



May 2006

The Two Julians: the Changing Face of Hemophilia Treatment

About a year and a half ago, twin baby boys were born in the Milwaukee area. One of the boys was born with a severe form of hemophilia A, and the other was not.

The baby who was born with the bleeding disorder was named "Julian". His maternal uncle, also named "Julian," shares the same diagnosis. Their stories highlight the changes in the treatment of this severe bleeding disorder since the older Julian, age 29, was diagnosed. He and his sister, Monserrate, the mother of baby Julian, agreed to share their hemophilia experiences with CCBD social worker, Jane Volkmann.

The older Julian cannot remember when he first realized that he had hemophilia. He does remember recognizing that he was somehow different from other children. He

remembers the pain of his bleeds and being hospitalized. At that time children with hemophilia were only treated after a bleed developed; there was no preventive (prophylactic) treatment as there is today. When he was young his family took him to the hospital for his infusions of clotting factor; later he was trained in self infusions. Repeated bleeds damaged his knee and he required surgery at age eight. Today he is an active father of three who is attending college to become an engineer. He is now very responsible about taking care of his hemophilia and he has been a strong support for his sister, Monserrate, as she adjusted to the challenges of raising a child with severe hemophilia.

Monserrate chose the twins names early on, and did not know that the twin who had hemophilia was the one



named after her brother, who also has hemophilia. She recalls that when she was told about baby Julian's diagnosis right after delivery, she began to cry, realizing that she would be going through some tough times ahead. She had some initial fears that proved unfounded, such as

whether baby Julian would have to stay in the hospital for a longer time than his brother, but she also knew from the beginning that her brother would provide support for her and her child. One great difficulty for her was her anxiety about baby Julian developing a bleed from normal activities. As he began to walk he naturally

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Menorrhagia and Women with Bleeding Disorders

Hematologists define menorrhagia as heavy menstrual bleeding that requires a change in saturated feminine protection every 1-2 hours. Many females with a bleeding disorder may experience menorrhagia; however, it is not a symptom that needs to remain untreated.

A female with a bleeding disorder who experiences menorrhagia should consider oral contraceptives, Stimate nasal spray or Amicar. All of these medications help the body decrease the amount of bleeding that occurs with a woman's cycle.

Oral contraceptives contain hormones that help regulate a woman's menstrual flow and frequency. It is the most inexpensive way to help manage menorrhagia and can be used with any type of bleeding disorder.

Stimate helps the body release von Willebrand factor

from the body's stored supply. More von Willebrand factor in circulation will allow more platelets to bind to it. Therefore, the body is able to form a clot easier. Stimate can only be used in women with von Willebrand disease, a platelet function defect or in hemophilia A carriers. It is an expensive medicine and a person's pharmacy benefits should be considered.

Amicar is an oral medication that helps maintain a clot by preventing the body from breaking it down. Like oral contraceptives, it also can be used with any type of bleeding disorder. Amicar can also be expensive and a person's pharmacy benefits should be considered.

All of the above mentioned medications can be used alone or in conjunction with each other. To get more information on whether or not one of the above mentioned medications is appropriate for you, contact CCBD.

Are You Having Surgery or Major Dental Work?

As soon as you know that you may need surgery or a major dental procedure, please contact CCBD with the following information: your name, the type of surgery, the surgeon's name and phone number, and the date and location of the procedure.

For patients with bleeding disorders (hemophilia, von Willebrand disease, platelet function defects, etc.), we will make recommendations to your surgeon regarding treatment of your bleeding disorder at the time of the procedure, so that you do not experience bleeding complications.

If you are a patient with a clotting disorder and you are taking oral anticoagulants (Coumadin, warfarin), or injection anticoagulants (heparin, low molecular weight heparin), you need to have a plan in place for anticoagulation before, during and after a procedure.

Please be aware, if you are having an elective (non-emergency) procedure, if we don't have notification at least 1-2 weeks prior to the procedure, your surgery may need to be rescheduled in order to allow enough time for the proper recommendations to be made and discussion held with your surgeon.

The Two Julians (continued)

started bumping into things. And every time he had a fall or a significant bump or showed some sign of a bleed, she had to bring him into the hospital for an infusion. Aware of her anxiety, her brother encouraged her to consider becoming certified to do the infusions at home, through a medical device called a port. A port is a device surgically implanted under the skin, typically in the chest wall. Because small children do not usually have veins which are easy to access, ports are often placed in small children who need regular infusions. Ports make doing prophylaxis, the regular (usually two or three times a week) administration of

clotting factor to prevent bleeds, much easier for parents and saves the small veins from repeated needle sticks.

