri Robbins conducted 412 face-to-face Patient Satisfaction Surveys with patients or parents of patients. One hundred thirty-three respondents were patients previously diagnosed with bleeding or clotting disorders attending a comprehensive clinic visit. The remaining 279 patients were new to CCBD and attending a diagnostic work up clinic. Below are some of the findings from the 2009 survey:

**Satisfaction with Services**

In the face-to-face interviews, 98% (131 out of 133) patients or parents of patients were “very satisfied” with CCBD services, while 2% were “moderately satisfied.” Eighty-one percent of these patients (99 out of 122) had no further improvements to suggest. Twenty-three (23) patients or parents expressed the following concerns:

- Several patients wished that CCBD would hold clinics closer to their homes, or that clinic hours could be expanded to include more days of the week and additional afternoon hours. We are currently unable to increase the times available for clinic, but we will continue to explore the possibility of outreach clinics for patients who live far away.

- Some patients were concerned about problems at the lab, including wait times. Changes in the lab scheduling process made in late 2009 were designed to improve the lab’s efficiency. We will continue to monitor this situation as the year progresses.

- Several patients reported problems with the prompt return of CCBD phone calls and delays in receiving clinic-related paperwork. To address these concerns we increased our CCBD staff and developed new procedures for returning calls.

- A number of patients expressed their hope for a cure for their disorder. CCBD and the BloodCenter are involved in a number of research studies related to potential cures and improved treatments for bleeding and clotting disorders. We will keep you informed of these research studies through this newsletter.

- Although many patients said that clinics have become more efficient over the years, there were still a few patients who felt we could do better in this area. We agree, since there is always room for improvement. We will continue to work on keeping clinics as focused and productive as possible.
Information Regarding Diagnosis
Ninety-eight percent (130 of 133) of patients or parents of patients previously diagnosed felt they had received sufficient information about their disorder. We provided additional information for three patients upon request.

Impact of Disorder
Patients over the age of 23 diagnosed with bleeding disorders report more impact on their daily activities (see chart below). One potential reason is that older patients have more significant joint disease; some are also living with Hepatitis C and HIV contracted from blood products administered in the 1980s.

Impact of Disorder on Daily Activities
Emotional Impact of Disorder
For all age groups, a small percentage (3%-8%) of patients reported that the emotional impact of their disorder was positive (see the section on “Success” for possible explanations). Most indicated not much emotional impact (64%-67%) and a significant minority indicated a negative impact (27%-28%), as illustrated in the following chart:

Other observations regarding impact:
• Eleven patients indicated their disorder had a major impact on their daily activities and that the emotional impact was mainly negative. All of these patients were adults with severe bleeding disorders.
• Eight patients or parents of patients reported that the disorder had no impact on daily activities, but that the emotional impact was mainly negative. Five of the eight patients were boys between the ages of 12 and 22 who felt their disorder prevented them from playing sports; the other three were parents of children ages 4 to 6 who felt challenged by the demands of raising a child with a severe bleeding disorder.
• Many patients indicated that their disorder did not have much emotional impact, despite its impact on their daily activities. They reported that they have adjusted well to their diagnosis over the years.

Emergency Room Visits and Physician Knowledge
Most patients or parents of patients (97%) were aware that CCBD should be contacted if the patient goes to an emergency room. This is to make sure that a CCBD hematologist is immediately involved in the treatment plan. Most patients also indicated that their primary medical doctor and dentist had sufficient knowledge.
about their disorder. If you feel that your doctor or dentist does not have enough information, please contact CCBD for assistance.

Exercise
More young patients reported getting regular exercise. Seventy-nine percent of patients ages 12 to 22 reported exercising at least once a week, while 66% of patients 23 and older reported doing so. The most frequent form of exercise was walking, but patients reported a wide variety of activities, from weight lifting to golf.

Attendance at Clinic
The most frequently cited reasons for not attending clinic at the recommended intervals were problems with transportation, insurance or the impact of high out of pocket medical costs. These can be significant barriers for patients. If you have one or more of these concerns, please contact a CCBD social worker or financial counselor for assistance.

Employment
Of the 53 adult patients responding to a question about their employment status, 57% (30) reported that they were employed full time, 9% (5) worked part time, 9% (5) were retired, 17% (9) were unemployed, and 8% (4) are receiving Social Security Disability.

