

## coming events >>>

**\*Parents Empowering Parents:** A weekend support program for parents of youth up to age 8. This is a nationally recognized program and will be conducted by a PEP social worker, nurse and two parents in BOTH the Upper Peninsula and Lower Peninsula.

**\*Steps for Living:** Topics can include transitions, women & girls, overall bleeding knowledge (Jeopardy), bullying behaviors, sibling support or safety and artistic expression.

**\*Insurance, Primary Care and Specialty Care:** The benefits to patients and families in having all of these, and patient responsibilities.

**\*Recommended by Patients Prior:** Women and Teen Girls; Aging with a Bleeding Disorder; Hemophilia, HIV & Hep C; Transitions – It's a Process at All Ages; Patient Assistance Programs – What's there for me?



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A Bi-yearly Newsletter from the MSU Center for Bleeding & Clotting Disorders

# CBCD details

## friendly reminders >>>

### Need pain medications?

#### Important Reminders

- These require hand-written prescriptions that can not be faxed to your pharmacy.
- Signatures will be obtained weekly on Thursday for mailing or pick up on Friday, please allow ample time for processing.

### Having Surgery?

#### Important Reminders

- All patients must attend clinic in the month prior to planned surgery or major procedures. We will coordinate directly with your surgeon.
- Call the office about procedures too! Colonoscopy, dental work, and biopsies (among others) all have a risk of bleeding. Help us help you by being proactive!

*Every patient at every clinic visit needs to bring their current insurance card, a list of medications, and contact information for their Primary Care Physician or referring provider or surgeon.*

## Primary Care Pros(e)

### 5 Reasons You Need a Primary Care Physician

*Managing your disease is hard work. And if you add multiple doctors to that, the result can be overwhelming. The good news is that your Primary Care Physician (PCP) is specially equipped to handle all of your medical needs. Here are five ways your PCP makes the best first step for your care.*

- **Preventative Care:** High blood pressure, despite it's name is probably not related to your bleeding disorder. Your PCP provides screenings for common ailments like high blood pressure, as well as helping you identify problems that you can work on together to correct before they get out of hand.
- **Continuity of Care:** It is important for everyone to be able to maintain their health over their lifetime. A PCP treats a patient as a whole while taking into account their history, family history and existing conditions.
- **Central Point of Contact:** Communication is key in all aspects of life, but it is especially helpful in medicine. Having a PCP gives you a hub for communication. If you have a PCP coordinating all your care (even your bleeding disorder) they can prevent duplication of care or testing and make sure nothing is left out or missed. You may forget to tell one doctor what another has recommended, but your PCP should know it all!
- **Resources:** Your PCP should be your first point of contact for questions about your health. They can offer solutions to questions, recommend specialists who can further your care, and find other resources, support groups or classes.
- **Fewer ER Trips:** Having a PCP who knows you and your history may mean the difference between a long wait in the ER and a restful recuperation at home. An ER can not replace a good relationship with a PCP. Some PCPs reserve appointment times for emergent patient appointments and most PCPs can call in a prescription or suggest an action plan that you can use at home.

*As your bleeding disorder specialist we are happy to be a cog in your health care wheel and we want to continue caring for your hematological needs, but we can't replace the holistic and preventative care your PCP provides. For help finding a PCP in your area call our office.*



## programs >>>

We held another successful **Upper Peninsula Retreat in September at Bay Cliff Health Resort** this year for patients and their families. Although there were several last minute cancellations the week and day of the Retreat, the weather was perfect and the presentations provided a balance of medical education, recreation, team building and supportive conversations. Educational highlights included: Goal-development & Transitions by Inalex Communications; New Research & Medications by Dr. Renuka Gera; Physical TRX Strengthening, Yoga & Paddle boarding by Kristina Neil; Playing It Safe For Kids, Do You Bleed Like Me, and a Family/Staff Jeopardy Game of Bleeding Disorders by NHF Steps for Living; Stress & Mindfulness by MSU Extension; and PEP 101 for New Parents. Sunny, calm fall weather enabled the participants to enjoy lots of recreation and support activities throughout the weekend. We were able to have an early morning fishing trip and late evening pontoon boat rides in addition to the regular pool exercise, open family pool time, massage therapy and beach walks.

