

Tony D'Ambrosio



Cheryl Nineff D'Ambrosio

Girls with Bleeding Disorders: Building a History

When I married Tony, I became stepmother to Teresa and Maria (ages 13 and 10), who have severe factor V deficiency* and require treatments with fresh frozen plasma (FFP) to control bleeds. Within a few months, I thought I had entered the plot of a disaster movie. To me it was horrific. But to them, it was normal.

At first, much of the information I found on bleeding disorders related to boys and men. Now, after spending the past 17 years learning the ropes, I'm used to the smiling urgent care physicians who enter the exam room and say, "Wow, I heard there's a girl with hemophilia in here, and I just had to stop by and see for myself!"

Taking the girls for treatments, sleeping overnight at the hospital during extended bleeding episodes . . . this became a normal part of my life. Often, when I spent time with my best friend, one of my daughters was having or recovering from a bleed. "You have to write a book," said my friend, "because nobody will believe what your life is like!" And I finally did just that. I thought, if doctors are still fascinated by a girl with a bleeding disorder in the 21st century, then somebody had better write it all down.

Finding a voice to write my book wasn't easy. What my stepdaughters really think and feel, I will probably never know. But as a new stepmom, I went from relaxed and fun-loving to protective and grouchy, and I can tell you how they felt about that. So I decided to write this book in my own voice – a nearly hyster-

ical mother of two girls who seem to bleed all the time.

I had a complex story to tell, a history to share. Many times I had brought my laptop computer to the hospital and taken copious notes in real time, so there was no question about the precise number of hours involved in the delay in getting treatment, the miscommunication between staff due to shift changes, or the problems that sometimes ensued from a lack of trust between parent and medical team.

Luckily, we now have an agreement with our urgent care provider that our daughters will immediately receive FFP – no questions asked – whenever we call. We treat first, and we run tests afterward.

But it wasn't always like this. Doctors are trained to diagnose a problem, order tests, and evaluate each situation. But tests don't stop a bleed. Often, we'd sit in the ER for hours, waiting to get the FFP ordered and infused. When I'd explain that my girls were bleeding, I'd get the raised eyebrow as if to say, "Well, I don't see any blood on the floor."

We each bring our own perspective to any situation. I have a business back-

ground, and just as I do at work, at the hospital I wanted to see an effective organization where team members understand their roles and are motivated to get the job done. When I presented a process flow to one ER manager, showing who-calls-who when we need FFP, it involved multiple roles across multiple organizations. The time from FFP order to infusion was sometimes as long as 12 hours. Why, I wondered, couldn't this process be done more effectively?

Our interpersonal dynamics changed dramatically when we enlisted help from our hemophilia treatment center, Puget Sound Blood Center Hemophilia Care Program. And the time it took to get FFP infused dropped to just two or three hours. Now, that's something to write about!

I wasn't afraid to publish my experiences in my own voice. Not everyone will agree with my opinions, and that's fine. Honestly, I was more scared *not* to publish my book. If there's nothing in writing a decade from now, I thought, it will be my fault. It became my personal mission to be a good reporter and to make a contribution to the world.

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* Ed. note: Factor V deficiency is not hemophilia. It is extremely rare: about 1 person in 1 million. Also called Owren's disease, labile factor deficiency, proaccelerin deficiency, or parahemophilia, factor V deficiency differs from factor V Leiden, which is more common and results in increased blood clotting.

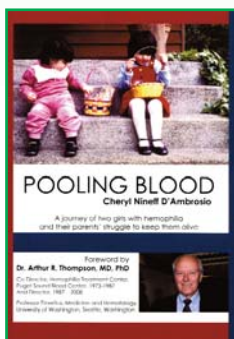
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But no publisher was interested: “No thanks, not my genre, but good luck!” So I saved my pennies and self-published.

