

International Consensus Expert Panel Meets

It was the first in-person meeting of the International Consensus Expert Panel. Around the table was a collection of researchers, clinicians, patients, and patient advocates from all over the world. VWD Connect's 2023 U.S. National Type 3/Severe VWD Patient Conference was starting to wrap up, and everyone was reeling from a wonderful but long weekend. The conference may have been winding down, but for those gathered in the West Palm Beach Marriott meeting room, work was still getting started. After virtual Zoom meetings and months of emails back and forth, many of the International Consensus Panel members were finally getting to meet face-to-face for the first time. This group, members of a project sponsored by VWD Connect Foundation, had taken on the difficult task of addressing the seemingly simple but deceptively complicated question: What exactly is severe VWD?

For years, the medical community has recognized that Von Willebrand Disease presents on a spectrum, but that there is a subset of patients who struggle with much more severe and/or frequent bleeding than most. Unfortunately, there has never been an agreed upon set of criteria to determine which patients should be diagnosed as having severe VWD. There are many factors that could be considered when establishing a diagnosis of "severe" VWD, including genetic and laboratory test results, along with bleeding and family history. By Panel members working together bringing different expertise and perspectives, the International Consensus Panel will develop a criteria definition for severe Von Willebrand Disease. This collaboration will then issue an expert consensus opinion on the diagnosis of severe VWD, aiming to catalyze more specific treatment recommendations and targeted research opportunities. *story continues on page 3*

Have you heard?

As the U.S. National Patient Organization for sVWD, we need our collective voices to be heard and validated by a healthcare system that often marginalizes or misunderstands our struggles and issues.

The Severe Von Willebrand Disease Patient Registry

is our stake in the ground: we're serious about finding and funding a cure. The quality and value of our data will only grow with each new sign-up. Please consider becoming a participant – this is your chance to make a significant difference!

Whether you're already enrolled or not, if you have any questions or would like more information, please email our Research Coordinator Johnna Cesta at coordinator@vwdregistry.org.

MARK YOUR CALENDAR



VIRTUAL EVENT BOOK CLUB:

ALL THE BEAUTY IN THE WORLD: The Metropolitan Museum of Art and Me
TUESDAY, NOVEMBER 7
AT 8PM EST

A fascinating portrait of the famed museum and its treasures by **Patrick Bringley**, a former *New Yorker* staffer who spent a decade there as a guard.

[REGISTER HERE](#)

IN-PERSON EVENT MENTAL HEALTH WORKSHOP

NOVEMBER 17-19

Click below for all the information on this first-ever event dealing with mental health and Type 3/ severe VWD.

[DETAILED INFO HERE](#)

VIRTUAL EVENT HOLIDAY PARTY

WEDNESDAY, DECEMBER 20
AT 8PM EST

Instead of having all of our regular monthly club meetings we will be holding one big Holiday Party! Join us for games, connection and more.

Register by December 1 to receive a special surprise activity box!

[PRE-REGISTER HERE](#)

RESEARCH AND RESOURCES



You can always access more resources on our website page: [Helpful Apps and Articles](#)

GIVING THANKS

Gratitude is strongly and consistently associated with greater happiness. People feel and express it in many different ways. Learn how to cultivate gratitude in your life.

[VIEW](#)

MAKE A SIMMER POT

Use this recipe from Perry's Plate to give your home the delicious aroma of fall.

[VIEW](#)



IS YOUR ANXIETY RUNNING YOUR LIFE?

Everyone experiences anxiety. But if feelings of intense fear and distress have become overwhelming, it could be a treatable situation.

[VIEW](#)

PREPARE FOR HOLIDAY TRAVEL

Click for a travel letter template to make bringing your factor along easy and hassle-free.

[VIEW](#)

VWD CONNECT FOUNDATION
SEVERE VWD PATIENT REGISTRY

Every voice counts! Have you joined yet?



