



November 2009

In Transition – Tyler Schweder's Adventure

The transition from parent-centered infusion to self infusion is an adventure for many young patients. Often, it starts with a trip to hemophilia camp, practicing that first IV start in a room full of young people all learning together.

The need to “put on a brave face” in front of your peers can help patients overcome a very natural reluctance to stick themselves with a needle. It’s a challenge to take on a responsibility that parents have previously owned, but it’s also a right of passage for every hemophilia patient.

Tyler Schweder, age 12, is one young man who has stepped up to the self infusion plate and hit a home run! Tyler, a 6th grader at East Troy Middle School, is now an accomplished self infuser. With the support and encouragement of his parents, Tyler made this important transition after learning the basics at camp and working with Dr. Moss. To celebrate his success, Dr. Moss presented him with a special bracelet after a recent home visit. Tyler plans to wear his bracelet as a reminder that he can overcome many challenges in life, including managing his bleeding disorder.

When asked what the easiest thing about the infusion process was, he responds: “Mixing up and pushing in the factor.” The hardest thing is “definitely getting over sticking yourself with the needle and getting into the vein,” he says. His advice to others is “the earlier you start (self infusing) the better!”



Another Option for Infusing Factor

Learning to infuse clotting factor concentrate to prevent and treat bleeds takes time and courage for boys who have hemophilia. For Zachary Albert, an outgoing 20-year-old, it has been an even bigger adventure.

Zachary Albert transferred to CCBBD in October 2007. Zachary has a challenging medical history: in addition to his severe hemophilia diagnosis, he was diagnosed at age four with leukemia (now in remission) and developed partial paralysis on his right side that same year from a head injury and resulting brain bleed. The partial paralysis and weakness caused him a great deal of pain. He spent time in a wheelchair before having orthopedic surgery in 2007. Now, he is able to walk and even ride a bike.

When he was very young, Zachary had a Medaport implanted surgically for factor infusions, but it was removed in 2008 following an infection. Although he wanted to be able to infuse himself peripherally, his right side paralysis and weakness made this impossible, so his mother administered his factor infusions.

In late 2008, Dr. Gill, CCBBD's Medical Director, presented Zachary and his family with another option: an AV (Arterio-Venous) Fistula. This is a surgical procedure often used for kidney dialysis patients to establish a connection between an artery and a vein. When this connection "matures" after the surgery, the vein enlarges enough to promote easy access for infusions. Zachary and his family agreed to try the procedure and his AV Fistula surgery was scheduled for early 2009. By July 2009, Zachary was able to infuse himself (with his non-dominant left hand) using the AV Fistula in his right upper forearm. He reports that it is much easier to infuse with the Fistula, although it still requires some skill. The

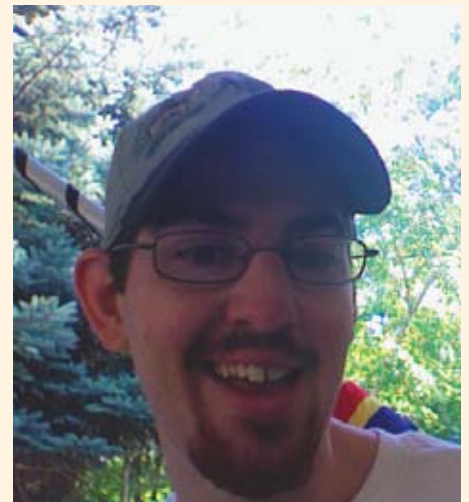
Fistula has given Zachary more control over his own medical care. He infuses 2-3 times a week and rarely experiences bleeds.

Perhaps because of his many medical crises, Zachary is a very compassionate and caring young man. He volunteered this summer at the Salvation Army day care center. He loves working with disadvantaged children, enjoys writing, and is interested in health issues.

Zachary has always exhibited a great deal of determination. He completed high school and college courses concurrently under a Youth Options Program and graduated from North High School in Sheboygan in 2008. He is currently enrolled in

an Emergency Management program at Lakeshore Technical College in Cleveland, WI. His career plans are to get a degree in Emergency Management and find work in that field through the federal

government. In addition to attending college, Zachary works at Wal-Mart and is helping to start a church.



Welcome Dr. Moss!

On July 6, 2009, Dr. Sherry Moss joined CCBD as our first Outreach and Home Care Coordinator. Dr. Moss is a board certified pediatrician with 20 years experience as a private practice physician in Wauwatosa. She graduated from the Medical College of Wisconsin in 1980. In 1983, she completed her pediatric residency at Children's Hospital of Wisconsin. She spent the last year in Green Bay and other points north, caring for families, remodeling houses, and exercising her fondness for kayaking. She is thrilled to join the CCBD staff, and looks forward to growing this exciting new program for BloodCenter of Wisconsin.

