

FROM THE EDITOR

The State of the Foundation

On January 24, in what has now become an annual tradition, VWD Connect held its annual “State of the Foundation” Zoom meeting. Members convened virtually from across the country to hear updates about the Foundation’s new and ongoing initiatives, and to share their hopes and ideas for the future. Over the years, this meeting has also served as an opportunity for members to reconnect with familiar faces and welcome new ones, and to start the new year off with a reaffirmation of community. If you couldn’t make the event, read on for a summary of the session, grouped by main topics.

ANNUAL CONFERENCE 2024

The VWD Connect Foundation’s eighth (can you believe it?) annual U.S. National Patient Conference

will be held Friday, July 19 – Monday, July 22 at the West Palm Beach Marriott hotel. Registration for the event will open in early March. Sessions focusing on mental wellness and exploring ways of self-care will be emphasized this year, following a successful Mental Health Workshop weekend in 2023. At this month’s Member Meet-up we will be discussing all things conference. Join us to learn more!


**PROVIDER
EDUCATION
WORKSHOP**

This Fall, the weekend of Friday, November 8 – Sunday, November 10, 2024 is set for the Foundation’s Provider Meeting. This in-person event will bring together hematologists, social workers, nurses,

and other healthcare providers for an educational weekend where knowledge can be shared about the specific challenges of treating severe VWD. The Foundation is looking for a small group of patients who would be willing to attend and represent the patient population. This group of six would participate in a Patient Panel session to share their experiences. If you are a member and interested in learning more, contact Jeanette for more information. Additionally, as the date of the event gets closer, the Foundation will provide event information materials that members can share with their healthcare providers to help spread the word.

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VIRTUAL EVENT

BOOK CLUB

THE AVIATOR’S WIFE

WEDNESDAY, FEBRUARY 7
AT 8PM EST

Melanie Benjamin’s fictional biography of Anne Morrow, wife of famed aviator Charles Lindbergh and the first licensed female glider pilot in the U.S.



[REGISTER HERE](#)



ZOOM EVENT

MEMBER MEETUP

**ALL ABOUT THE CONFERENCE:
2024 EDITION**

THURSDAY, FEBRUARY 22
AT 8PM EST

Get a sneak peek at what we’re planning for this year’s conference: some exciting new things are on the way!



[REGISTER HERE](#)

FEBRUARY RESOURCES: IT'S NOT ALL ABOUT VALENTINES DAY!

FEBRUARY 7 NATIONAL GIRLS AND WOMEN IN SPORTS DAY

It's time to get active! Check out this guide from the National Hemophilia Foundation on best practices when it comes to sports, exercise, and bleeding disorders.

[VIEW](#)



FEBRUARY 10 CHINESE NEW YEAR

Did you know 2024 is the Year of the Dragon? Read this article from *Readers Digest* to learn what that means, and see if you were born under this Chinese zodiac sign (and what that might say about you).

[VIEW](#)

FEBRUARY 11 INTERNATIONAL DAY OF WOMEN AND GIRLS IN SCIENCE (& SUPER BOWL SUNDAY)

Celebrate this international holiday by getting to know the incredible women on VWD Connect's Medical and Scientific Advisory Board!

[VIEW](#)



FEBRUARY 16 NATIONAL CAREGIVERS DAY

Living with a severe bleeding disorder is not an easy thing to do alone. Maybe you have caregivers in your life you'd like to do something special for today! Check out this list of ideas.

[VIEW](#)

The Journey of Meditation Series: Part 3

In this last installment of this series, Ed offers a recorded meditation that can be used anywhere, any time, to calm the mind and bring awareness to back to the body. The video begins with a short introduction and includes a 15-minute guided meditation.

ED
KUEBLER



[Ed's Guided Meditation video](#)

FEBRUARY NATIONAL CHILDREN'S DENTAL HEALTH MONTH



Now is the perfect time to make that annual appointment! Use this sheet from the West Virginia NHF chapter to help the visit go a little smoother!

[VIEW](#)

MORE RESOURCES

You can always access more resources on our website page:

[HELPFUL APPS AND ARTICLES](#)



MEMBER SPOTLIGHT

The Boatrights

This month we are getting to know the Boatrights. The family is fairly new to the Foundation, but they have quickly become important members of our community... and trivia champions too!

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

Hello, we are the Boatrights: Jamie, Jerrod and our 22-month-old daughter Ryan. We found the Foundation after Ryan was diagnosed with Type 3, shortly after birth. Conveniently, our hematologist is on the Medical and Scientific Advisory Board for the Foundation and quickly put us in contact with Jeanette.

What are your favorite and least favorite parts about where you live? What would you show a first-time visitor?

