

2024 Conference Preparations Underway

The February Monthly Member Meet-up was a special edition dedicated to discussing all things related to the upcoming 2024 U.S. Patient Conference. If you couldn't make the Zoom event, read on to see all the stuff you missed!



Group photo from the first Conference in May 2017

VWD Connect held its first national conference in May of 2017. Since then, every summer Foundation members, Staff, and Faculty have gathered together for community, education, and fun. Even a global pandemic couldn't stop us- in 2020 and 2021, conferences were held virtually, which ended up kicking off the Foundation's series of Zoom events and clubs that still continue every month. (See our upcoming events at right.)

This year's conference will be held at the West Palm Beach Marriott hotel, the same location as the past two years. The hotel is conveniently located only a few miles from the Palm Beach International Airport. Many of our members choose to spend some extra time in South Florida before or after the Conference events, exploring the beaches and enjoying the sunshine!

The Conference will offer two educational tracks to chose from. The Core Education track will

cover topics such as diagnosis, treatment, and management. This is strongly recommended for those who are attending for the first (or even second) time. Once attendees feel they are ready to dive deeper, they can choose the Specialized Topics track of sessions that will go into greater depth in specific areas.

Adult patients who are registering for the Conference are allowed to bring one guest free of charge to accompany them. Patients under 18 can bring two free guests, but one of them must be the patient's parent or legal guardian. Childcare will be provided for any patients or siblings 12 and under. All meals will be covered for the patients and their guests, and one hotel room will be provided for the party. Meals are quite the production – keep an eye out for the hotel's famous grilled cheese platter during arrival and registration!

Patients may register additional guests for an age-dependent registration fee to cover the additional food expense.

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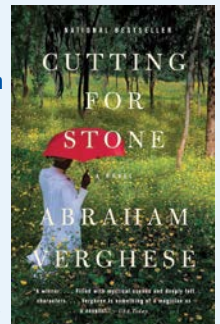
COMING UP



VIRTUAL EVENT BOOK CLUB:

CUTTING FOR STONE
WEDNESDAY, MARCH 6

AT 8PM EST
In his debut novel, **Abraham Verghese** tells the story of twin brothers Marion and Shiva, and their journey through love, loss and the complexities of family



[REGISTER HERE](#)

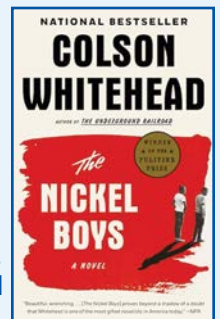
VIRTUAL EVENT MONTHLY MEMBER MEETUP

THURSDAY, MARCH 28
AT 8PM EST

[REGISTER HERE](#)

VIRTUAL EVENT BOOK CLUB: THE NICKEL BOYS WEDNESDAY, APRIL 3

AT 8PM EST
This 2019 novel by **Colson Whitehead** is based on the Dozier School, a Florida reform school that operated for 111 years and was revealed as highly abusive



[PRE-REGISTER HERE](#)

MARCH RESOURCES

Click to access more resources on our website



MARCH 11 NATIONAL NAPPING DAY

We'll be losing an hour of sleep when Daylight Savings Time happens this month. Check out this article about the importance of sleep, and make sure to take a nap to catch up on zzz's!



MARCH 17 ST PATRICK'S DAY

Go the classic route with this recipe for a traditional Irish dinner of corned beef and cabbage. Experts say the meal originated on American soil in the late 19th century as Irish immigrants substituted corned beef for bacon, the meat of choice in the homeland.



MARCH 25 HOLI

Throwing colored powder and water during Holi, the Hindu Festival of Colors, symbolizes the triumph of good over evil, the arrival of spring, and the celebration of love and unity.



MARCH 31 EASTER

More than just keeping the kids busy, this article from *Country Living* magazine lists lots and lots of creative, easy and fun Easter crafts for all skill levels.



FOUNDATION MEMBER NEWS



VWD Connect Foundation member **Jack Thompson** will be attending The Catholic University of America in Washington D.C. in the fall. He'll be a member of the swim team and will be studying Sports Management.

Congratulations to Jack and to his parents Heather and Scott!



MEMBER SPOTLIGHT

Jan & Zuzanna Golec

Thank you for taking the time to be our Member Spotlight family this month! Please introduce yourselves and describe your connection to VWD Connect.