The UP Fall 2015 Retreat was possible due to the financial support of the MSU CBCD Patient Education Fund, Bayer, Baxalta, Biogen Idec, Emergent Bio-Solutions, Grifols, The Hemophilia Alliance, Hemophilia Foundation of Michigan, Inalex Communications, National Hemophilia Foundation, NovoNordisk, Octapharma, Option Care and Pfizer, Accredo, CVS Caremark and Matrix provided give-away items. A special thank you to the MSU CBCD Staff & Physicians who supported this weekend and to Stephanie and Dustin VanDuine who volunteered their time with dental and youth activities!

We held our annual **Lower Peninsula Picnic and Summer Education Program** at Potter Park Zoo. Almost 70 patients, family members and CBCD staff participated in this August event. Youth participated in the "Playing It Safe for Kids" Steps for Living activity with research nurse Julie Rose and social worker Marcia Bird. Teens and adults enjoyed a presentation by the Genetics Counselors (Joe Jacher and Shelia Saliganan) and their interns, and were able to ask specific family questions. All attendees participated in a SFL Scavenger Hunt to learn more about different bleeding disorders and meet new people. The event was funded by the CBCD Patient Education Fund and a NHF Steps for Living grant.

We hope to see more youth, teens and adults at upcoming educational and support events. Please complete the on-line **Survey Monkey @ <http://www.surveymonkey.com/r/B9H8Jp2>** to provide suggestions for programs and events you would be interested in attending in the future.

Please contact Marcia Bird, MSW at (517) 432-5127 if you are interested in attending or assisting with any of these programs, the ones listed in the coming events section on the front page, or if you need a paper copy of the survey.

## Insurance Changes that affect YOU!

**CSHCS (Children's Special Health Care)** annual plans of care and financial agreements are mandatory for yearly enrollment. You must contact your County Health Department to maintain your enrollment. DO NOT ignore the 90, 60 and 30 day letters and phone calls from the state and county.

**Michigan Medicaid & Expanded Medicaid (Healthy Michigan)** is available to anyone not in another Medicaid or Medicare plan that earns up to 133% of Federal Poverty. Apply for all Medicaid and Healthy Michigan Plans by calling 855-789-5610 or by visiting [healthymichiganplan.org](http://healthymichiganplan.org) OR [mibridges.michigan.gov](http://mibridges.michigan.gov). Please also note that if you are enrolled in Sparrow PHP through Medicaid or Molina Healthcare through Medicaid, MSU clinics will no longer be a participating member as of January 1, 2016. You have likely already received notice by mail that you need to renew your Medicaid program before the end of the year, please DO NOT ignore these messages, but take this opportunity to make any necessary changes. Also, look for a generic letter from the MSU billing department outlining the need for change and how to do it. To avoid problems with coverage other options available are McLaren PHP and Blue Cross Complete, both through Medicaid. If you have questions about this please contact Marcia Bird, social worker, at 517-432-5127.

**MiChild** will be converted to a Medicaid Health Plan under the Expanded Medicaid Program in Michigan. There will be no gap in service but you must

respond to any letter that is received by the Michigan Department of Health & Human Services. MDHHS will continue to provide dental coverage for MiChild enrollees; however, it will be under the Delta Dental/Healthy Kids Dental Program and NOT Golden Dental. If you have to switch plans, please pick one that has MSU CBCD physicians as an approved MiChild/Michigan Medicaid Provider. Call 800-292-2550, email [ProviderSupport@michigan.gov](mailto:ProviderSupport@michigan.gov), or visit [www.michigan.gov/mdhhs](http://www.michigan.gov/mdhhs) for the MiChild Provider website.

If you do not have commercial or Medicaid dental coverage, you may qualify for the HFM/Cascade/Delta Dental Plan. If you are re-enrolling, please complete the forms that you receive from HFM making sure all questions are answered for new or renewal applications.

## research >>>

## Research Improves Care!

*Our research office is busier than ever with twelve new studies opening early next year. Be a part of advancing care in the future! Studies range from questionnaires, to observational studies with just a blood draw or two, to full clinical drug trials. If you're interested, please call the office and speak with Kathleen or Julie. We are currently enrolling children and adults with hemophilia, vWD and thrombosis. You can find more information at [www.clinicaltrials.gov](http://www.clinicaltrials.gov), or by calling the office at (517) 353-9385 or toll free at 1-800-759-5595.*





# Track It!

## What You Need to Know About Logging Your Bleeds & Factor Infusions

You've probably heard this many times from your hematologist and our nurses: You need to keep logs of your factor usage and bleeds! Well, they are right. There are many benefits to keeping accurate records of the factor you use and the bleeds you treat. As the world becomes more technology oriented, there are also new, more efficient ways to keep logs. Here are the why's, what's and how's of factor logging.

