

## Getting Involved

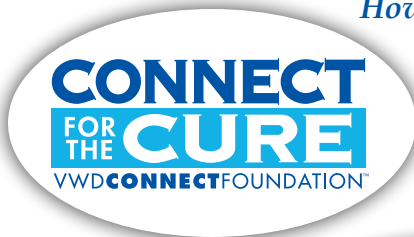
Lately it feels like researchers, clinicians and other community stakeholders are really starting to take notice of VWD. While historically we have been years behind other diseases like hemophilia, now I am hearing more about research in VWD. It almost seems like each week a new opportunity for our members to participate in research or a clinical study crosses my desk, or I hear about another possibility in the pipeline for better management.

*How do you choose what to participate in?*

*What questions should you ask?*

*Who is behind the study and does it really have the potential to bring about improvements in your care?*

*How do you find out about these opportunities?*



The Foundation's mission statement includes the phrase "and support research which will benefit the Von Willebrand Disease community." As part of our response to that goal we will be introducing a new section in our monthly newsletter: "Getting Involved."

Here we will be listing research and clinical studies that our members may want to consider participating in. It will not be a list of every opportunity available, simply ones that the Foundation has become aware of and feels may help move the needle for advancement in VWD care.

We believe that the sharing of lived experiences by VWD patients and their participation in studies plays a critical role in research. If you want your voice heard, then please consider "Getting Involved." Look for the new section in our July issue!

- Jeanette Cesta  
Executive Director



### COMING UP



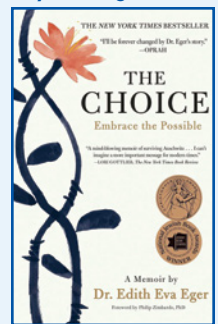
#### VIRTUAL EVENT BOOK CLUB:

*THE CHOICE*

WEDNESDAY, JUNE 5

AT 8PM EST

Edith Egen's 2017 autobiography chronicles her journey through hell to true freedom. She must learn to let go of the past as she struggles to build a new life after the murder of her parents and first love.



[REGISTER HERE](#)

#### VIRTUAL EVENT MONTHLY MEMBER MEETUP

THURSDAY, JUNE 27

AT 8PM EST

[REGISTER HERE](#)

#### IN-PERSON EVENT 2024 CONFERENCE

WEST PALM BEACH, FL

JULY 19 - 22

Registration is open!

[LEARN MORE](#)



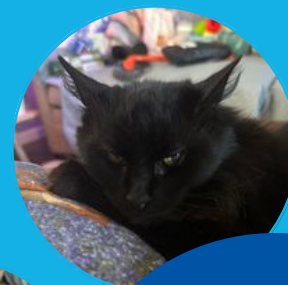
## JUNE 4 NATIONAL HUG YOUR CAT DAY

In honor of National Hug Your Cat Day, we asked our members to share pictures of their beloved furry friends. Say hi to some of our honorary feline Foundation members!



**Teaguen Donahue** with  
(top row, from left) Max, Elsa, Ronan  
(bottom row, from left) Frannie, Lulu, Eric  
Greenville, TN

**Rexanne J.'s cats**  
(from top) Bella,  
Cooper, Dennis,  
Munchkin, Nosie  
Jacksonville, AL

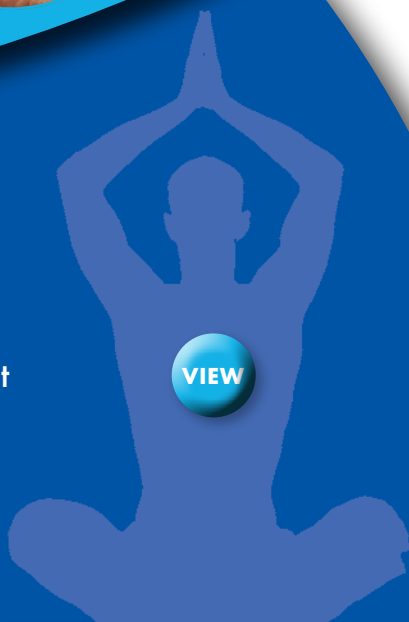


**SHOUT OUTS!**  
Got something to share? **EMAIL JOHNNA** to be featured in this section where we celebrate our members each month!



## JUNE 2 INTERNATIONAL YOGA DAY

Yoga is an ancient practice that is customizable to all ages and physical mobility needs. It has been proven to strengthen the mind as well!



