

# My Story

*Our Mission* The Hemophilia Federation of America (HFA) is a national nonprofit organization that assists and advocates for the bleeding disorders community.



## “One Man’s Story”

By John Jarratt, M. Ed., L.P.C.

It is my hope that the new millennium will bring about a better understanding of hemophilia and bleeding disorders, along with an improved relationship and collaboration with consumers, chapters, foundations, hemophilia treatment centers, clinics, private practitioners, emergency room personnel, national organizations, and industry. After all, isn't our goal one and the same; an enhanced quality of life for those we serve?

No doubt, we will continue to see and welcome the advances in medical science. Yes, there have been set-backs, but let us remain hopeful that tomorrow is a new day; gene therapy, perhaps a pill to swallow, the elimination of life-time caps, but more importantly insurance for all persons, making access to care a reality; not merely a dream.

Many of us “kids” have now grown-up. I'm now sixty-one years young. I remember when I was six, when there were no chapters, foundations, hemophilia treatment centers, much less care and treatment for hemophilia other than hundreds of pints of whole blood or fresh frozen plasma, combined with weeks in the hospital. Many of our parents were forced to sign insurance waivers excluding us from their employers' group insurance policy due to our hemophilia. We had no HIPAA, COBRA, federal regulations, or advocacy groups, for that matter, protecting or advocating for us. Some were forced into getting a divorce in order to qualify for Medicaid so that those with hemophilia and other chronic and/or terminal illnesses could have access to medical care. How my parents managed, I'll never know. What I do know is that I was blessed with parents who provided me with loving care, their knowledge, wisdom, and courage. Not only did they give me life, but they gave me a sense of self-worth. As a result, I have become my own “Chairperson”, able to advocate for myself, making my own decisions as I travel this journey of life.

No, “I was never promised a rose garden”. We must talk about our past and share the stories which often haunted our early lives. We must talk about HIV/AIDS, the “alphabet soup” of hepatitis “A”, “B”, and “C”, and how that has affected the lives of many of our blood brothers and sisters. We must talk about the present and the joy we experience when our six year old has learned at camp to self-infuse with a product that has been genetically engineered, with the knowledge of its safety and efficacy, which allows him or her a normal life expectancy. We must look to the future with hope, as opposed to hopelessness, turning challenges into opportunities, and recognize that we are productive citizens, contributing members of society, with strengths and weaknesses no different from the next fellow. We have become laborers, businessmen and women and professionals in the working world. This was not possible 25, 35, 45, 55, or 105 years ago. It's no accident that I became a counselor by profession, as hemophilia is far more than a medical disorder. Oh, how I could have benefited from psycho-therapy/ “talk-therapy” when I was much younger and feeling so alone and isolated at school, community, or workplace. I grew-up in an era when only the “rich and famous” could afford therapy. We must think holistically, with mind, body, and spirit



*For additional stories or to share yours, contact HFA*

## *Continued...*

working together, which has brought healing into my life, and the lives of many. Hemophilia, von Willebrand Disorder, and numerous other chronic illnesses affect one not only medically, but emotionally, socially, psychologically, and spiritually as well. We must recognize that without shame. We must also recognize our possibilities as being unlimited. No longer should we be placed in a glass box marked “FRAGILE”. Whether it’s hemophilia, von Willebrand Disorder, platelet dysfunction, or related bleeding disorder, it is NOT our identity.

Sure, there have been interruptions in our lives, and we will continue to face these. But with continued advances in medical science, coupled with open, honest, communication amongst ourselves, our fellow consumers, the medical community, industry, and the community at-large, nothing is impossible. We are not to be feared. Allow us the freedom of knowledge, empowerment and self-advocacy, as we so vividly remember the days when we were told we would not live past our teens. We now have a control, not a cure, but a control that many have learned to self-administer. And with that, I ask you...please allow us the dignity of risk...the dignity to question...the dignity to answer when we question, without becoming threatened or defensive of our knowledge of a disorder for which “we” have become the experts through experience.

So to the new millennium, I ask to be allowed the “risk” of discovering what we can do instead of trapping us with what we can not do. I and others like myself shall always look toward a hope for tomorrow.

My parents were charter members of the Cumberland Chapter National Hemophilia Foundation ( now The Tennessee Hemophilia & Bleeding Disorders Foundation) along with a very small group of other committed, dedicated and loving families, with the guidance, direction and leadership of Dr. Jan van Eys and Dr. John Flexner. The Tennessee Hemophilia & Bleeding Disorders Foundation, the World Federation of Hemophilia, the National Hemophilia Foundation, Hemophilia Federation of America, the Committee of Ten Thousand, Save One Life, Inc, chapters, foundations, and comprehensive hemophilia treatment centers throughout the world, manufacturers and home-care companies, along with a lengthy list of supportive agencies; all with its dedicated, professional, and compassionate staff and volunteers became...and have remained my “life-blood” and “foundation” for hope, health, and happiness. 💧