Monserrate was worried about the surgery and her ability to do the "pokes". But with her brother's encouragement she began the training and scheduled the surgery. Baby Julian now has a port and Monserrate has been certified to do his infusions. She said this has been a great relief to her. She is less worried about him getting hurt doing normal kid things and she is now more willing to let him lead a normal life. She knows if he does get a bump from his equally active brother, she

can promptly infuse him. Today he is a very outgoing and happy boy who keeps his mother on the run as he does all the normal boy activities.

When asked about their hopes for baby Julian, Monserrate and her brother had similar goals: that he would grow up healthy and happy and have a normal life. Older Julian also hoped that his namesake would feel freer to reveal to his playmates and peers that he had hemophilia, something the older Julian did not feel comfortable doing as a child. Both stressed how important it is for individuals with bleeding disorders and their families to get prompt medical

treatment for bleeds, to get prompt medical advice about any potential bleed, and to connect with others who have a similar diagnosis, as they have. If you have questions about the information in this story please contact the nurse or the social worker at CCB, 414-257-2424.

SATURDAY SEMINAR CORNER – Fall, 2006

DISORDERS THAT CAUSE EXCESSIVE BLOOD CLOT FORMATION

***(FACTOR V LEIDEN, PROTHROMBIN GENE MUTATION,
DEFICIENCIES OF ANTITHROMBIN III, PROTEIN C,
PROTEIN S, ANTIPHOSPHOLIPID SYNDROME)***

Presented by Kenneth Friedman, M.D.

***Associate Director of the Comprehensive Center for
Bleeding Disorders – Director of the Hemostasis Laboratory,
BloodCenter of Wisconsin***

*All seminars will be held from 9:00 - 11:30 AM in the
Blood Research Institute Building, 8739 Watertown Plank Road,
Milwaukee, WI*

9:00 - 9:30 Registration & Refreshments

9:30 - 10:30 Presentation

10:30 - 11:30 Questions

*Refreshments will be provided courtesy of
Great Lakes Hemophilia Foundation.*

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 New Staff

Hello, my name is **Bridgit Cornale** and I am a new *Nurse Coordinator* at the CCBD. I will be working with patients with clotting disorders, more frequently with patients who have hemophilia. I am very excited about beginning this new phase of my life and look forward to meeting patients and families who are affected by bleeding disorders and the staff who are involved in all aspects of a patient's management and treatment.

I attended the University of Wisconsin-Milwaukee School of Nursing and have worked at St. John's Home in Milwaukee, Waukesha Memorial Hospital and Heartland Home Care and Hospice of Brookfield, WI. I live in Waukesha and have two children, ages 6 and 8, and a Spinone named Lily.

My name is **Courtney Pickar** and I am one of the new *Nurse Coordinators* for the CCBD. I am looking forward to meeting and assisting the staff, patients and families of the CCBD. I hope to be involved in all aspects of care for patients and families. Previously, I have worked with GE Medical Systems, Alverno College, and Elmbrook Memorial Hospital. At Elmbrook, I helped care for new moms, babies, and surgical hysterectomy or mastectomy patients. I was born and raised in Waukesha, WI and I graduated from Marquette University. I am currently a student at UW-Milwaukee pursuing my Master's in Nursing. I recently bought a house with my husband in Vernon, WI, which we are temporarily sharing with my sister, her husband, her 7 month old son, and their dog Bailey. My husband and I have a dog named Kona and a cat named Nemo.

Hello, my name is **Cathy Mistir** 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 Jendora to support the medical staff, coordinate clinics, and interface with other departments in BloodCenter and the hospitals.

In March and April, I filled in for Patient Services Coordinator Samantha Rice while she was out of the country for an Army exercise. During Samantha's absence, I learned a lot about CCBD and our patients as well as Samantha's job duties.

The previous 3 years I worked at an Internal Medicine Clinic at Columbia-St.Mary's Hospital as a Customer Service Representative. In my spare time I enjoy spending time with my husband and 4 year old son Caleb. Thank you for the opportunity to introduce myself.

I look forward to meeting you in person.



Left to right,
Courtney Pickar, Cathy
Mistir, and Bridgit Cornale.

Phone in your infusion logs!

Many patients with severe or moderate hemophilia (as well as a few other severe but more rare bleeding disorders) are trained and certified by our staff to self infuse (or infuse their child if the child has a severe bleeding disorder) the medication they need to treat or prevent bleeds. These patients are required to keep calendars of the infusions as well as any bleeding episode associated with the infusions. In last quarter's newsletter, we discussed one new way available for patients to record the infusions and bleeds: a personal data assistant (PDA). We are now piloting an additional way for patients to record their calendars or logs of infusions: by phone. The instructions for this are below. We would really like your feedback on this option. Is it easy to use? Can you think of changes that would make this easier to use? Please call us with your comments (414 257-2424).

