Self-Infusion Training Gives Patient More Freedom and Confidence

Just a few days before his sixth birthday, Jomar had an injury to his tongue that wouldn’t stop bleeding. He and his family were referred to the Comprehensive Center for Bleeding Disorders (CCBD) where he was diagnosed with mild hemophilia. Over the next sixteen years, in order to get infusions of factor replacement product to treat his bleeds, he and his family made regular trips to Milwaukee from their home in Racine. At times he was traveling to Milwaukee every other day. In 2010, to help him manage his bleeding disorder more independently, he participated in self-infusion training and certification through the CCBD Home Care Program.

Dr. Sherry Moss, coordinator of the program, made a number of visits to his home to teach him the infusion process. The training made a huge difference in Jomar’s life. Fewer trips to Milwaukee have given him the freedom to focus on other aspects of his life. Now at 25, Jomar is planning to continue his education and hopes to start working towards a career in the medical field. His positive experience in managing his own disorder has given him the confidence to help others with medical problems.
Results of 2012 Patient Satisfaction Survey

In 2012 CCBD social workers conducted 387 face-to-face Patient Satisfaction Surveys with patients or parents of patients. One hundred forty respondents were patients previously diagnosed with bleeding or clotting disorders attending a comprehensive clinic visit. The remaining 247 patients were new to CCBD and attending a diagnostic work up clinic. Below are some of the highlights from the 2012 survey:

Satisfaction with Services

In the face-to-face interviews, 99% of patients (132 out of 133 responding to this question) or parents of patients were “very satisfied” with CCBD services, while one patient was “moderately satisfied.” Of these patients, 94% (131 out of 140) had no further improvements to suggest. Nine patients or parents had the following suggestions for improvement:

• 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 or evening hours. We asked patients if adding a Saturday clinic would be more convenient. Fifty (46%) of the 108 responding to this question thought a Saturday clinic would be more convenient. The other 54% said that a Saturday clinic would either be less convenient or that it didn’t matter to them. We will be actively working to increase the number of clinics and/or the time of day for clinics. In addition, we are looking at the possibility of holding outreach clinics to meet the needs of patients who travel a long distance to attend.

• One patient cited a concern with not receiving appointment letters early enough to rearrange his work schedule. We agree that appointment letters should be sent out promptly after the appointment has been scheduled and will be working with our staff to ensure 100% achievement of this goal.

• Several patients mentioned the need for calendars (infusion log forms) to be available on our website. The website has been updated and the calendars are again available at: http://www.bcw.edu/cs/groups/public/documents/documents/mdaw/mda4/~edisp/ccbd_infusion_calendar.pdf

• Although many patients said that clinics have become more efficient over the years, there were still a few patients who felt we could be 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.

• In addition to these concerns, patients also mentioned how satisfied they are with patient care, our communications with them, and the “excellent school in-services” provided by our staff.

Information Regarding Diagnosis

Ninety-nine percent of patients (139 of 140) or parents of patients previously diagnosed felt they had received sufficient information about their disorder. We did provide additional information for the patient who wanted more information. If you feel that you do not have as much information about your diagnosis as you would like, please contact us at (414) 257-2424.

Impact of Disorder

The majority of patients with bleeding disorders (these are almost entirely patients with hemophilia or type 2 or 3 von Willebrand Disease) reported that the physical impact of their disorder is not significant (however, see Chart 2 for the greater emotional impact).

Chart 1: Impact of Disorder on Daily Activities

<table>
<thead>
<tr>
<th>Impact</th>
<th>Ages 23+</th>
<th>Ages 12-22</th>
<th>Parents</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>10%</td>
<td>10%</td>
<td>40%</td>
</tr>
<tr>
<td>Some Impact</td>
<td>60%</td>
<td>60%</td>
<td>40%</td>
</tr>
<tr>
<td>A lot</td>
<td>30%</td>
<td>30%</td>
<td>20%</td>
</tr>
</tbody>
</table>

Emotional Impact of Disorder

For all age groups, a small percentage of patients (2%-4%) reported that the emotional impact of their disorder was positive and was most often related to the social connections that families or individuals felt to the bleeding disorder community. Many indicated not much emotional impact (45%-88%) and a significant minority indicated a negative impact (9%-45%), as illustrated in the chart below. As a group, the parents of children with
significant bleeding disorders experienced the negative aspects of the diagnosis more than the older children and adults. Obviously, parents of children with these diagnoses are concerned about the impact on their children and have had less time to adjust to all aspects of the diagnosis and treatment. The good news is that, as children get older and become adults, they do begin to find positive ways to handle the emotional impact of the disorder.

