

PRESENTED ONLINE VIA ZOOM
Saturday, June 12, 9:30a - 5p



wwd

Von Willebrand Education Day & Symposium

Connection, education,
community, belonging, hope
& fun await you!

Saturday, June 12

9:30a **Welcome**

Introductions and agenda overview

- **Speakers:** Susan Fenters Lerch, HFM Executive Director, Federal Great Lakes Region V-E Network HTC Director, Ypsilanti, MI; Takeda

9:45 – 10:45a **VWD in Males**

VWD in men and boys is not usually a primary focus of medical research and education. This session will look at the diagnosis of VWD in males. We will have a time to share stories and discuss treatment recommendations available. Bring your questions about yourself, your spouse, or your child with VWD with an emphasis on men who have this diagnosis.

- **Speakers:** Jim Munn, MS, BS, BSN, RN-BC, Program Administrator, Nurse Coordinator, Hemophilia/Coagulation Program, University of Michigan Health System, Ann Arbor, MI; Donal McCann is a self-employed agricultural mechanic, Type 2a VWD, member of the AFFIRM program along with various other organizations; Cody Kester, first responder with VWD Type 3, member of the AFFIRM program, former president of the Hemophilia Foundation of Arkansas.

10:50 – 11:45am **VWiD – a Session by Takeda**

A patient presentation to learn about VONVENDI® in the treatment of adult patients with VWD.

Our goal is to continue to educate the von Willebrand disease community with impactful, relevant von Willebrand disease programs. The VWiD program provides the opportunity for members to hear stories, receive information, and connect with other members of the community.

- **Speaker:** Jean Marandola, Clinical Specialist, Takeda
- ◆ Session sponsored by Takeda

11:50a – 12:30p **Round Robin Discussion with Industry Partners**

Fill in your **BINGO card** to have a chance to win a prize!

12:35 – 1:40p **Lunch Session: Ask The Expert – VWD**

Our expert medical providers will answer your questions related to diagnosis and treatment of VWD. Although they cannot provide specific medical advice, they can respond generally to common VWD concerns.

- **Speakers:** Roshni Kulkarni, MD, Professor Emerita of Pediatrics and Human Development, and former Director for the Michigan State University Center for Bleeding and Clotting Disorders, Lansing, MI; Shawn M. Jobe, MD, PhD, Medical Director for the Michigan State University Center for Bleeding and Clotting Disorders, Lansing, MI

1:40 – 1:50p **Break**

1:50 – 2:50p **Educational Breakout Sessions (Choose One)**

- 1 The Basics of VWD**

This session discusses the different types of VWD, symptoms, and diagnosis. You will also learn more about what to expect at the doctor when you're first diagnosed and receive a brief overview of treatment options.

- **Speaker:** Skye Peltier, MPN, PA-C, instructor, Augsburg University, Minneapolis, MI
- ◆ Session sponsored by Hemophilia Federation of America

- 2 Disease State: The Science Behind Your Bleeding Disorder – Von Willebrand Disease: A to Z A Session by Takeda**

Get to know inheritance patterns and types of VWD and its various symptoms, including those that are specific to women. Treatment approaches available to people living with VWD will be described, as well.

- **Speaker:** Jean Marandola, Clinical Specialist, Takeda
- ◆ Session sponsored by Takeda

3 Important Life Milestones for Children with VWD

We'll investigate the challenges for parents and children during all life stages.

■ **Speaker:** Mary Jane Frey, RN-BC, BSN, CPN, Midwest Hemophilia Nurse Advisor

◆ Session sponsored by CVS Specialty

2:50 – 3p Break

3 – 3:50p VWD New Guidelines, 2020

Dr. Weyand will review the new guidelines for diagnosis and treatment of VWD.

■ **Speaker:** Angela Weyand, MD, Pediatric Hematology/Oncology, University of Michigan Health System, Ann Arbor, MI

3:55 – 4:50p Overview of Von Willebrand Disease

This interactive program will provide a history of VWD, its diagnosis, laboratory testing and classification of subtypes, as well as the current trends in the management of VWD, including the consensus data on reproductive issues.

■ **Speaker:** Liz Schwab, PharmD, BCPS, Medical Science Liaison, Grifols

◆ Session sponsored by Grifols

4:50 – 5p Wrap-up, Bingo Winner, Evaluation

round robin guidelines

The Round Robin was created to provide you with information and to offer a space to ask questions. This is your opportunity to interact with industry representatives in a small group setting.

