VWD CONNECT FOUNDATION
NEWSLETTER
APRIL 2024

Meet Teaguen Donahue – a real VWD Warrior!

On April 20, at 1:00PM ET, VWD Connect invites members of all ages to a virtual read-along and discussion of the children's book *Fun Facts about a von Willebrand Warrior,* authored by one of our own Foundation Member families, the Donahues. Read on to learn more about this resilient, creative, and determined family!

As soon as seven-year-old Teaguen Donahue was born, her family noticed unusual bleeding and bruising that was hard to manage. Shortly after her first birthday, when she had an accident that caused prolonged mouth bleeding that got doctors attention, the family was finally given an explanation: Type 2A von Willebrand disease.

Searching for answers and ways to help their daughter, the Donahue's tried to learn everything they could about Teaguen's rare condition. They noticed that most sources of knowledge were geared toward adult learners, and struggled to find educational tools to explain what VWD was in ways their daughter could understand. "We got the idea to write a children's book about VWD because there was really no literature available for kids to read about this disease," says Cortni Donahue, Teaguen's mother. "As a family of educators, we knew the need for children to hear and know about their disorder, but we also knew that parents/caregivers that had just found out their child was diagnosed with VWD had a need to know as well." The family decided to face the problem head-on. They wrote the book themselves.

Fun Facts About a von Willebrand Warrior is a dual reader, designed for children and their parents or caretakers to read together. The story follows Teaguen and her Granna as they take a trip to the zoo and learn "fun facts" about the animals. Along the way, Teaguen also becomes curious

continues on page 4

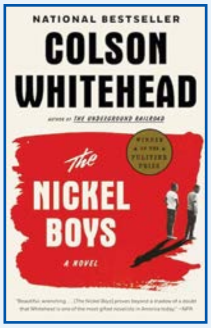
COMING UP

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



REGISTER HERE

VIRTUAL EVENT
BOOK CLUB READ-ALONG

MONDAY, APRIL 20

AT 1PM EST

Members of all ages will enjoy a virtual read-along and discussion of the children's book *Fun Facts about a von Willebrand Warrior.* See details at left.

REGISTER HERE

VIRTUAL EVENT
MONTHLY MEMBER MEETUP

THURSDAY, APRIL 25

AT 8PM EST

REGISTER HERE

APRIL NEWS + NOTES

Click to access more resources on our website

VIEW

SHOUT OUTS!

Do you have an anniversary, birthday, or milestone to share? Want to surprise a family member or friend with a special shout-out? EMAIL JOHNNA to be featured in this section where we celebrate special occasions each month!

APRIL 2 INTERNATIONAL CHILDREN'S BOOK DAY

Read about a children's book written by one of our own member families and get your own copy here!

VIEW

APRIL 8 SOLAR ECLIPSE

On April 8, a total solar eclipse will pass over North America, a celestial event that hasn't happened since 2017! Click on this article from NASA to learn more, including how to view from your area.

VIEW

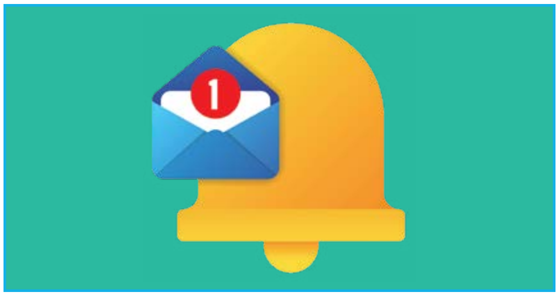
APRIL 8 JULIE CESTA'S BIRTHDAY!

We'd like to wish Julie Cesta, a conference Staff member since 2017, a very happy birthday! Julie is an avid pickleball player and will be turning 24 this year. *Happy Birthday Julie!*

APRIL 20 EARTH DAY

Did you know that EarthDay.org, the global organizer of Earth Day, announces a global theme for the holiday each year? This year's is "Plant vs. Plastics." Check out this article to learn some easy ways to reduce your plastic waste at home or at work.

VIEW



PATIENT NOTIFICATION SYSTEM

The Plasma Proteins and Therapeutics Patient Notification System sends confidential notifications of medication withdrawals or recalls that may be relevant to you. Click to read more and learn how to sign up.

VIEW

MEMBER SPOTLIGHT: Heather Thompson

Hi Heather! Please introduce yourself and describe your connection to the Foundation.

My name is Heather Thompson, and my youngest child, Jack (18), has type 3 vWD. We knew there was a problem with Jack's blood when he was two days old, but initially the doctors thought he had hemophilia. At three weeks old he had a bloody nose that wouldn't quit (thanks to the infant nasal aspirator that I was using for his congested little nose), which prompted an ER visit, factor treatment and additional testing when the hemophilia factor didn't stop the bleeding. And that's how Jack was diagnosed. The rest of our family was subsequently tested and we learned that my mom, my husband, our other kids (Meg, 22, and Will, 21) and I all have type 1. We had no previous knowledge of any bleeding disorders in our family, so Jack's birth really changed our lives, in more ways than one! We've been fortunate enough to be part of the Foundation since the very beginning.