Chart 2: Emotional Impact of Disorder

<table>
<thead>
<tr>
<th>Impact</th>
<th>Ages 23+</th>
<th>Ages 12-22</th>
<th>Parents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positive</td>
<td>100%</td>
<td>80%</td>
<td>60%</td>
</tr>
<tr>
<td>Not Much</td>
<td>0%</td>
<td>20%</td>
<td>40%</td>
</tr>
<tr>
<td>Negative</td>
<td>0%</td>
<td>20%</td>
<td>0%</td>
</tr>
</tbody>
</table>

Emergency Room Visits and Physician Knowledge
Most patients or parents of patients (99%) were aware that CCBD should be contacted if an emergency room visit is necessary. This is to make sure that a CCBD hematologist is immediately involved in the treatment plan. Most patients (94%) 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 frequent regular exercise. Sixty-two percent of patients ages 12 to 22 reported exercising at least four to seven times a week, while 37% of patients 23 or older reported doing so. A small percentage of patients reported getting no exercise (only 8% of the 12-22 year-olds and 26% of the over 23-year-old patients). The most frequent form of exercise reported was walking, but patients described a wide variety of activities, from weight lifting to swimming.

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 increasingly 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 58 adult patients responding to a question about their employment status, 41% (24) reported that they were employed full-time, 12% (7) worked part-time, 22% (13) were retired, 16% (9) were unemployed, and 9% (5) are receiving Social Security Disability.

Transition to Adulthood
Another series of questions focused on the transition to adulthood in patients ages 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, 21% (7 of 34) said that they were completely responsible. Seventy-nine percent (27 of 34) shared the responsibility with a parent or parents, with most indicating that their mother was mainly responsible.

Most of this age group are doing their own infusions, and about half are completing their own infusion logs (calendars). About half have also decided on a career in fields such as criminal justice, business, surgery, law, city planning and civil engineering. Most knew that both access to medical insurance and low physical impact are important issues when choosing a career.

Parent Responses
One of the questions in the parent survey asked whether or not parents felt they had sufficient contact with other families in the bleeding disorder community. Forty-three percent (12 of 28) reported having sufficient contact; 43% (12) said that they did not have much contact but were satisfied with the situation, while 14% (4) 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.

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Results of 2012 Patient Satisfaction Survey
Continued from page 3.

New Resources
This year we also asked parents and patients if there were additional resources they would like to have available during clinic visits. Of the 116 patients who responded to this question, 29% (34) were interested in utilizing the services of a nutritionist; 24% (28) were interested in having a career specialist available (this included both parents of young children and the over 23 age group); 18% (21) thought an orthopedics specialist would be useful; 16% (19) thought that they would utilize the services of a pain management specialist, and 12% (14), mostly parents, felt that an education specialist would be helpful. We will discuss these results with our team and look at ways to provide access to these resources.

New Patient Referral Sources
All 247 patients attending the diagnostic work-up clinics were asked how they first heard of CCBD or were referred to CCBD. Below are their answers:

- 26% (65) were referred by their primary medical doctor
- 21% (53) were referred by an ENT (Ear, Nose, and Throat Specialist)
- 21% (52) were told about CCBD services by a family member or friend
- 7% (18) were referred because of a child advocacy (child abuse) referral
- 4% (10) were referred because they had an inpatient consult with a CCBD hematologist
- The rest were referred by other specialists including neurologists, gastroenterologists, obstetricians/ gynecologists, geneticists, orthopedics, outside hematologists, dentists, nephrologists or cardiologists.

Summary
We genuinely appreciate your feedback regarding our services. Your comments and suggestions 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) 257-2424, or toll free at (888) 312-2223.

New Clinic Provides Services for Young Women with Problematic Periods
CCBD (in collaboration with Children’s Hospital of Wisconsin’s Adolescent Medicine department) is now offering a specialized clinic for young women with menorrhagia (unusually heavy menstrual periods). Many young women experience problematic periods:

- periods lasting seven or more days,
- flooding or gushing that limits daily activities such as exercise, or
- passing clots bigger than a quarter, or
- having to change protection every two hours or more frequently on the heaviest days.