"I've learned so much during my brief tenure here at CCBD," says Dr. Moss. "Managing hemophilia and other bleeding disorders is a costly and time consuming task for patients and their families. It's a privilege for me to be invited into their homes, to provide one-on-one care that can make such a difference in their lives. I am truly excited to be a part of the CCBD team, and am committed to helping our patients meet their challenges with grace and good humor."

The mission of CCBD's new Outreach and Home Care Program is to provide in home infusion training to patients in preparation for surgery or to complete post-operative treatment. Dr. Moss will offer comprehensive training to rarely infused patients who have not yet developed self infusion skills. She will also work with families to teach infusion skills to parents, and will promote self infusion skills for all qualified patients, young and old.



Are You Having Surgery or Major Dental Work?

As soon as you know about an upcoming surgery or major dental procedure, please contact CCBD with the following information:

- Type of surgery
- Name, address, and phone number of surgeon
- Date and location of procedure
- Your name and bleeding diagnosis.

For patients with bleeding disorders (hemophilia, von Willebrand Disease, platelet function defects), CCBD will contact your surgeon with important recommendations for avoiding bleeding complications during the procedure.

Patients with clotting disorders taking oral anticoagulants (Coumadin, warfarin) or injection anticoagulants (heparin, low molecular weight heparin) will need a plan for anticoagulation before, during, and after the procedure.

If you are having an elective (non-emergency) procedure, please notify CCBD at least 1-2 weeks prior to allow enough time for proper recommendations to be made to your surgeon. If this is not done in time, your surgery may need to be rescheduled.

If you order blood products through BloodCenter of Wisconsin:

- Please order your product at least two (2) business days prior to the desired delivery date. Remember there are no deliveries on holidays or weekends.
- Next day or same day deliveries should only be used in case of emergency. This service should not be used as a convenience!
- Please inform CCBD immediately of any changes to your insurance coverage that may delay or complicate 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.)

Meet “Pharm Techs” Julie Velasquez and Mark Santiago

My name Julie Velasquez and I have been working at BloodCenter of Wisconsin since 2006. I started out working in the Hospital Services Department as a Customer Services Representative. At the end of my first year, a pharmacy technician position opened up. After the application and interview process was complete, I started out the new year as a pharmacy technician. As the year progressed, I transitioned from splitting my time between both positions to working full time as the pharmacy technician.

My role at BloodCenter includes sending pharmaceutical products to hospitals and home care patients, keeping track of inventory, and ordering infusion supplies for our home care patients, just to name a few.

After being accepted into the pharmacy technician program at Milwaukee Area Technical College, I began the one-year program full time in 2008 and will have my diploma by this December. When I have completed the program, I plan to take the National Pharmacy Technician exam and become a Certified Pharmacy Technician.

I have also been working as a back-up for our patient services coordinator at the Comprehensive Center for Bleeding Disorders. This has helped me to better understand the process of filling patient orders, and has allowed me to meet several of the patients face-to-face. It is my goal to give the best service and care that I can to our bleeding disorder community.

My name is Mark Santiago and I have been working at Blood Center of Wisconsin since October of 2004 as a Customer Services

Representative in the Hospital Services department. The main role of a customer service representative is to work closely with the hospitals and supply them with blood and pharmaceutical products to keep on-hand, as well as for emergencies. After my first year, I took on more responsibility as a trainer of new employees in my department. Although we strive to go above and beyond to serve our hospitals, our main focus has always been on the patient.

Recently this year I was given the opportunity to take on another role, that of a Pharmacy Technician. Because Blood Center of Wisconsin continues to grow and change with the number of patients that we care for, more assistance was needed in this area. I was more than happy to come aboard and learn about this whole other aspect of BloodCenter. I am looking forward to working with the staff and patients of CCBD.



Holiday Product Delivery Schedule

It's hard to believe, but the holidays are fast approaching! Now is the time to address supply orders and product delivery from BloodCenter of Wisconsin.

Be sure to double check your inventory on a weekly basis. 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. Remember, there are no deliveries on holidays or weekends. A great deal of background information is necessary to process your order, so waiting until the last minute may delay your delivery. (Although BloodCenter of Wisconsin drivers can make next day or same day deliveries in an emergency or life threatening event, this service should never be used as a convenience!)

In addition to holidays and weekends, CCBD is closed and unable to process orders on the following days:

- Thanksgiving Day (November 26) and the day after (November 27, 2009)
- December 24 and 25, 2009
- New Year's Day, January 1, 2010

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

ON THE WEB

The CCBD webpage is hosted on the BloodCenter of Wisconsin site: www.bcw.edu/CCBD.

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.)

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: _____

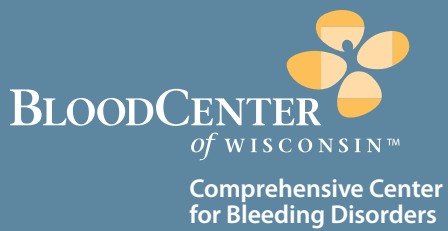
DOB: _____

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.***