## WHY?

- ⇒ **Optimal Treatment**—keeping a factor infusion and bleeding episode log will help in recognizing patterns of bleeds and infusions. Do you frequently bleed on Saturdays while doing prophylaxis on Monday and Thursday? Adjusting prophylaxis days to Wednesday and Saturday could help you prevent those breakthrough bleeds, but it is hard to recognize patterns if you don't keep a log.
- ⇒ **Insurance**—that's right, some insurance companies are requiring you keep a treatment log to ensure you are using factor as ordered, as a condition for continued reimbursement. This may become more common in the future, so get in the habit now.
- ⇒ **Disability Benefits**—If you need to apply for financial help from the Social Security Administration or your employer, having a clear record of your bleeding episodes will make it much easier.
- ⇒ **Factor Recalls**—this may be rare, but if you have a complete infusion log you will be able to check specific lot numbers you used in the past against those recalled.

## WHAT?

Record this information each time you have a bleed and/or infuse.

- ⇒ For Prophylaxis Infusions:
  - The date and time of infusion
  - Name of factor, expiration date & lot #.
  - Number of units infused
  - Reason for infusion (scheduled or pre-activity)
- ⇒ For Bleeding Episodes:
  - All of the above
  - Date and time of the bleed
  - Location & Severity of the bleed
  - Cause of the bleed, or whether spontaneous
  - Other treatment: pain medication, ice, compression wrap, etc.

## HOW?

- ⇒ Handwritten Factor Log Sheets or Factor Calendar Logs: These can be obtained from our clinic and should be exchanged at your yearly comprehensive clinic visit or earlier.
- ⇒ ATHN Advoy Website (or iPhone app): Once you have registered through our clinic you can download the app or login on the website to record data. Our nurses can then login and see your data in real time.
- ⇒ Smartphone Apps:
  - Beat Bleeds: This app allows you to log infusions and bleeds, track your Annual Bleed Rate and email your logs directly to our nurses.
  - MicroHealth: HIPAA compliant platform that syncs across devices. Allows you to connect to our nurses through the app and to receive personalized reminders.
  - Other apps to check out: HemaGo, HemMobile, FactorTrack, Hemo-Tool, HemoTrax, MyFactor.

## Welcome to the team!

### Santosh Hanmod, MD

*Pediatric Hematologist*

*Dr. Santosh Hanmod received his medical degree from Grant Medical College and earned his Masters of Public Health from the University of Texas. He completed his pediatric residency at Children's Hospital of Michigan at the Detroit Medical Center and continued on there for three years of clinical fellowship in pediatric hematology/oncology. Dr. Hanmod spent the last year as an instructor of clinical pediatrics for the Cancer and Blood Diseases Institute at Cincinnati Children's Hospital before joining us here at MSU.*

*Dr. Hanmod joins our comprehensive-care team as a board-certified pediatric hematologist/oncologist.*





## Michigan State University

Center for Bleeding & Clotting Disorders  
2900 Hannah Blvd. Ste. 202  
East Lansing, MI 48823

Phone: 517-353-9385  
Fax: 517-353-9421  
E-mail: [hemophilia@hc.msu.edu](mailto:hemophilia@hc.msu.edu)

**SPARTANS WILL**



Bring your genetic-specific questions to your next comprehensive clinic appointment where you will have the opportunity to meet with Joseph Jacher, our genetic counselor.



## MICHIGAN STATE UNIVERSITY

DEPARTMENT OF PEDIATRICS AND HUMAN DEVELOPMENT  
DEPARTMENT OF MEDICINE

### CENTER FOR BLEEDING & CLOTTING DISORDERS



*John Penner, MD, F.A.C.P, Professor, Director*  
*Roshni Kulkarni, M.D., Professor, Director*  
*Renuka Gera, M.D., Professor*  
*Ajovi B. Scott-Emuakpor, M.D., Ph.D., Professor*  
*Diane MacDonald, M.D., F.A.C.P, Associate Professor*  
*Aghiad Chamdin, M.D., Assistant Professor*  
*Santosh Hanmod, M.D., Assistant Professor*  
*Diane Willman, PA-C*

Michigan State University  
2900 Hannah Boulevard,  
Suite 202  
East Lansing, MI 48823  
Telephone: (517) 353-9385  
Fax: (517) 353-9421