



## VWD Connect Hosts Inaugural Mental Health Workshop Weekend



The "Taste" sensory experience was enlightening... and delicious!

During the weekend of November 17-19, 2023, VWD Connect Foundation marked a significant milestone with its first Mental Health Workshop Weekend. This transformative event brought together individuals impacted by severe VWD, including patients and their loved ones, to focus on mental well-being.

The weekend featured a diverse array of educational sessions addressing topics such as medical trauma and pain management. Faculty, familiar with the unique challenges our members face, shared valuable insights and coping mechanisms that can be used in maintaining mental wellness.

Beyond the informative sessions, the event was designed to promote holistic healing and self-discovery. Attendees had the opportunity to engage in enjoyable, sensory-based activities such as self-massage and music therapy. The power of healing through creative expression was evident during the group drumming sessions, where attendees found a sense of play and connection through rhythmic beats. Each activity was themed to utilize one of the five senses: sight, smell, touch, hearing, and taste, encouraging attendees to explore and strengthen the mind-body connection throughout the weekend.

Perhaps the most impactful aspect of the weekend was the creation of small, intimate groups where participants could openly share their experiences with mental health and living with sVWD. The setting fostered a sense of understanding and provided a safe space for individuals to authentically connect, which might have been difficult to achieve in a more formal setting.



The "Smell" sensory experience demonstrated the power of scent

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### MARK YOUR CALENDAR



#### VIRTUAL EVENT HOLIDAY PARTY!

WEDNESDAY, DECEMBER 20  
AT 8PM EST

Celebrate the season with games, crafts and connection! Register by December 12 to receive this adorable latch hook rug making kit we will work on together during the party.



[REGISTER HERE](#)

#### VIRTUAL EVENT BOOK CLUB: THE TIE THAT BINDS TUESDAY, JANUARY 9

AT 8PM EST  
In his critically acclaimed first novel, **Kent Haruf** delivers the sweeping tale of 80-year-old murder suspect Edith Goodnough.



[PRE-REGISTER HERE](#)

# RESEARCH AND RESOURCES



## JEANETTE'S FAVORITE COOKIES

"I grew up making these holiday spritz cookies, and I've made them every year with the kids. It's one of our favorite holiday traditions!"

- 1 cup butter or margarine
- 2/3 cup sugar
- 3 egg yolks
- 1 tsp almond or vanilla flavoring or 1/4 cup glazed almonds
- 2 1/2 cups Gold Medal Flour (not self-rising)

Heat oven to 400° F. Mix butter, sugar, egg yolks and flavoring thoroughly. Work in flour. Using 1/4 dough at a time, force dough through cookie press (or shape by hand) on ungreased cookie baking sheets. Bake 7 to 10 minutes, or until set but not brown. Makes about 6 dozen small cookies.

– Betty Crocker's Cookie Book

You can always access more resources on our website page:  
Helpful Apps and Articles

## HANDLING HOLIDAY STRESS

For people managing a chronic illness like a bleeding disorder, remember that your physical and mental health come first

[VIEW](#)



## HOLIDAY RECIPES

Click on the photos to check out some holiday recipes sent in from Foundation Members around the country:

- ▲ Hanukkah Potato Latkes
- ▼ Squash and Corn Casserole



## 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 Ed Kuebler

VWD CONNECT FOUNDATION BOARD MEMBER

Thanks for everything, Ed!



In this issue we are introducing a brand new column about meditation led by our very own Ed Kuebler. A co-founder of the Foundation, Ed has been a part of the family since the very beginning. Let's get to know him a little better!

### Where do you live? What do you like about it? Do you have any pets?

I live in Lewes, Delaware. My pet is Monkey, my cat. I have had her for ten and a half years, since she was seven weeks old.

I love where I live. Lewes is one of the oldest towns in the U.S., with Delaware being the first state. There is no tax on anything you buy, and property taxes are pretty low.