For Patients • By Patients • Advancing Together

FOUNDATION MEMBER DIRECTORY

Complete and submit the form to receive a copy of our Member Directory, and be included in the next edition

[VIEW](#)



MEET Jenna Hoffman

VWD CONNECT FOUNDATION MEMBER

Jenna has been a part of our community since 2017, when she attended our very first conference. Thank you for taking the time to answer some questions and let us get to know you!

Where do you live? What is your favorite and least favorite thing about it?

I live in Canton, Ohio near the Pro Football Hall of Fame. Many people in Ohio complain about the weather being their least favorite part of living here, but I appreciate the season changes. The colorful fall leaves right now are beautiful!

What do you do for a living?

I'm a private piano teacher with about 35 students who come to my home for weekly lessons. I also offer group workshops and camps for my students. I work at a church part time as music director, pianist, and ministry coordinator.

What is something surprising about yourself you could tell us that people would never guess?



International Consensus Panel

continued from page 1

Dr. Tung Wynn (left), a pediatric hematologist at the University of Florida and a member of VWD Connect Foundation’s Medical and Scientific Advisory Board, is heading the project. “I am excited about the

project to define the entity of severe Von Willebrand Disease. I think most patients who have severe VWD already know that they have severe symptoms, but having a definition will help them to understand the things that they have in common with one another and gain an identity,” he says.

“There are so many things that we want to learn about severe VWD starting with the effects and benefits of prophylaxis, but also the life experience living with severe disease and how we can best utilize new therapies to benefit those with severe VWD.”

To come up with a consensus opinion defining severe VWD, the International Consensus Panel is using a modified Delphi approach. Developed by the RAND Corporation and UCLA, the modified Delphi approach is a structured method used to gather opinions and insights from a group of experts to reach a consensus or make informed decisions about a particular topic. Panel members will participate in multiple rounds of questionnaires to distill a consensus on what indicates a diagnosis of severe VWD versus moderate or mild.

During this meeting, the attending members of the Panel shared their thoughts on the importance of this

project and how developing a published expert consensus opinion on diagnosis will impact not only the medical community, but more importantly, the patients. Impacts discussed included patients’ access to appropriate management and support services, insurance coverage and proper identification within the medical system. Defining sVWD could also improve the quality of research by offering a universally agreed upon inclusion criteria for the population being studied. Further, this publication can serve as a foundational document for future opinions and guidelines written for the sVWD community.

The in-person meeting during the Type 3/Severe VWD Patient Conference of 2023 was a significant milestone in this process of international collaboration. The goal of the Panel is to have their expert consensus opinion ready for publication by June 2024.

[Click here](#) to learn more about Dr. Wynn and the other members of our Medical & Scientific Advisory Board.

DO YOU HAVE A SPECIAL OCCASION OR MILESTONE TO SHARE?

From weddings, anniversaries and graduations to those small but significant moments and events, what are you thankful for right now?

CLICK TO EMAIL US your news and we’ll post edited versions in the newsletter for our membership community to share! Contributors will be identified by first name and last initial.

I have my motorcycle and boater’s license! I drive a small motorcycle around occasionally in the warmer months of the year and driving a jet ski is basically the water version!

How long have you been a member of the Foundation? What has being a member meant to you?

I’ve been a Foundation member since the first conference. Being a member means connection to me. It has connected me with amazing people – the other members! We share similar medical challenges, but I enjoy that we share similar interests and hobbies and get together through book club, craft club, the conference, and more. More recently, being a Foundation member has brought several young ladies with VWD and their families into my life, who I hope feel that they can ask me anything and that I can inspire them that you can be a perfectly “normal,” independent adult despite having severe VWD.

What is the first piece of advice you would give to someone who has been newly

diagnosed with Type 3/severe VWD?

You are your best and strongest advocate, so learn as much as you can, and don’t be afraid to stick up for yourself and what you need. It is important for you to make your voice heard to doctors, insurance companies and legislators, as well as people at school, work, etc. about VWD and the care you need.



New puppies at the Hoffman house!