

# CCBD Connection

November 2016

## Families Use Software App to Manage Hemophilia

CCBD hemophilia patients are using a smart phone application to help track their condition and share information with their care team. Patients (or parents) use the app to keep track of factor infusions, doses and bleeding incidents, and get reminders using an electronic calendar. They can also take photos of bleeds and send them electronically to the Comprehensive Center for Bleeding Disorders so care teams can advise as needed.

About 12 CCBD patients so far are using the MicroHealth Hemophilia app, which is compatible with iPhone, iPad, iPod Touch and Android devices. Other hemophilia apps are available, but MicroHealth is the app most commonly used by CCBD patients and staff. It is free and available online, with English and Spanish versions.

The app helps reduce the use of paper forms, calendars and stickers to keep track of infusions, medications and medical appointments. Patients can quickly email or send information via the app, instead of having to mail, fax or take lots of papers to clinic visits. Some versions of the app can scan barcodes on factor boxes to automatically record lot number, expiration date or dose.

"I've been so impressed with the detail our patients provide with the MicroHealth electronic calendar," said Dr. Sheryl Moss, Outreach Coordinator at CCBD. "This is a fantastic tool because patients and providers can quickly see bleed frequency at any time. In this app, bleeds appear in a different color than your prophylaxis. Patients can easily spot a problem and call the center. We can then adjust treatment plans instead of trying to reconstruct a calendar at your clinic appointment," she said.

### Two Moms Who Are Making it Work

Two Milwaukee-area moms have been dedicated app users, and they say it has made life easier.

Julia Morales, whose 5-year-old son Miguel has Hemophilia A Severe, has used the MicroHealth app on her iPhone for at least 4 years. She learned about it from her older brother, who also has hemophilia. Julia uses the app to get reminders for factor. If her son has a bleeding incident, it makes it easy to keep track of when

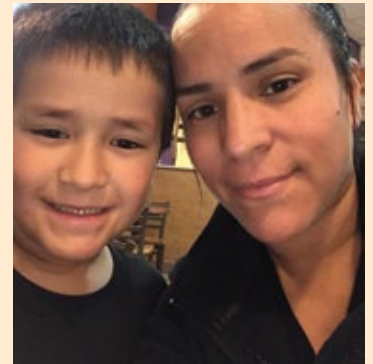
and why he may need an extra dose.

"I think the app is awesome," Julia said. "It's not hard – all you have to do is click to send the information. It makes your life a whole lot easier. If we go on vacation, I don't have to bring all the paperwork I used to. I just have to bring all of his supplies. It's also easier to fit all of the info into the app. If you have any problems with it, you can ask MicroHealth. There are other apps out there, but this one seems like the easiest and most convenient to use," Julia added.

Christina Ruiz, whose 4-year-old son Yadir has Hemophilia B Severe, has used the MicroHealth app for about two years. She uses it on her Android phone to see reminders and keep track of her son's bleeding incidents. She also takes photos of any bumps or bruises her son gets, then sends the photos to CCBD so they can advise her about extra factor doses if needed – which she can keep track of more easily with the app.

"It makes life easier," Christina said. "It's simple to use with easy steps to follow, and I've had no problems with it. It syncs up with Gmail and Google calendars, and it's a lot easier to stay on the infusing schedule on a regular basis," she said.

If you are interested in using the MicroHealth Hemophilia app, please call CCBD at 414-257-2424. Our nurses can explain how to use the app and answer your questions.



Above: Julia Morales and her son Miguel.

Below: Christina Ruiz and her son Yadir.



# 2016 GLHF Hemophilia Walk at Milwaukee County Zoo

Thanks to all CCBD staff and families who participated in the 2016 GLHF Hemophilia Walk at the Milwaukee County Zoo Sept. 24! CCBD was proud to support the Hemophilia Walk this year as a sponsor and through our team participation. Our team, the Milwaukee Globeclotters, raised \$329 with 29 members participating.