Self Reported Success
Because a serious bleeding or clotting disorder can have a major impact on an individual’s life, this year we asked adult patients if they felt that they had been successful in life, and what factors contributed to their success. Eighty-five percent (39 of 46) reported feeling that they had been successful. When asked what factors contributed to their success, seven indicated their education, 17 said their family’s support (including parents, spouses and children) and 12 said that determination, hard work, a good attitude, and flexibility helped them succeed. Good medical care was also mentioned by several people.

One group of patients gave poignant answers about why they felt successful. They said that when they were children, they did not feel that they would survive. One patient who had several brain surgeries related to head bleeds said that he felt the last 34 years had been a gift. He is very happy that he has been able to hold down a good job, despite his surgeries. Another patient said that she almost died as a child and her life view changed for the positive as a result of this experience by making her more empathetic. Another patient who thought he would not live long began making many positive changes in his life, including quitting drinking, when he realized that he really was going to survive.

The 7 patients who did not feel that they had been successful in life cited the following reasons. Several mentioned that they had not gone on to college. One patient said he was bullied in school because of his diagnosis and this held him back from furthering his education. Another patient who feared he would have a short life developed a “live for today” attitude and as a result, did not go to college or take good care of himself. Several patients mentioned the difficulty in finding employment and insurance when diagnosed with a severe bleeding disorder.

Transition to Adulthood
Another series of questions focused on the transition to adulthood in patients aged 12 to 22. These questions are designed to help us gauge the level of readiness in this patient population to assume responsibility for their own medical care, and to identify where more support and/or information is needed. When asked who in the family has the
major responsibility for taking care of their bleeding disorder, 38% (11 of 29) said that they were completely responsible; 14% (4 of 29) shared the responsibility with a parent or parents; 38% (11) said a mother was mainly responsible; 7% (2) said a father was responsible; one (1) reported that his fiancée had most of the responsibility.

Most (79%) of this age group are doing their own infusions, but only 42% are completing their own infusion logs (calendars). Eighty-three percent have decided on a career in fields such as medical technology, criminal justice, diesel mechanics, biological engineering, teaching and graphic design. When asked what issues were most important when choosing a career, a surprising 46% did not mention access to medical insurance.

**Parent Responses**

Helping a child understand the issues related to appropriate career choices and adequate insurance coverage was one of the questions in the parent survey. Seventy-two percent (13 of 18) of the parents responding to this question indicated they had started discussing this issue with their child. CCBD staff are available to provide support and information to parents on this topic.

One of the other questions in the parent survey asked whether or not parents felt they had sufficient contact with other families in the bleeding disorder community. Twenty-nine percent (10 of 34) reported having sufficient contact; 53% (18 of 34) said that they did not have much contact but were satisfied with the situation, while 18% (6 of 34) said they would like more contact. The last group was given information about Great Lakes Hemophilia Foundation, which provides support and advocacy for patients with bleeding disorders. Where appropriate, parents from this group were also linked individually to mentor families.

**New Patient Referral Sources**

Two hundred seventy nine patients attending the diagnostic work up clinics were asked how they first heard of CCBD or were referred to CCBD. Below are their answers:

- 29% (81) were referred by their primary medical doctor
- 20% (56) were referred by an ENT (Ear, Nose, and Throat Specialist)
- 15% (41) were told about CCBD services by a family member or friend
- 6% (16) were referred because they had an inpatient consult with a CCBD hematologist
- 5% (15) were referred by a neurologist
- 4% (11) were referred by a gastroenterologist
- 4% (10) were referred by an obstetrician/gynecologist
- 3% (8) were referred because of a child advocacy (child abuse) referral
- 3% (7) were referred by an outside hematologist
- 2% (6) were referred by a cardiologist
- The remainder were referred by other specialists including geneticists, orthopedics, dentists, nephrologists, etc.

**Summary**

We genuinely appreciate your feedback regarding our services. Your comments and suggestions will help us improve care for all CCBD patients. Over this next year we will continue to ask you to rate how well we are doing in meeting your needs. If you have any suggestions or comments about the survey, this article, or your own concerns, please call CCBD social workers Jane Volkmann or Sheri Robbins at (414) 937-6575 or toll free at (888) 312-2223.
Attention Homecare Patients

Monthly calendars/logs have always been an important and required part of home care. They not only give medical staff important information about your treatment needs, but they also provide the necessary documentation for insurance companies for payment of treatment as well as to document eligibility for disability initial applications and reviews. If there is no documentation of bleeding, then your insurance may deny the claim or disability may deny you.