Instructions for Phone Entry of Infusions

You can now record your factor replacement product infusions by phone. If you choose this method, please call:

1. Once a month if you did not infuse at all. Just say the patient name and the fact that there were no infusions.
2. Once a week for prophylactic infusions (regular preventive infusions). Say the patient name, indicate that these are prophylactic infusions, for each infusion give:
 - the date of infusion
 - the product name
 - the total dose (units)
3. After each dose if you are treating a bleed. Say the patient name and indicate that this is treatment for a bleed. Please also give the following information:
 - The site of the bleed
 - The date and time the bleed started
 - The date and time of the infusion
 - The product name
 - The total dose (units)
4. The phone number is **1-866-INFUSE-0** (1-866-463-8730) or (414) 937-6599
5. This phone number is for a mail box only. It is not for emergencies or medical questions. Please call our direct line for medical questions or emergencies: toll free 1-888-312-2223 or 414 257-2424. The mail box is confidential. The information from your calls will be transcribed by CCBD staff.
6. Please let us know if this is a convenient and useful way for you to record your infusions. Thank you!

Upcoming Programs and Events Sponsored by Great Lakes Hemophilia Foundation

Fun and Educational

June 17-18

ACCESS – Empowering Yourself, Empowering Your Community

Madison Marriott West *

1313 John Q Hammonds Drive

Middleton, WI

August 5, Saturday, from 11:00am – 12:00pm

Betty Brinn Children's Museum or Children's Health Education Center*

Children, ages 2-10, explore the museum while parent's meet with Dr. Joan Gill - Director Comprehensive Center for Bleeding Disorders

Topic - TBD

September 23, Saturday

Walk with the Animals at the Milwaukee County Zoo *

Walk through the zoo and learn ways to live a healthy lifestyle. Specific details to follow.

* You must register for these programs. To register for programs or for more information, please call 414-257-0200 or 888-797-4543.

Be Safe This Summer!

The school year will soon be ending, and summer is just around the corner. That means activities... lots and lots of activities! The summer season in Wisconsin seems so short, and you want to pack in as much fun as you can before it's over and it's back to school time! Here are some helpful hints for making your summer fun, but safe!

1. Make sure you are participating in sports and activities that are recommended by your treatment center and that are deemed safe for people with bleeding disorders. If you don't know which activities are safe and which are more risky, call the CCBD and request a copy of our Sports and Activities List, or the new NHF booklet entitled "Playing it Safe. Bleeding Disorders, Sports and Exercise."
2. Be sure to wear your protective gear. Helmets are a must if you are riding a bicycle, skateboarding, rollerblading or using other types of wheeled vehicles (dirtbikes, 4-wheelers, etc.). Also remember to wear your knee pads, elbow pads and wrist guards if you are rollerblading or skateboarding. Your summer will definitely not be fun if you sustain a fracture and have to wear a cast for the season.
3. If you have hemophilia, be sure to contact CCBD prior to trips out of the area. We will provide you with a "travel letter" that explains your diagnosis and gives treatment recommendations, in the event you need treatment while you are away. If you will be flying and you are on home care, the travel letter will state that you are carrying factor and supplies that must be in your possession at all times and not checked with regular baggage. We will also provide you with the name and contact information for the closest treatment center to the area you will be visiting. This is important in the event you need hemophilia care while you are away.
4. If you are vacationing, make sure you have enough factor replacement for routine prophylactic infusions, plus extra doses in case of an injury, breakthrough bleed, or other emergency.
5. Be sure you are wearing your Medic Alert emblem or carrying a Medic Alert card with you at all times.
6. Be sure to wear a sunblock if you are spending time outside. It is important to protect your skin from sun damage.

Remember, summertime should be carefree and fun. By taking some simple precautions, you should be able to have fun and enjoy the whole summer season!

If You Order Blood Products Through BloodCenter of Wisconsin:

- Please order your product at least 2 business days prior to the desired delivery date. There are no deliveries on the holidays or on weekends.
- Next day or same day deliveries should only be used in emergency/ life threatening occurrences. This service is not to be used as a convenience!
- Please tell Samantha right away if changes to your insurance occur to prevent problems with your claims.
- Every order must be approved by a CCBD nurse. If you are behind in your infusion calendars, this can delay the process. (This is true for any pharmacy.)

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: _____

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.