There was a great energy at the walk as we joined more than 400 other walkers. This year, the Great Lakes Hemophilia Foundation raised more than \$70,000! These dollars will support Wisconsin families through programs like the Wisconsin Bleeding Disorders Conference, Camp Klotty Pine, Family Camp and scholarships.



## CCBD Holiday Hours

Our normal business operating hours are Monday - Friday, 8:30am - 4:30pm.

If an urgent matter arises after hours or on a holiday, please contact the hematologist on call.

**For (ADULT) patients 18 years old and older call:**

- Froedtert Hospital 414-805-3000 (ask to speak to hematologist on call)

**For (CHILDREN) patients 17 years old and younger call:**

- Children's Hospital 414-266-2000 (ask to speak to the hematologist on call)

## Holiday Office Hours

**Open Monday–Friday, 8:30 am to 4:30 pm**

**Closed**

**Christmas: Monday, December 26, 2016**

**New Year's: Monday, January 2, 2017**

# Open Enrollment for Health Insurance: Now's the Time

As Fall brings changing colors and cooler weather, it's also the time of year many employers will notify employees of upcoming changes to your health insurance. This time period is called open enrollment, and it varies from employer to employer.

Did you know if you do not have access to employer insurance you may be able to enroll in health insurance through the Health Insurance Marketplace? The Marketplace also has open enrollment once a year. Some people may even qualify for Medicaid. If you have questions about enrolling in health insurance, please contact CCBD and ask to speak with a social worker.

## MyChart is available. Sign up today!

MyChart lets you view portions of your medical record online. It's free, and a safe and secure way you can help manage and receive information about your health. MyChart offers patients personalized and secure online access to portions of their medical records. You can:

- View medical history, including medications, immunizations and allergies
- Receive most outpatient lab results online
- Access trusted health information resources
- Send secure messages to your provider
- Request prescription renewals online
- Track your child's growth

To create a MyChart account at Children's Hospital of Wisconsin, your provider must give you an activation code during a clinic visit. Once you have the activation code, you have 60 days to go to [mychart.chw.org](http://mychart.chw.org) and activate your account. If not used, the code will expire after 60 days. For general MyChart questions, send an e-mail to: [MyChartSupport@chw.org](mailto:MyChartSupport@chw.org), or call the MyChart Patient/Family Support Line at 414-266-6678.

### Answers:

A. Because he had the drumsticks! B. The outside! C. The MOO-flower! D. Because it's in KNOW-ember! E. Quack! Quack! Quack! F. Because they suspected it of FOWL play!

### Important dates to remember for the Health Insurance Marketplace:

- November 1, 2016: Open Enrollment began. It was the first day you could enroll, re-enroll or change a 2017 insurance plan through the Health Insurance Marketplace. Coverage can start as soon as January 1, 2017.
- December 15, 2016: Last day to enroll in or change plans for coverage to start January 1, 2017.
- January 1, 2017: 2017 coverage starts for those who enroll or change plans by December 15.
- January 31, 2017: Last day to enroll in or change a 2017 health plan. After this date, you can enroll or change plans only if you qualify for a Special Enrollment Period.

## Turkey Time

(Answers below)

- Why did the musicians let the turkey join the band?
- Which side of the turkey has the most feathers?
- The pilgrims' cows came to America on what ship?
- Why is Thanksgiving such an intelligent holiday?
- What did the turkey say to the turkey hunter?
- Why did the police arrest the turkey?