Here is what you can expect:

You will be placed in a small group with other event attendees for industry rep meetings, which we call "Round Robins." Each industry rep meeting will be brief but full of information. At the end of the allotted time, the industry reps will rotate so that you and the others in your group will have the opportunity to interact with each company. Once you enter the Zoom room, you will stay put, so don't worry about having to navigate between multiple rooms.

You do not need to do any preparation. Industry reps will come prepared with a topic, video, or information that they would like to share with you.

A HFM staff person will be present to keep conversation flowing, to keep everyone on track with time, and to answer any questions that you may have about the process.

You can also expect:

Industry reps will not ask you about your personal medical history, treatment, or bleeding disorder.

Industry reps will not offer medical advice as this is a conversation that should take place between you and your healthcare team.

Here is what we ask of you:

Please come ready to participate with the people in your small group and the representatives. Ask any questions that you may have.

Please consider keeping your camera on. The quality of your experience is largely dependent on the participation of everyone.

The Hemophilia Foundation of Michigan (HFM) exists to enhance the quality of life for all affected by bleeding disorders. **HFM does not endorse any specific product or company.**



Frey



Jobe



Kulkarni

Mary Jane Frey, RN-BC, BSN, CPN, Midwest Hemophilia Nurse Advisor, CVS Specialty

Ms. Frey (also known as Missy) is currently the CVS Health Midwest Bleeding Disorder Nurse Educator. Previously she was the hemostasis/thrombosis coordinator at Children's Hospital of Michigan in Detroit. She started with hematology/oncology patients initially in 1982 and then transferred to the bleeding disorders community in 2003. Her duties in that position included education and management of the hematology staff, coordinating education and care of patients with hemophilia, VWD, bleeding disorders and thrombosis. She also enjoys being active in the local camp for bleeding disorders patients. Missy has contributed to publications, abstracts and posters, and is an active speaker to patients, parents, teachers and health care members on bleeding disorders topics at local, national, and international venues. Missy is licensed as a registered nurse in several states and currently has both a Hemostasis Nursing and Pediatric Nursing Certification.

Shawn M. Jobe, MD, PhD, Medical Director for the Michigan State University Center for Bleeding and Clotting Disorders, Lansing, MI

Dr. Jobe is a pediatric hematologist and director for the Michigan State University Center for Bleeding and Clotting Disorders. He has worked in the medical field for over 22 years. He graduated from the Medical College of Wisconsin medical school in 1999. Prior to his 2021 appointment at MSU, Dr. Jobe served patients in Milwaukee, Wisconsin. He has a particular research interest in platelets.

Roshni Kulkarni, MD, Professor Emerita of Pediatrics and Human Development, and former Director for the Michigan State University Center for Bleeding and Clotting Disorders, Lansing, MI

Dr. Kulkarni is currently Professor Emerita of Pediatrics and Human Development and former director of the Michigan State University (MSU) Center for Bleeding and Clotting Disorders, and Pediatric and Adolescent Hematology/Oncology (PHO). She was the director and distinguished hematology consultant, Division of Blood Disorders, at the Centers for Disease Control and Prevention (CDC), Atlanta GA. She is a founding member of the Foundation for Women and Girls with Blood Disorders. She is a member of various professional societies and committees, including the World Federation of Hemophilia Women with Inherited Bleeding Disorders Committee, CDC Joint Outcomes Committee, and Inhibitor Committee. She has been a past member of the Medical and Scientific Advisory Committee of the National Hemophilia Foundation (NHF), American Thrombosis and Hemostasis Network leadership committee, American Society of Pediatric Hematology/Oncology, and the Hemophilia and Thrombosis Research Society. She is a founding member of the MSU Women and Girls Blood Disorders Clinic, a collaborative comprehensive care clinic of the MSU Departments of Pediatrics and Human Development, Ob-Gyn and Reproductive Biology and Internal Medicine. She has received numerous awards that include NHF's "Physician of the Year," the MSU "Distinguished Faculty" award, and distinguished service award from the Federal Drug Administration and CDC and named to the Best Doctors in America since 2007.