## JUNE 19 JUNETEENTH

Learn about the history of Juneteenth, and read about the specific struggles Black women in the bleeding disorder community face to find validation and proper medical care.



# MEMBER SPOTLIGHT: Brandee Cookston

**Hi Brandee! Thanks so much for letting us get to know you this month! Please introduce yourself, and tell us a little bit about how you got connected with the Foundation:**

Hey there! I'm Brandee Cookston, and I was diagnosed with severe vWD in 1999, three years after losing my brother to a different blood disorder. Growing up, I only knew boys with hemophilia in my area and couldn't fully relate to them. In 2015, I jumped into the community and started finding other severe vWD patients, including my best friend, Stacy Bond. She told me about VWD Connect, but I couldn't attend the first year. Since then, I've made it a point to be at every conference.

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

I was born and raised in Bayou La Batre, a small fishing community on the Gulf Coast of Alabama. If you're familiar with *Forrest Gump*, you'll know it as Bubba's hometown. Most of my family works in the seafood industry, and I love being able to cook with fresh catches straight off the boat. Despite living on the coast, I have a fun fact to share – I actually dislike the beach. However, I do enjoy going out on the boat and fishing.

**Those of us who've known you in the Foundation know you are a dedicated pet person. In honor of this month's National Hug Your Cat Day, please tell us more about your pets!**

I have three cats and a rabbit. Usually, you'll only see one of my cats and my adorable bunny. The other two are quite shy and tend to hide whenever they hear or see someone other than myself. Mozzie, my calico, is the oldest at 13 years old. I rescued her from a family member who couldn't care for her anymore. Livi, my second cat, is 10 years old. I was only supposed to be fostering her until her owner found her a new home, but she ended up becoming a permanent part of my household. Savannah, my Ragdoll, is the one you'll often see on



our Zoom calls. She was a gift from a sweet student I was tutoring. Poppy the bunny, showed up in my backyard as a baby last January. She ended up following Savannah inside my house and has been here ever since. I tried to find her owner, but nobody claimed her. She is free-roam in my house and is litter box trained. Although she's caused me to lose quite a few phone chargers, she seems to have finally mellowed out and stopped chewing on all of my things.

**I think everyone will want to know: Do the bunny and the cats get along?**

All of the cats get along with Poppy. The older two really just tolerate her, but she and Savannah have the closest bond. It's so heartwarming to watch them play. I still don't think Savannah understands that Poppy can't play with her like a cat would.

**You've been such a present and beloved member of our community, and as you said have attended most of the conferences. Do you have any favorite conference memories?**

My absolute favorite conference memories are the moments I shared with the amazing doctors and other medical professionals. I'll never forget watching them being pulled to the dance floor by patients, belting out karaoke tunes, and playing in our super competitive trivia night. These unique experiences are what make VWD Connect so special!

# SPOTLIGHT: VEGA THERAPEUTICS

## HAVE YOU OR SOMEONE YOU KNOW BEEN DIAGNOSED WITH VON WILLEBRAND DISEASE?

Finding the right treatment option can be a journey, and researchers at Vega Therapeutics might have a path for you to explore. They are looking for Von Willebrand patients to participate in the VIVID 2 Study (NCT# 05776069), a Safety, Tolerability, Pharmacokinetic, and Pharmacodynamic Study of a new drug called VGA039.

### WHAT IS VGA039?

VGA039 is a drug that is a human monoclonal immunoglobulin (also called an antibody) directed against a protein in the blood called Protein S that plays a key role in regulating bleeding tendency. VGA039 may decrease key functions of Protein S, which may reduce bleeding for individuals with VWD.

### WHO MAY BE ELIGIBLE?

Patients with VWD who are symptomatic, ages 18-60 years old

### WHAT DOES PARTICIPATION MEAN?

- Eligible patients will be asked to come to the clinic up to 14 times:
  - Screening: 1 day visit to assess eligibility.
  - Treatment: 1 day visit for VGA039 administration.
  - Follow-up: up to 56 days (12 visits) to monitor safety.
- Eligible patients will receive a single injection of subcutaneous (under the skin) study drug (VGA039)
- Participation may help other VWD patients in the future by helping us learn more about treating VWD with VGA039.
- Eligible patients will receive compensation for their time.

## VIVID 2

Single Subcutaneous Administration

### INTERESTED IN LEARNING MORE?

Visit the link below or contact your provider

<https://clinicaltrials.gov/study/NCT05776069>



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