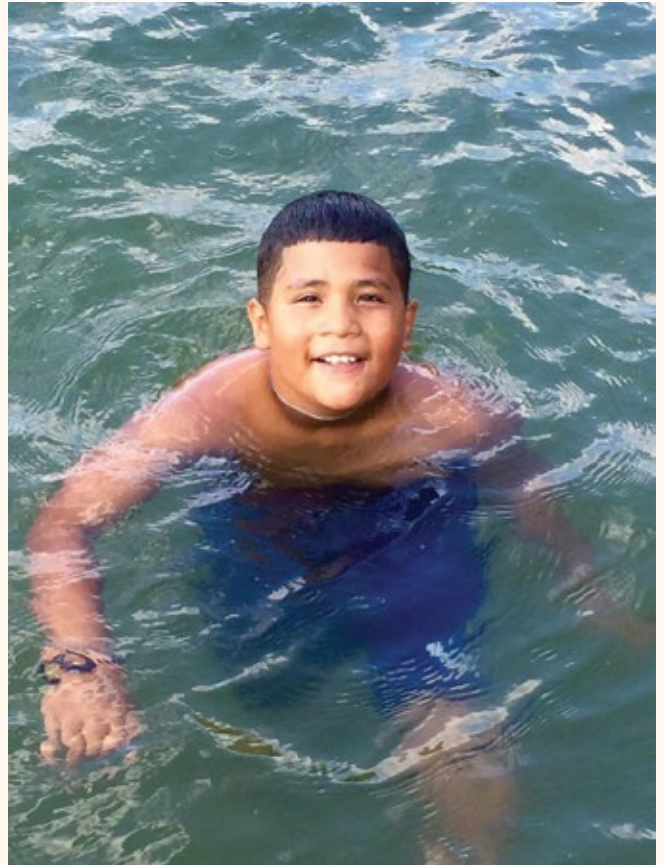


# Camp Klotty Pine – Summer 2016

For the third summer in a row, Great Lakes Hemophilia Foundation (GLHF) helped kids with bleeding disorders develop independence as well as life-long friendships through a week-long summer camp experience at Camp Klotty Pine in Wautoma, WI. This past summer, 37 kids attended the camp, 19 of whom are patients of The Comprehensive Center for Bleeding Disorders. Excitement continues to grow as more and more families learn about the benefits of kids connecting with other kids within the bleeding disorder community, in a safe and fun camp environment.



The mission of Camp Klotty Pine is to enhance the lives of children affected by a bleeding disorder by providing life-changing camp experiences that are exciting, empowering and educational. Children ages 7 to 15 take part in activities such as swimming, canoeing, hiking and fishing. They also learn how to self-infuse from a collaborative effort of various volunteer medical staff from The CCBD, Hemophilia Outreach Center (Green Bay) and The Comprehensive Program for Bleeding Disorders (University of Wisconsin Hospital and Clinics). CCBD staff members at camp this year were: Dr. Shawn Jobe; Dr. Sheryl Moss; Tiffini Mueller, RN; Corbett Reinbold, RN; Bridgit Hansen-Helminski, RN; and Traci Knebes, MSW.



To learn more about Camp Klotty Pine, talk with your HTC social worker, contact Great Lakes Hemophilia Foundation, or visit [glhf.org](http://glhf.org).



# Say Hello to These CCBD Staff

## BloodCenter of Wisconsin Comprehensive Center for Bleeding Disorders Staff

### Dr. Lynn Malec

Dr. Lynn Malec recently joined our CCBD team. Dr. Malec attended medical school at the University of Wisconsin School of Medicine, and completed her training in Internal Medicine and Pediatrics, and specialty training in Hematology/Oncology, at UPMC/Children's Hospital of Pittsburgh, in Pittsburgh, PA. Most recently Dr. Malec served as Associate Director for the HTC in Pittsburgh, the Hemophilia Center of Western Pennsylvania. She is passionate about caring for both adults and children with bleeding and clotting disorders as well as participating in patient-related research in this area. Dr. Malec recently relocated to Wisconsin with her husband Dave and daughter Estelle and is excited to join the CCBD team.



### Dr. Sharma

Dr. Ruchika Sharma joined BloodCenter of Wisconsin and CCBD staff in September 2016. She will start seeing CCBD patients in January of 2017. Dr. Sharma comes to us originally from New Delhi, India and most currently from Columbus, Ohio's Nationwide Children's Hospital/The Ohio State University. She has a specific interest in Benign Hematology, Hemostasis and Thrombosis, and Young Women's Hematology. Dr. Sharma has an extensive background of presentations, awards, honors and publications. She obtained her medical education in New Delhi at Maulana Azad Medical College and her internship and residency in pediatrics at the University of Toledo in Ohio.



