



VWD CONNECT FOUNDATION

NEWSLETTER

JANUARY 2024

FROM THE EDITOR

The Year in Review

When I look back at the past year, I think what a wonder 2023 has been. Personally, I've noticed so much progress in how our lives have been returning to "normal" after the pandemic years changed everything. Some things will always be different. Many of us lost loved ones. We all lost experiences and memories that we will never recover.

Along with the acknowledgement of what we lost, I see in myself and the people around me a new sense of resilience – or maybe one that was there all along, but just had to be uncovered. I see a fresh sense of gratitude for so many aspects of daily life and community. Especially for those living with a chronic medical condition, such as severe VWD, loss and opportunities for adaptation have always been a part of life. Those skills have truly been put to the test the past few years when the world at large shut down. I'm so proud of how our community not only sustained each other, but grew as so much else was falling apart.

After two years of virtual conferences, its incredible to me that 2023 was the first year VWD Connect hosted two in-person events! While our seventh annual National Patient Conference in July offered education and a chance to reconnect as a whole, our first Mental Health Workshop weekend in November provided a more intimate space for community support. The Zoom clubs and events we began in 2020 have continued and become such a special way to connect yearlong. What blessings 2023 has brought us!

Looking ahead, there are so many exciting things coming in 2024. We are continuing to support the work of the International Consensus Panel, and will be hosting a Provider Meeting in November that will engage medical providers in a brand-new way that has been sorely needed.

Join us for our now annual "State of the Foundation" meeting on Wednesday, January 24 at 8PM ET to learn more and check in with us as we start a new year.

With gratitude for everything that got us here and excitement for what's to come,

Johnna Cesta



VIRTUAL EVENT

BOOK CLUB

THE TIE THAT BINDS

TUESDAY, JANUARY 9

AT 8PM EST

Kent Haruf's critically acclaimed first novel, delivers the sweeping tale of 80-year-old murder suspect Edith Goodnough



[PRE-REGISTER HERE](#)



ZOOM EVENT

STATE OF THE FOUNDATION

WEDNESDAY

JANUARY 24

AT 8PM EST

Join us for this special annual meeting to hear updates about the Foundation's activities and plans, as well as to share what you'd like to see in 2024!

[PRE-REGISTER HERE](#)

RESEARCH AND RESOURCES

EMERGENCY CHECKLIST

A checklist for families with bleeding disorders containing guidance on what to have ready in the home

[VIEW](#)

MORE RESOURCES

You can always access more resources on our website page:

Helpful Apps and Articles



RESOLVED TO DITCH SOCIAL MEDIA IN 2024?

Spend your screen time scrolling through this playlist instead!

[VIEW](#)

FOUNDATION MEMBER DIRECTORY

Submit your completed form to receive a copy of our Member Directory, and be included in the next one.

[VIEW](#)



PEACH FUZZ

Started in 1999, the Pantone Color Institute has chosen a "Color of the Year" as part of an educational program striving to "engage the design community and color enthusiasts around the world in a conversation around color."

Click the swatch to learn about PEACH FUZZ – Pantone's official color of 2024!



The Journey of Meditation Series: Part 2

In the last newsletter, I asked you to be open minded and try the short five-minute meditation at least one time. Hopefully you tried it a few times and now have experience with meditations and how they feel and can work for you.

Meditation is defined as "a practice of mindfulness, or focusing the mind on a particular object, thought, or activity to train attention and awareness, and achieve a mentally clear and emotionally calm and stable state." (Wikipedia)

In this part of our series, become aware of the different meditation *techniques, types, ways* and *methods* that you would you like to work with and practice:

Techniques for meditation

- Breathing meditations
- Mindfulness meditations
- Focus meditations
- Movement meditation or Walking meditation
- Mantra meditations
- Buddhist meditations such as Loving Kindness
- Guided meditation

- Christian meditation or Spiritual meditation

Types of meditation

- Deep breathing
- Guided meditation
- Relaxation
- Attention meditation
- Loving kindness meditation
- Body scan meditation

Ways to meditate

Guided meditation involving imagery or visualization

Focused methods of meditation

- Paying attention to breath
- An idea or feeling
- A single point meditation

The meditation in Part 1 was a Guided Meditation to get you connected to breath and your body. Now visit this website and see where your interest takes you!



ED KUEBLER

The Ten Best Types of Meditation Practices for Self-Development



MEMBER SPOTLIGHT

Kayla Mack



Where do you live? What are your favorite and least favorite parts about it?

After being gone for 20 years, we recently moved back to Kansas City, where I grew up. It has been wonderful to be back in a familiar place with nearby family and friends. My favorite thing about Kansas City is the cultur. We have an amazing Symphony, Ballet and Opera and Art Museum. My husband and I are living downtown which has been a lifelong dream of mine. I love being able to walk in any direction to find small businesses, delicious food, and coffee shops where I can write. My least favorite thing about Kansas City is probably the suburban spread of it. The area where I grew up is now two to three times the size it was and all new construction. I prefer to frequent the more historical areas.

What do you do for work?

I have not yet gotten back into the work force following our move. My most recent job, however, was in the Emergency Room on the registration team. I was able to react with a lot of compassion and empathy to the patients and their families from my own experiences in the ER. Also, seeing blood did not phase me in the least!

What do you do for fun?

The older I get, the more fun I'm having. My 50s have been magical. I began them by attending Mermaid Camp. During Covid I began fostering Monarch Butterflies (egg to butterfly) and have released more than 300 butterflies into the world. I'm an avid writer (or have imagined myself as one anyway) and hope to write a memoir in the next year or two.

Severe Type 3 VWD has never stopped me from doing the things I enjoy. Instead of saying "I can't do that" I find a way around. I couldn't run a marathon like my friends were doing (for instance) so I found a vertical stair climb to compete in instead. Instead of ballet classes I am taking aerial dance (hoop, sling, etc.) that leave my ankles out of things entirely!

How and when did you get connected with VWD Connect?

I am quite new to VWD Connect! My journey has been unusual in that I have been isolated in it for much of my life. Two years ago I had a bleed that was a wake up call for me. I realized had been dealing with my VWD on a reactionary basis and needed to become proactive about it instead. I began researching what resources were available online and through that found the Foundation.

What has being a Foundation member meant to you?

Meeting others like myself (with Severe Type 3 VWD) has been a life changing experience for me. I found out I wasn't alone after all! I've also learned so much. It feels so much better, being proactive. I am no longer just waiting for the next bleed to happen. I am taking the steps to prevent them. I have gained the knowledge to have informed discussions with my care team and this has made a huge difference.

Do you have any favorite Conference or other Foundation event memories to share?

I have absolutely loved the evening activities we've had at Conferences. Karaoke, trivia, bingo, dancing have been amazingly fun and wonderful. It's a chance to sit back, relax and share some laughs. I have enjoyed the opportunity to get to know people better.

Any News Year's traditions or resolutions?

My husband and I received a set of toasting glasses as a wedding present and we get these out on NYE to toast the New Year with. Like many others, on New Year's Day we make black eyed peas for good luck.

A few years ago I started choosing a "word of the year" vs. making resolutions. The word I have chosen for 2024 is "SHINE" – and I plan to!

DO YOU HAVE A SPECIAL OCCASION OR MILESTONE TO SHARE?

CLICK TO EMAIL US your meaningful life events and we'll post edited versions in the newsletter! Contributors will be identified by first name and last initial.