Calendars are available on the CCBD website and can be submitted to CCBD in several ways. Below is an example of the information needed and how to submit your calendars.

The following information is needed for each infusion:

Date: ____________ Date of Infusion
Product: __________ Name of product used.
Total Dose: _________ Total number of units infused
Reason for Infusion (please check one):
   Prophylaxis __________
   Bleed ________
   Ongoing Treatment of a Bleed________

If the infusion is for a new bleed, please provide the following information:

Time Bleed Started: __________
   For Example: 8:00 AM
Time Infusion Started: _______
   For Example: 9:00 AM
Site of Bleed: ______________________________
Where is bleed, include whether left or right side

When completed, return to:
Comprehensive Center for Bleeding Disorders
P.O. Box 2178
Milwaukee, WI 53201-2178
Or: Fax: 414-937-6580
Or: To email: ccbdcalendar@bcw.edu
Or: Call 414-937-6599 & follow the instructions
Thank you for your attention to this important topic.

Meet Robin

Hello, my name is Robin Bortmann. I have been a registered nurse for sixteen years. I graduated from MATC in 1994 with an Associate Degree in Nursing. During the past 12 years, I have worked at Froedtert Hospital in the Bone Marrow Transplant unit, Labor and Delivery and Colorectal surgery. I also worked with Dr. Friedman and Dr. Lankiewicz at Froedtert Hospital in the Benign Hematology Clinic. I am looking forward to meeting all of the patients and family members and being part of the CCBD Hemophilia Team. I enjoy biweekly gatherings with my daughters to cook and just spend quality time together.
Platelet Function Defects

Platelet function defects are a type of bleeding disorder in which the body’s platelets do not function properly; the body has enough platelets however, the ones present do not work as they should. Without functioning platelets the clotting process does not occur as well and can cause prolonged bleeding.

Types—both males and females are affected
1. Mild platelet function defects: The most common and mildest type.
2. Bernard Soulier: Rare and severe type.
3. Glanzmann’s Thrombasthenia: Rare and severe type.
4. Acquired platelet function defects: Related to medication (i.e. Depakote, aspirin).

Inheritance
Mild platelet function defects are a heterogeneous group of disorders. Therefore, the exact mode of inheritance is not clear. Severe platelet function defects are autosomal recessive (both parents carry the abnormal gene and pass it on to the child). Regardless of the severity, family members of an affected individual should be studied if symptomatic or if asymptomatic and surgery is needed.

Symptoms
1. Easy bruising
2. Gum bleeding
3. Epistaxis (nosebleed)
4. Menorrhagia (heavy menstrual bleeding)
5. Increased bleeding with pregnancy, injury or surgery (including dental work or circumcision)

Treatment
1. DDAVP (desmopressin): Intravenous form. DDAVP is used in the hospital setting usually for surgery or injury. Effective for mild platelet function defect.
2. Stimate: Intranasal DDAVP. Used at home for management of nose bleeds or heavy menstrual bleeding. Effective for mild platelet function defect.
3. Platelet transfusion: For patients with severe platelet function defect or in patients with mild platelet function defects whose symptoms do not improve with DDAVP.
4. Recombinant VIIa: For patients with severe platelet function defect whose symptoms do not improve with platelets or in patients with a platelet function defect who cannot receive platelets due to an antibody.
5. Amicar: For all platelet function defects to prevent or control bleeding related to the mucous membrane (oral, nasal, uterine).

Medical recommendations
1. Aspirin and ibuprofen products should be avoided.
2. Full contact sports (football, wrestling, hockey, boxing) should be avoided.
3. Inform other medical providers (especially surgeons) of your diagnosis.
4. Contact CCBD for treatment recommendations if injury occurs or surgery is needed.
5. Patients with mild platelet function defects should consider being restudied if…
   • Diagnosed at a young age without any bleeding symptoms and have continued to not have any bleeding symptoms.
   • Diagnosed at a young age and bleeding symptoms present however, now no longer have symptoms.

Please contact the Comprehensive Center for Bleeding Disorders at 414-257-2424 to discuss any of the above information.
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.
BloodCenter of Wisconsin advances patient care by providing life-saving solutions grounded in unparalleled medical and scientific expertise.