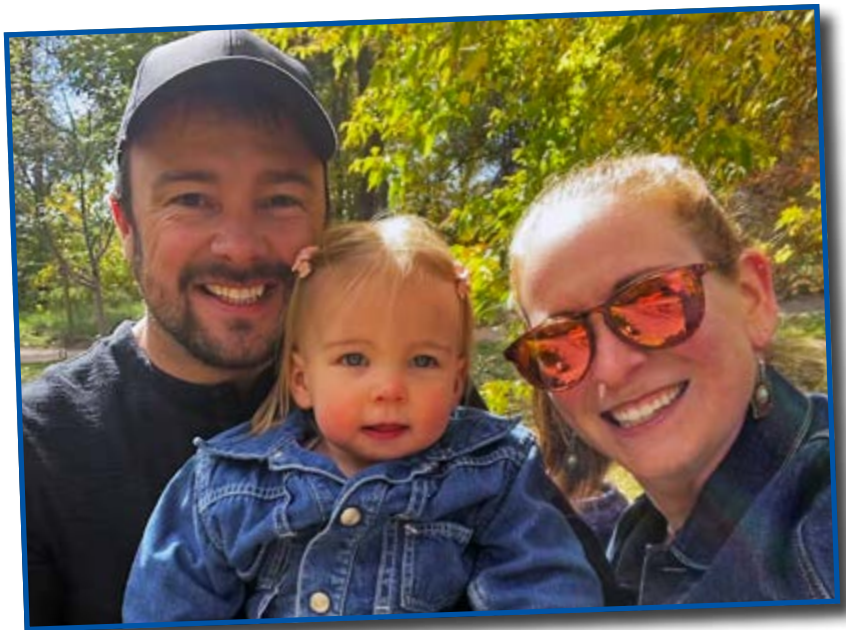
We live in Arvada, Colorado, a suburb just outside Denver. Some of our favorite things about living in Colorado are the sunshine, the mountains, and the outdoorsy culture here. One of our least favorite things is fighting traffic to get into the mountains to do outdoorsy things on the weekends. When friends and family visit, we enjoy taking them to Rocky Mountain National Park, going to Red Rocks for a concert, or spending a day exploring a unique little town.

What do you both do for work? For fun? What are some of Ryan's favorite things?

Jerrod is a manager of a finance team at Lockheed Martin. Jamie was a special education teacher but is currently taking a break to be a full-time mom. For fun, we enjoy camping, playing ice hockey, traveling, and exploring new restaurants and breweries. Ryan's current favorites are: "spicy!?" (trying spicy foods), "Ryka bone!" (giving the dog a treat), "Help 'itcheh??" (helping cook meals), "wimming!" (swim lessons), and her stuffed bunny, "Bunny."

What advice would you give to new parents of a child with severe VWD?

Well, we aren't very far along on this journey but if we had one piece of advice to give, it would be to find



your people. Not everyone in your circle is going to get it and that's okay. Let's be honest, most people are not going to get it and not everyone is going to be helpful or supportive. It's tempting to put up walls and weather the storms on your own but that path is simply not sustainable. Find the experienced person you can call/text when you have a question at 10pm on a Sunday. Find the supportive person that celebrates your victories with you and empathizes with your battles (and cries with you over a bottle glass of wine). Find the local person you can rely on to show up when you really need it. Keep this person informed – take them to appointments and have them trained on how to infuse so you have another person in your corner in an emergency situation. Find your people – the special, select few – and let them in.

Do you have favorite Conference or Workshop memories to share?

We remember how it felt to attend our first conference this past July. We had an overwhelming feeling of gratitude, knowing that we weren't alone and that this amazing resource exists for us. Oh and a certain special little girl's karaoke performance of a *Hamilton* song with her dad was pretty great too.

What has been the best part of being a member of VWD Connect?

Trivia. Just kidding... but we've enjoyed it! The best part for us has been the friendships we've made and continued throughout the year!



Red Rocks



Rocky Mountain National Park

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INTERNATIONAL MEMBERSHIP

VWD Connect is going global! The Foundation is now offering an international membership option for severe VWD patients outside the U.S. If you have friends or family members who might be interested in this membership option, [CLICK HERE](#) to check out our Membership page.

CONSENSUS PANEL

In 2023, the Foundation sponsored an International Consensus Panel of experts on VWD including physicians, scientists, patients and family members of those affected, and other advocates of the VWD community. The Panel is tasked with coming up with a definition of severe VWD. The goal is that with a universally agreed-upon definition of what constitutes a VWD disease state as “severe,” treatment options will be streamlined and research opportunities will become more targeted to the right population. The Panel is expected to have results in time to submit for publication this summer. In an exciting update, this initiative is now a listed project under the International Society on Thrombosis and Hemostasis (ISTH)



Von Willebrand Factor Subcommittee. [CLICK HERE](#) to read more.

WAYS TO GET INVOLVED

2024 is looking to be a busy year for the Foundation! If you would like to become more involved, here are some ways you can connect with the Foundation that were discussed at the meeting:

- Join our ongoing **Zoom programming**. Book Club, Member Meet-ups, and other special Zoom events will continue this year. Check out the newsletter each month for registration links!
- Volunteer for the new **Member Advisory Board**. This will be a group of patients who will meet virtually a few times a year to share their ideas and feedback about Foundation activities. If you are interested in joining, [CONTACT JEANETTE](#).
- Contribute to our **Newsletter**! Do you have an anniversary, birthday, or milestone to share? Have an idea for an article? Interested in being interviewed in our Member Spotlight section? Don't be shy – [CONTACT JOHNNA](#) with any and all of the above! This publication is meant to be a space for everyone to have a voice and share our successes and updates as we all navigate life with severe VWD together.