One goal of my book was for medical staff, who go home after their shift *during a bleeding episode*, to read what happens after they leave. I wanted them to understand the consequences of waiting too long to treat a bleed. I wanted them to be with us as we endured a bleed that lasted days, weeks, or even a month.

My second goal was to help parents, who sometimes need support when speaking up to the medical community. If nothing else, new parents could read my book and take steps to avoid the traps our family fell into.

My third goal was to help patients build confidence when advocating for their own healthcare. My message: It’s time to stop feeling like you’re all alone or a victim. The more you know about what others experience, the more you can stand up for yourself. Even though my book is about two girls with factor V deficiency, I believe that men and women with



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For information and to hear Cheryl’s radio broadcast: www.poolingblood.com
For stories about girls and women with bleeding disorders worldwide: www.mygirlsblood.com

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healthy eating, exercise – and of course, factor. “I don’t let anything get me down!” he says. “If I’ve got to go somewhere, I go. If I can’t go, I don’t go!”

Today, Perry lives on beautiful Drummond Island, Michigan. Betty has passed away, so he now lives alone. But he enjoys spending time on his computer, visiting casinos, going on cruises, and staying with his daughter in Phoenix.

Perry told me how fortunate he feels to have escaped viral transmissions, considering the amount cryoprecipitate and blood that he received during his early years of treatment. And he’s

other bleeding disorders will find common themes.

Ultimately, my book *Pooling Blood* shows what I consider the keys to success in working with medical staff to get the best treatment:

1. Create a sense of urgency by letting others know that the bleed must be treated immediately.
2. Build a network of people you trust and who trust you. Your HTC is crucial in making sure your bleeding episode is managed expediently.

Do you notice that these two keys to success have to do with people, not technology or science? That’s why I wrote my personal history of parenting two girls with a bleeding disorder. ☺

grateful that although his daughters are carriers, none of his grandchildren has inherited hemophilia.

Thanks to the evolution of HTCs during Perry’s long lifetime, and advanced treatments with bypassing agents, Perry may just be the oldest living person with an inhibitor – an amazing accomplishment for an inspiring man. ☺

Kerry Fatula is executive director of the Western Pennsylvania chapter of National Hemophilia Foundation. She is also the mother of four boys, three with severe hemophilia A and inhibitors.

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was Metamorphosis, to celebrate the camp’s 10th anniversary. Just like butterflies, the campers had transformed from boys into young men, with teens now serving as counselors to new campers. Their spirits transformed too, as camp showed them their potential, a community that cares for them, and a future.

The Clarks’ package included a custom-made photo album of camp, dedicated to Bryan and the Clarks; some locally made wooden butterflies to hang on the wall; and handmade letters, decorated with butterflies, each signed by several campers and translated. One read,

From all the children registered with the foundation, we want to thank you for donating factor . . . and we are sorry for the loss of your loved one. In the name of the Lord, we are all born for a purpose.

With all of our affection, we are very thankful by your magnificent, humanitarian kindness. May God bless you!

Henry, Diogenes, Angel, Jorge, Luis, Ronnie

Another read,
The reason for this letter is to tell you that we’re sorry for the death of your son. We did not know him, but we know that he was a good son and we know that you, his parents, were by his side, fighting hemophilia.

Also, we want to thank you for the donation that we obtained on your behalf. Because of this donation we were able to enjoy camp, strong and healthy.

Luis, Isaac, Elian, Yoan, Manual, Bryan, David, Edward, Richard

Since summer 2009, when they made camp possible for the Dominican children, the Clarks have sent more donations to Project SHARE. Bryan’s donations helped patients in the Philippines, Jamaica, and the DR.

Thanks to Bryan’s family, children with hemophilia all over the world have had the good fortune to enjoy fun times at camp, to leave their hospital beds, or to celebrate their school graduations. We are honored that the Clarks chose to donate to Project SHARE in Bryan’s memory. Thank you, Dan and Linda, and thank you Bryan, for these gifts. ☺