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

We live in Downingtown, PA, about 45 minutes from Philadelphia in one direction and Lancaster's Amish country in the other. The kids think it's boring here, but my husband, Scott, and I have found it to be a great place to raise our family. We're close to the city, beaches, mountains and countryside. We have every amenity, great schools… and multiple HTCs and children's hospitals. I love that we get all of the seasons, and that we only live two hours from my parents. My least favorite thing? Probably that we're not on the beach!

What do you do for work? For fun?

I've been a stay-at-home mom since we started our family and moved to Pennsylvania in 2000. My prior career wasn't anything I loved or wanted to do for the long term. I majored in history in college and would love to be a Civil War historical re-enactor someday. But all I've ever wanted is to be is a mom, so I've had my dream job for the last 22+ years! I volunteer with an organization that breeds, raises and trains service dogs. I also love to cook… nothing makes me happier than serving a home-cooked meal to a table filled with people I love. Our family loves to adventure all over the world, including RV trips to Bryce Canyon and Yosemite, visiting the D-Day beaches of Normandy, hiking Kauai's Kalalau Trail, visiting Northern Cascades National Park, exploring Pompeii, and our biennial trips to Hilton Head Island.

Favorite Foundation conference memories?

I've attended every single Foundation conference, including both virtual ones; Jack attended all but 2023; and my husband attended the very first one with us. I'll never forget standing with my husband at that first conference in 2017 and watching the patients gather for a picture. To see Jack surrounded by 50 people just like him, and to be in a room with other parents and family members who know just what our son and family deals with was so incredibly moving! After all these years, attending the conference now feels like a family reunion. I love meeting new families who feel overwhelmed and terrified, and sharing our experiences to maybe provide some hope and strength. I love the big brainstorm session with doctors, families and patients. I love talking with my mom squad and knowing that we're bonded for life as we raise this next generation of severe vWD kids.

As a parent of a child with severe VWD, what advice would you give to parents of a newly diagnosed child?

The first is from our HTC: he is just a normal kid who happens to have a bleeding disorder. They told us not to put him in a bubble and that he could do almost anything that other kids could do. We've learned how to make this bleeding disorder fit into our lives, not the other way around. The other is from my mom: remember that we have two other kids who are just as important as Jack, and who need us just as much as he does.

So that's our story! Jack's arrival changed our family in so many ways, but I always try to focus on the good that has come out of his diagnosis. Yes – some days that is really, really hard to do. I hate that my baby has to live with this, that there any limitations on his dreams, that he needs to stick himself with an IV three times a week. But I love the empathy that he has, the brave warrior that he is, the resiliency and strength he shows in everything he does. Early on we realized that there were two ways of moving forward after receiving the news of such a serious and chronic diagnosis. We can be better, or we can become bitter. There was no question which path we would choose for our family or our son, and we've worked really hard to make sure this lifelong challenge makes our entire family better, together, and individually. VWD doesn't define who our son is, or how our family operates. It's just part of what makes our family the way that it is, and Jack the great kid that he is.

continued from page 1

about herself, asking "What are some fun facts about me?"

Throughout the rest of the book, children learn what VWD is and how it will affect their life, with Teaguen's personal story as a guide. Alongside this text, there is in-depth discussion of these topics and resources to explore for adults. In this way, children and their loved ones can enjoy the book together and both learn something new.

Since the initial idea, it took two years for the book to be published. Cortni says the first year was spent "jumping in" to the book writing process, while the second year brought the challenge of editing and finding someone to publish the book. After being referred to the Foundation, the Donahues not only found a partner for publication but a lifelong community as well!

The family attended their first VWD Connect Conference in 2023. Through active participation in sessions (and karaoke!) they quickly became beloved members. "At my first conference, I met one of my very best friends who I'm able to bounce ideas off of, ask advice from, and receive support from. I am in awe of the magnitude of joy, love, and connection that my family experienced at our first VWD Connect conference," Cortni says of the experience. "While there and after leaving, we felt seen, heard, understood, valued, cared for, and loved."

Join us at our special edition Book Club event to meet Teaguen and the Donahues, hear more about the writing process, and discuss the book. The event is for all ages, but children are especially encouraged to attend. Every family that registers for the event by April 10 will be sent a free kit to help write their own story! We would like to extend a huge thank you to CSL Behring for sponsoring this event. Learn more about them in our Community Corner below.

The Donahue Family

COMMUNITY CORNER

Behind everything the Foundation does is our community of supporters that make our connections possible. Click on the logos below to learn more about our wonderful sponsors!

CSL Behring

octapharma

VEGA THERAPEUTICS

Takeda