Summers in Lewes/Rehoboth are busy so traffic can be a challenge. However there is always something to do and something for everyone. I believe Lewes is the fourth largest chicken producer in the U.S., so lots of rural areas with cornfields.



## Mental Health Workshop

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For Michelle Ryzak, a patient attendee from Brighton, Michigan, the Workshop was her first in-person Foundation event since the National Conference in 2018. When asked if she felt moments of connection with other attendees, she laughed. "Oh, all weekend! There are probably too many moments to even pin-point one," she said. "You come in expecting there to be some common ground, but then once you get talking it's all 'Oh, me too! Me too!'...it's so weird that across the board we are all experiencing these similar things."

Be on the lookout for your opportunity to experience some of these fun sensory activities at the upcoming July 2024 National Conference!



## DO YOU HAVE A SPECIAL OCCASION OR MILESTONE TO SHARE?

Share your meaningful life events 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. [CLICK TO EMAIL US](#) your news!

## SPECIAL ZOOM EVENT THE 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](#)

My favorite season is the Fall. The colors are so amazing and the sun rising over the cornfields is breathtaking. I live four miles from the ocean.

### What is something people would be surprised to know about you?

You would be surprised to know I am a pretty good ballroom dancer... or I used to be! I was fired from McDonalds when I was 19 years old.

### You co-founded the Foundation in 2017 with Jeanette. How have you seen it grow and evolve over time?

I was very fortunate to find the connection with Jeanette to be in on the front end of the VWD Connect Foundation. It was a vision to meet the needs of VWD patients and families in a way that was about community, education and connection. I have watched the foundation grow into the vision we had and then so much more. I am so proud of the VWD Connect Foundation, Jeanette's hard work making the dream come true and my new family the Cestas!

### How long did you work in helping professions? What has working with people taught you about them? About yourself?

I have worked in the "helping" profession for over 40 years. As a social worker, it was my calling in life and I have had the honor to work with people, families and other professionals who taught me so much about helping others and myself. What a journey!

What I have learned more recently is there is no wrong way to do life, only better choices. If you know better... do better. People are amazing if you take the time to get to know them and kindness goes a long way.

Lastly, people are more important than politics, pandemics and disagreements. Those come and go, but the relationships you build, nurture and cultivate will be with you for a very long time.



# The Journey of Meditation Series: Part One

The journey of meditation begins with the willingness to try it out and see how it feels for you. Many people are reluctant to try to meditate. They may feel that it's silly, they don't know how, or that it wouldn't work. Whatever you think or feel about meditation, try it and see for yourself. We will offer a series of pieces and guided meditations to you over the next several months, including some that will be recorded for you. Enjoy the journey and see what you discover ... it's a whole new world!

## *Two things to remember:*

1. There is no wrong way to meditate!
2. It takes some practice to feel comfortable for many people, so give it a few chances.

It would be helpful to start with why you would try meditation. Some reasons may be: to reduce stress, to feel more empowered, to relax, to increase mindfulness, to gain focus and direction, to have more peace in your life... or just because you're curious.

Once you have a place to start, look for guided meditations that offer what you want. There are so many to choose from.

*Try Googling guided meditations, asking Alexa to do a meditation for you, or just start by:*

Sitting comfortably and uncrossing your arms and legs for better circulation. Then close your eyes and take a deep breath in through your nose and out slowly through your mouth. Do this five or six times until you start to feel your body relax.

Hear yourself say out loud or to yourself: "All is well in the world today just as it is and as it unfolds."

With your next breath say out loud or to yourself: "All is well with me right now."

Take three or four breaths, exhaling slowly into your words. On the last breath, open your eyes and notice how you feel.

Be willing to try this again in the next day or so.

This was probably about a five-minute meditation to get you started. As we approach the holidays, try this meditation while you explore what kinds of meditations you would like to learn about and practice.

*by Ed Kuebler*

