

Preface

Although many people have never heard of von Willebrand disease (VWD), it is a bleeding disorder that affects millions of people worldwide from all cultural, ethnic, and economic backgrounds. VWD is also a diverse disorder—symptoms range from mild bruising to potentially life-threatening bleeding. The majority of people with VWD have a mild form. However, for approximately 10% to 15%, it creates a significant disruption in their daily lives and threatens both their physical and emotional well-being.

Everyone has medical challenges, from chronic conditions such as high blood pressure, diabetes, or asthma, to acute illnesses such as chicken pox or appendicitis. I have von Willebrand disease. It is no different than any other chronic condition; it must be managed, but in no way does it define who I am. As we say in Las Vegas, *what is important in life is not what cards you get, but how you play them*. Von Willebrand disease is simply the hand we have been dealt. It is neither a good hand nor a bad hand; it is simply *our* hand. Regardless of what hand life deals us, we only have two choices—play or fold. In the book, I hope to show you how to play your hand by educating you on how to overcome challenges presented by VWD.

If you are reading the book, you are likely a person with VWD, a friend or family member of someone with VWD, or a healthcare provider interested in learning more about VWD. I hope to address the needs of each one of you. However, my ultimate goal is to show people whose lives are significantly disrupted by VWD that *you have the power to regain control of your life*. For those whose lives are not significantly disrupted by VWD, I hope the book helps you keep it that way. For healthcare providers, I hope the book provides you with greater insight into the disorder and how it can affect people both physically and emotionally. That you have taken the time to gain additional knowledge and insight into the disorder is commendable.

Whoever you are and whatever your connection to VWD, I hope the book not only educates you, but also inspires you with personal stories about people conquering the challenges VWD has presented to them and their families.

Renée Paper, RN
Las Vegas, Nevada
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Preface

I have long been an admirer of Renée Paper and her crusade to educate people throughout the world about von Willebrand disease (VWD). We met in Dallas, Texas, in 1993 when we were both speakers at a women's weekend retreat. It was the first time I had heard about VWD. Meeting Renée was unforgettable. She is great in intellect, great in spirit, great in heart, and great in compassion. She commands attention when she walks into a room and long after she has left. Her speech stirred me.

After that day, we met repeatedly over many years at various bleeding disorders meetings, and I heard her speak several more times. Each time, I was filled with a sense of purpose and urgency about educating people with VWD. People were suffering in silence. No one was making a strong effort to reach them and educate them. I had already published my book, *Raising a Child With Hemophilia*, and felt I had helped educate one segment of the bleeding disorders community. Indeed, after the book was published, many people with VWD would approach me and ask, "When are you going to write a book like that about VWD?" My answer? I don't live with the disorder, I don't know enough about it, and it is not my main focus. As a parent of a child with hemophilia, I considered hemophilia my crusade. What could I do for VWD? I felt frustrated but did not feel compelled to act. Not yet.

Then in Nebraska, 1997, Renée and I again appeared as speakers together, and again I heard her speak out about VWD. This time, the message hit home hard. We *must* do something. Four years had passed since I had first heard Renée speak. Why wasn't anything being done to help the VWD community? I could sense the VWD community's frustration as well as my own. Listening to Renée for the fifth time, I could not remain passive. Renée's passion and commitment motivated me to act.

After her speech, I had an idea and approached her at dinner. "What about a book?" I proposed. "We could adapt *Raising a Child* and make it a book about VWD. We could encourage people with VWD to write and share their own stories with us. We would make it comprehensive and patient oriented, and it would be written by one of the foremost speakers on VWD. Let's put that motivating speech on paper and reach everyone, not just those in the audience." As I expected, Renée answered, "Let's do it!"

Four years later, the world's first book on VWD was born. It is not merely an adaptation of *Raising a Child*. Instead it stands on its own merit. It is

A Guide to Living With von Willebrand Disease

tailored to meet the needs of people with VWD and their families. It is truly a labor of love—something created in between our heavy work schedules and trips around the world, through e-mail, over the telephone, and during three long, fun, and frustrating days locked in a Massachusetts hotel room in the middle of winter. Even more challenging than writing the book was learning the delicate art of compromise. I am convinced that if Renée and I could write the book and remain great friends, then nothing is impossible!

Readers, *nothing* is impossible for you, too! Get inspired by Renée's personal story and the wealth of information presented here. Renée, a person with VWD, emergency room nurse, advocate, and founder of the Hemophilia Foundation of Nevada, has contributed an enormous amount of medical and consumer material. I, parent of a child with hemophilia, mother of three, businesswoman, author, and advocate, have helped contribute to the psychosocial and consumer information. Read this book, and be motivated to conquer your fears, get educated, and take action.

Laurie Kelley
Boston, Massachusetts
August 2006