Munn



Peltier



Schwab



Weyand

Jean Marandola, Clinical Specialist,
Takeda

Jim Munn, MS, BS, BSN, RN-BC,
Program Administrator, Nurse
Coordinator, Hemophilia/Coag Program,
University of Michigan Health System,
Ann Arbor, MI

Jim is the program administrator and nurse coordinator at the Hemophilia and Coagulation Disorders Program at Michigan Medicine in Ann Arbor, where he has worked since 1996. In addition to caring for pediatric and adult patients at the clinic, Jim has served as chair, vice chair, and regional representative for the National Hemophilia Foundation's (NHF) Nursing Working Group and as the US representative, vice chair, and chair of the World Federation of Hemophilia Nurses Committee. He is a board member of Partners in Bleeding Disorders Education, which provides comprehensive, broad-based education for providers from a variety of disciplines throughout North America's HTC network. Jim also co-founded Adult Fellowship for Integrating Responsible Mentors (AFFIRM) with retired social worker Edward Kuebler, MSW. AFFIRM is a two-year international advocacy and leadership development program to enhance participants' leadership and advocacy skills to improve care, programs, and treatment in their communities.

Skye Peltier, MPH, PA-C, Instructor,
Augsburg University, Minneapolis, MI
Skye Peltier, MPH, PA-C, graduated from the Augsburg PA program in 2005 and has been on the faculty since 2015. She worked in adult Hematology/Oncology at the University of Minnesota after graduating and then moved to the pediatric Hematology/Oncology program at Children's Hospitals & Clinics of Minnesota.

She has also worked in adult and pediatric hemophilia care in Portland, OR. She earned a public health masters degree in community health education from the University of Minnesota in 1999. She worked as a health educator for TAMS (Teenage Medical Services) before going to PA school. She enjoys traveling and has done medical volunteer work in Mexico and China.

Liz Schwab, PharmD, BCPS,
Medical Science Liaison, Grifols
Liz Schwab joined Grifols in 2018 and is currently a Medical Science Liaison and covers the West region of the US supporting coagulation, hematology, and critical care. She lives in Salt Lake City and earned her Doctor of Pharmacy from the University of Oklahoma Health Sciences and completed a post graduate residency in managed care with Intermountain. She is a board certified pharmacotherapy specialist and brings experience from managed care and specialty disease states. Prior to joining Grifols, Liz managed specialty disease patients within a specialty pharmacy and created programs to effectively manage high-risk patients

Angela Weyand, MD, Pediatric
Hematology/Oncology, University of
Michigan Health System, Ann Arbor, MI
Dr. Weyand is a clinical assistant professor at the C.S. Mott Children's Hospital at the University of Michigan and the University of Michigan Hemophilia and Coagulation Disorders program. She graduated from the University of Michigan Medical School, completed pediatric residency at the University of Washington/Seattle Children's hospital, and returned to the University of Michigan for her pediatric hematology/oncology fellowship.

National VWD Resources

The National Hemophilia Foundation (NHF)

<https://www.hemophilia.org/bleeding-disorders-a-z/types/von-willebrand-disease>

People with bleeding disorders and their family members are the center of the work of the National Hemophilia Foundation. We support research that has a measurable impact on people's lives; deliver education that helps people with bleeding disorders and their family members thrive; and advocate for policies at the state and local level that protects access to healthcare.

Hemophilia Federation of America, Inc. (HFA)

<https://www.hemophiliafed.org/home/understanding-bleeding-disorders/what-is-vwd/>

Hemophilia Federation of America, Inc. (HFA) is a patient education, services and advocacy organization serving the rare bleeding disorders community. We are exclusively focused on the bleeding disorders patient and caregiver community.

VWDConnect

<https://vwdconnect.org/mission/>

VWD Connect has been established to serve the bleeding disorder community, focusing on severe Von Willebrand Disease. The Foundation provides education and connection for patients and families, and supports research which will benefit the Von Willebrand Disease community.

The International Society on Thrombosis and Haemostasis (ISTH)

<https://www.isth.org/page/vwdguidelines>

The International Society on Thrombosis and Haemostasis (ISTH) advances the understanding, prevention, diagnosis and treatment of conditions related to thrombosis and hemostasis.

The Society is dedicated to transformative scientific discoveries and clinical practices, the development of young professionals and the education of physicians, scientists and allied health professionals wherever they may live.



community assessment

COMING THIS SUMMER!

Earn a gift card by
responding to
questions about
HFM's programming.

We value your input.

For more information, contact

Patrice Thomas, MS, MSW
Program Services Director
pthomas@hfmich.org

Take selfies during HFM's VWD Symposium!

Sharing photos of your VWD Symposium experience helps us tell the story of this event. Never shared a selfie before? Experiment by holding your phone out in front of you, smile, then take a photo! Remember to send us the largest photo size available on your phone. **Email your photos to: hfm@hfmich.org. Thank you!**

