

My Story

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



The Long Mile by Barry Haarde

There was only one more hill to climb as I rounded the corner that brought the finish line into view. I had ridden my bicycle 175 miles since lining up at the starting point back in Houston the day before. After more than 10 hours on the bike, I had finally arrived in Austin, along with 13,000 other cyclists, all pedaling for a purpose-to raise funds and awareness for the National Multiple Sclerosis Society in their local edition of their nation-wide ride series known as the MS150 (www.ms150.org)

I was finding it difficult to hold back the tears that flooded my eyes as I approached the final hill that would conclude the ride. I had been reflecting on all the hills I'd had to climb in my journey through life with hemophilia. I thought of the early years, before clotting factor concentrates-the years when my seemingly inexhaustible mother and I spent innumerable hours on the road to the hospital in Philadelphia, where I'd remain for hours or days, suspiciously eyeing the plasma as it dripped ever-so-slowly into my veins. It always gave us hives and was only marginally effective at controlling the hemorrhaging, but it was all we had. My brother John, also born with severe hemophilia A, always seemed to be there too. Sometimes we'd both be admitted to the hospital at the same time!

I recalled the advances in hemophilia care that had improved our lives so dramatically. There was cryo and then the factor concentrates, self-infusion, hemophilia treatment centers, home delivery of our meds...life was becoming almost normal! But a terrifying threat, as yet unseen lay before us. Before we knew what it was, it was among us. Eventually, it would be called AIDS, and it entered our lives concealed in the blood-based "miracle drug" that had given us our new lease on life. There would be more hills to climb, more tears to shed.

I thought about Pat, a factor 9 hemophiliac and my brother's close friend, who later became my sister's husband. The new enemy had found him first, and he succumbed to AIDS in 1990, leaving my sister and two young daughters to fend for themselves in a world that seemed to care very little about the AIDS pandemic and its growing list of casualties. AIDS was never mentioned at his funeral, of course. You didn't dare talk about it then.

I remembered my brother who, like me, had survived HIV infection, and lived to see the arrival of the many anti-viral medications that offered not a cure, but a new era of hope in the treatment of HIV/AIDS. Thirteen years my senior, John had been a brilliant engineer, a husband, and father of two, until his death in '07 from hepatitis C, the "other virus" that was now taking many of the hemophiliacs who'd, thus far, survived the AIDS pandemic. John had been in three different hospitals for over four months, awaiting a liver transplant that always seemed to be just around the corner, but never came. "I hope you never have to go through this," he'd said to me a few days before he slipped away. He was still looking after me, you see.

I was ascending the final hill, pedaling slower now as the fatigue from all the miles that lay behind me exacted their vengeance on my tired legs. I was thinking, then, of my friend Cindy, a female hemophiliac and champion of the



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women's bleeding disorders community, who once took me on a whirlwind tour of the Oakland/San Francisco area, where she lived. She had ridden next to me in my rented convertible as we cruised down Highway 1 towards Big Sur, the breathtaking scenery and cool Pacific breezes reminding us that there was still so much beauty in the world, so many things yet to live for. I only learned of her liver cancer diagnosis after I'd heard she had died. She had never mentioned it.

I had been thinking of another friend, Elaine, whose 26-year-old son, Nick, had also recently lost his battle with hepatitis C, never to receive the liver transplant they had so earnestly prayed for. "The end was devastating," she had written to me. "He had a brain hemorrhage and all his organs shut down as I held my son until I could no longer feel a pulse, nor heartbeat. I wondered if Nick felt pain-so much pain he felt all of his life...I had my son knowing I was a carrier [of hemophilia]," she wrote. "Do you think God forgives me?"

So many hills...so many tears...so many funerals...It made me wonder why I had lived such a long time, when so many of my "blood brothers" had not. How was it possible after a lifetime with hemophilia, thirty years of HIV infection, liver cirrhosis from hepatitis C, a knee replacement, peripheral neuropathy, and over two years of interferon therapy, that I could still climb on a bike and "go the distance" with all the healthy riders? I didn't know, but I knew that I had recently made a promise to myself and to God, that if I could only keep going, if my hep C treatments would only be successful, that I would begin to do everything in my power to raise awareness and support for those living with hemophilia, HIV/AIDS and hepatitis C. I promised that I would return to the hemophilia community, from whom I had become disconnected for far too many years.

The memories of those we'd lost echoed in my mind during that last mile, but my final thought as I crossed the finish line, while giving a friendly wave to the event photographer as he snapped my picture, was of the famous lines penned by Robert Frost:

"The woods are lovely, dark and deep,
But I have promises to keep,
And miles to go before I sleep.
And miles to go before I sleep."

And I knew that, God willing, I would return the following year to ride again and to keep climbing whatever hills fate might have in store in the intervening days. After all, I thought, I had a promise to keep.

Bio:

Barry Haarde is a 43-year-old severe hemophiliac who lives and works in Houston, Texas. He participates in many local cycling events including the MS150 bike tour from Houston to Austin. He receives medical treatment at the Gulf States Hemophilia Treatment Center and would like to acknowledge the hard work of its dedicated staff and brilliant physicians. He would also like to thank the CDC, HFA and Baxter International Inc. for their development and support of the "Blood Brothers" initiative that has been responsible for "bringing him back" to the bleeding disorders community. He invites others to visit his bike team website at tlsports.org or contact him at redsaleen97@yahoo.com. 📧