Young women whose periods show any of these symptoms may possibly have a bleeding disorder and may be helped with appropriate treatment. Dr. Veronica Flood is the CCBD hematologist providing services for this clinic. Dr. Seema Menon from Adolescent Medicine and Obstetrics & Gynecology also sees patients in this clinic to address hormonal management for their periods.

If you or a family member are experiencing any of these symptoms and would like to discuss how to be seen in this specialized clinic, please call CCBD at (414) 257-2424.
Campership Program
Summer Camp is a magical, life-changing experience for a child living with a bleeding disorder. At camp, children develop confidence and independence. They build life-long friendships and memories. Camp is also a place for kids to find encouragement, mentors and education on self-infusion. This enhances their role in self-care, which will be essential for the rest of their lives.

If your child is living with a bleeding disorder and is interested in the opportunity to play, learn and grow in a safe environment with other children facing similar challenges, please consider sending them to camp this summer.

Any child in Wisconsin with a bleeding disorder (hemophilia, von Willebrand disease, factor deficiency) wishing to attend camp in Illinois, Michigan or Minnesota may be eligible. Great Lakes Hemophilia Foundation (GLHF) provides Camperships to cover the cost of the approved summer camps for families unable to do so on their own. It is GLHF’s goal to ensure that all children living in Wisconsin, or receiving care from a Wisconsin Hemophilia Treatment Center, who would like to attend camp have the opportunity to do so.

Campership application deadline is May 30, 2013.

To apply for a GLHF Campership visit glhf.org or call (414) 937-6782 for more information.

Scholarship Program
Education, Career Development and College Bound scholarships are offered to individuals and families affected by a bleeding disorder. It is the Foundation’s goal that those living with bleeding disorders have access to educational opportunities that will enhance their lives and prepare them to become self-sufficient and productive members of the work force.

Program Goals:
• Improved patient and family access to insurance
• Decreased dependency on public sources of support
• Increased commitment to the bleeding disorders community

Eligibility:
• Diagnosis of hemophilia, von Willebrand disease or a factor deficiency
• Parents, caregivers and spouses of persons with bleeding disorders will be considered
• Resident in the state of Wisconsin or receive care at one of the Wisconsin Hemophilia Treatment Centers
• Technical school, college, or university must be accredited and not-for-profit

To apply for a GLHF scholarship visit glhf.org or call (414) 937-6782 for more information.

Patient Financial Assistance Program (PFA)
GLHF offers patient financial assistance to individuals and families needing funding assistance with medical bills, insurance premiums and emergency basic living expenses. GLHF also assists with payment of medical alert bracelets and membership renewals. Please contact the Foundation at (414) 937-6782 if you would like more information on the GLHF Patient Financial Assistance Program.
Welcome to the Team

Brenda Jackson

Hello, I am Brenda Jackson, one of the newest Clinical Services Specialist at CCBD. I am proud to be a part of such a great team that serves individuals with bleeding disorders. I am excited to assist patients and their families and look forward to meeting them all.

I have more than 20 years administrative experience, 10 of which was as an administrative pastor. After leaving the ministry and before coming to CCBD I worked for the Brain Injury Association of Wisconsin. I have a bachelor’s degree in Theology and am currently working on a Master of Business Administration. When I’m not at work or studying I enjoy spending time with my husband and two daughters.

School and Day Care In-Services

A school or day care in-service conducted by one of our CCBD staff members is important for our patients with severe or moderate bleeding disorders. These in-services, or education sessions, are for teachers, school nurses, and office administrators. We cover your child’s bleeding problem, 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.

If your child has just started attending a new school or day care or will be attending a new one and has not yet had an in-service, please contact us. It is important to have at least one parent and the child (if they are old enough to comprehend the in-service) present at the in-service. The typical in-service will take 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 or day care.

Corbett Reinbold, BSN, can help schedule in-service sessions as Nurse Coordinator with CCBD.
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, suggestions or call and let us know if you feel we are providing you with an informative newsletter. Call us at (414) 257-2424.
BloodCenter of Wisconsin advances patient care by providing life-saving solutions grounded in unparalleled medical and scientific expertise.