I am Jan, I have had VWD3 with many severe manifestations throughout my entire life. I've been with the Foundation since its inception. Even before it was formally announced I knew from Jeanette that something was going to happen. My wife Zuzanna and I came to the first conference in 2017 and it was a revelation.

Being with people who understand what I am going through so naturally and instinctively is amazing. It is wonderfully therapeutic. Nobody is trying to pretend or hide anything, we are just ourselves. Since then we have participated in all the conferences, except for one, when I was unable to attend due to Covid (I suppose it should be considered an excused absence).

My wife and I live in Yonkers, New York. Both of us were born in Poland and we came to the U.S. in 1986. I like being so close to New York City and its many attractions. On the other hand I miss the countryside and the mountains. I grew up in a small town in southern Poland with beautiful mountains, hills all around, a river and plenty of fresh air. I went to school, studied and worked in Cracow, a major town in southern Poland with many medieval churches and a strong presence of the past.

Zuzanna misses her town, Tarnow where she grew up, although she also lived in Cracow where she studied and worked.

What was it like growing up in Poland with severe VWD? Were you diagnosed early in life?

It wasn't easy. My brother was diagnosed first, my diagnosis just followed his. I think I was two years old when they diagnosed a bleeding disorder. More specific diagnosis of VWD followed at the Hematology Institute in Warsaw. My dad was a real hero. He took it upon himself – it was so painful for my mom that she usually did not go to the hospital with us except to give blood. I had her blood type and my brother our father's. But she always came to take us back home when the bleeding episodes were over. These were the happiest days in my life. I remember the joy until today.

My life is a history of bleeding disorders treatment: fresh blood, antihemophilic factor, cryoprecipitate, factor concentrates. I hope to see the next, even better treatment option in my life ...



PHOTO BY BILL BARBOSA

Do you have any pets at home?

We have two cats, Kika and Fifa. I must admit it was my wife's idea to have a cat and then two cats. I was not very enthusiastic at first but now I enjoy their gentle presence. (As I write these words, one of them is meowing and wants to go out).

What do you do for work? What do you do for fun?

I am a mathematician. I work at Fordham University in New York. I teach all math courses but most importantly Probability and Statistics. My research is in certain aspects of stochastic processes. It is in the intersection of pure and applied mathematics.

Zuzanna teaches French, Spanish and Latin at a private high school for girls. She is a real linguist, she speaks five languages.

I love classical music. A classical music station is on in our home all day long. My dream has been to play piano but somehow it has never been realized. My wife and I are opera fans. Living in New York, we go to the Metropolitan Opera. We choose a few operas per season and have a special night each time we attend. So far, since 2010, we have seen 51 operas.

I like driving the car, it relaxes me. Watching scenery change is great. Walking can be painful at times because of the joints but driving is never painful.

Besides, my real pleasure is reading math and trying to solve problems. Most of them are too hard to solve, but some are not and discovering the logic behind them is real fun.

Thanks for letting us get to know you, Jan and Zuzanna!

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It is important to arrange any extra guest rooms or extended stays at the hotel aside from the three nights provided by the Foundation as soon as possible, as rooms at the discounted group rate are very limited! More specific details about payment and guests will all be available upon online registration, which will open in early March. All Foundation members will be emailed a link to register. If you are not yet a member and are interested in attending, email Jeanette to get connected.

Throughout the year, the Foundation has been working to build a travel fund to help patients who want to attend but would be prohibited by travel cost. **CONTACT JEANETTE** if you would like utilize this travel assistance. We want everyone who would benefit from this event to be able to attend!

Last November, the Foundation held its very first Mental Health Workshop weekend, which was a great success and proved to be a lovely time for wellness education and community support. Expect

to see some of the sessions from that event integrated into this year's Conference – educational sessions surrounding mental health topics as well as fun, small-group sessions about different forms of holistic wellness techniques, such as music therapy and aromatherapy. As always, attendees can look forward to evening entertainment. Past activities include a

fire dancer, reptile show, and, of course, trivia. And yes... karaoke will be back this year by popular demand!

VWD Connect was built on these annual patient conferences. It's where many of our members have met other severe VWD patients for the very first time, and where these connections have become lifelong friendships over the

years. It's a chance to be around people who really understand the emotional, physical, and financial burdens of living with severe VWD. It's a chance to learn from researchers and medical professionals from all around the world who specialize in treating severe VWD. Most importantly, it's a chance for us all to learn from each other

We can't wait to see you this July!



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