### Michelle Zeirke, Nurse Coordinator

Hi – I am Michelle, the new nurse coordinator at CCBD, and I'm excited to be part of this team! I will mainly work with patients who have von Willebrand's disease and clotting disorders. I earned my bachelor's degree in Nursing from Alverno College. I began my career as a staff nurse in the Pediatric ICU at Children's Hospital of Wisconsin. I have also worked in home care settings and was a school nurse during the past several years. I believe my experience will be helpful in caring for patients here at CCBD.



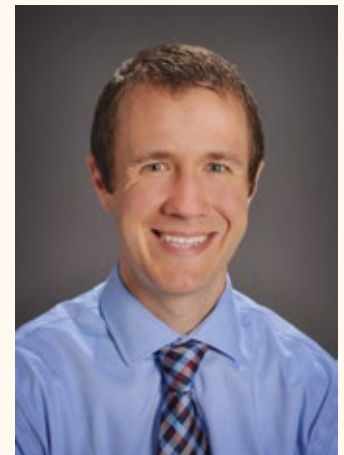
In my free time I enjoy the outdoors – at the dog park with my border collie, or hiking, walking, fishing and boating. I also love traveling and trying new foods and experiences. I look forward to getting to know everyone. Please don't hesitate to contact me.

### Children's Hospital Staff

**Jeffrey Karst, PhD**  
Assistant Professor,  
Psychology, Pediatric  
Hematology/Oncology/BMT

Children's Hospital of  
Wisconsin

Medical College of Wisconsin,  
Children's Specialty Group



**Lindsey Ray, PA-C**  
Hematology  
Children's Hospital of  
Wisconsin



## Abshire Appointed to Versiti Leadership Team

We are happy to announce that Dr. Thomas Abshire has been appointed to serve in the new role of Versiti Chief Medical Officer in addition to his Medical Sciences Institute position. As Dr. Abshire directs his attention to serve even more patients in a greater geographic area through our Versiti affiliation, his time at the Comprehensive Center for Bleeding Disorder (CCBD) will be minimized. Beginning January 1, 2017, patients who have previously seen Dr. Abshire will have the option to see another of our outstanding hematologists from the CCBD team. Dr. Abshire thanks the many patients and families he has had the privilege to get to know over the years, and is grateful for the opportunity to provide their care.

## Holiday Product Ordering & Delivery Schedule

With the holidays fast approaching it seems like a good time to address product delivery from BloodCenter of Wisconsin.

Please be aware of your inventories (product and supplies) at all times, and double check them on a weekly basis to assure proper inventories. You should never have less than 2 to 3 doses on hand at any time. At this time of year, place product orders when you have 4 to 5 infusions remaining at home, as delivery times may not be running as usual. If you are going on vacation, please order enough for the ENTIRE vacation, PLUS another 3 infusions.

Place your order at least 2 days prior to the desired delivery date, taking into consideration any upcoming

holiday or weekend. There is a lot of background information needed to process your order, and waiting until the last minute may delay your delivery.

***Although BloodCenter of Wisconsin drivers can make next-day or same-day deliveries in emergency/life-threatening occurrences, this service should never be used as a convenience.***

Keep in mind there are no deliveries on the holidays or on weekends. Additionally, CCBD is closed on the following days, and therefore there will be no staff available to take any orders:

- Monday, December 26, 2016
- Monday, January 2, 2016

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

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

New Phone Number: \_\_\_\_\_

DOB: \_\_\_\_\_

New Dentist or Primary Doctor: \_\_\_\_\_

New Address: \_\_\_\_\_

Office Phone Number: \_\_\_\_\_

City, State, Zip Code: \_\_\_\_\_

Is this the address of patient's:

MOTHER      FATHER      BOTH



PART OF VERSITI

Comprehensive Center  
for Bleeding Disorders

Non-Profit Organization  
U.S. Postage  
PAID  
Milwaukee, WI  
Permit No. 4426

PO Box 2178  
Milwaukee, WI 53201-2178

Address Service Requested

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***BloodCenter of Wisconsin advances patient care  
by providing life-saving solutions grounded in  
unparalleled medical and scientific expertise.***

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