From November 2013 HepCBull, by Andrew Cumming

Andrew and Hillary Cumming, *photo courtesy Osgoode Law School of York University, Alumni Organization,* ***Winter 2014***

MY STORY (September, 2013)

My adventures as a hemophiliac started when I tried to walk at nine months of age in early 1960 and my ankle blew up like a balloon. I was living in Gravenhurst at the time with my mom and dad. Dr. Bill Cumming, my father, was a young general practitioner in town at that time. He drove me to Sick Kids Hospital in Toronto to see if the problem could be diagnosed, but he had a pretty good idea what it was. Turned out I was a severe Factor VIII hemophiliac. And so it started. He brought me back up to Gravenhurst where I proceeded to wait another nine months before trying to walk again. I guess that bleeding ankle must have hurt quite a bit. Once or twice a week my mom or my dad would take me up to the nearest hospital, which was in Bracebridge, where I would get a unit or two of fresh frozen plasma in an attempt to treat my bleeds. Cryoprecipitate wouldn't come along for another five years, and freeze-dried Factor concentrates were in the far distant future at this time.

Mine has been a life of close calls and very fortunate timing. The fact that cryoprecipitate came out just as I started to get active and go to school, and the fact that my dad was a doctor, meant that we kept supplies of the stuff on hand at home and both mom and dad could infuse me at the first sign of trouble. This meant that I was on the vanguard of the first wave of hemophiliacs to lead relatively "normal" lives. By the time I was in grade one our family had moved to Toronto. I was able to participate in most gym and schoolyard games, and when I did have a bleed I was infused and sent off to school on crutches for a few days. I started to self-infuse at the age of eight. The remainder of my school days were uneventful. I ran cross country, joined the swim team, snow-skied, water-skied, played in the band, and in high school, became a competitive sailor, winning a number of regional and national championships. Many of you reading this will find all of this unremarkable. Most hemophiliacs today participate in a full complement of sports, recreational and social activities. Forty or fifty years ago this was not the case for most of us. No sports, poor academics due to lengthy absences from school and crippled bodies led many hemophiliacs raised in the '60s and before to lead unproductive lives, professionally and socially. It is in this sense that I was so very lucky to benefit, at an early age, from the miracle of cryoprecipitate.

In 1978, after a year of university I decided that I wanted to take a run at the 1980 Olympics in sailing. My dad helped me buy a Flying Dutchman-class sailboat, and I started dragging it around the continent, going to regattas to train for the Olympic Trials to be run in the spring of 1980. Half way through those trials to see who would be on the Canadian Olympic Sailing Team, the Americans and most of their allies announced that they would be boycotting the Moscow games because of Soviet military involvement in Afghanistan, and so ended my Olympic dreams. Ironically, we and the Americans engaged in pretty much exactly the same sort of military intervention in that same country some 30 years later.

As I was preparing to go back to university in the fall of 1980, I noticed an enlarged and hypersensitive testicle. Thinking this must be somehow related to my hemophilia I treated it with the then novel product known as freeze-dried Factor VIII concentrate. After a few weeks I was cajoled by my girlfriend to go see an urologist. I never made it back from the hospital. They whisked me into surgery to excise the offending organ and biopsy it. I was diagnosed with Embryonal Cell Carcinoma, an incredibly aggressive cancer that kills 95% of patients within a month. Cancer was on everybody's minds and tongues at that time. Terry Fox was halfway through his historic run across the country and had visited Toronto a scant few weeks before. My dad told me that I probably had a couple of weeks to live.

Luckily, my oncologist knew better. There was a new drug, cis-platinum, which was barely a few months old, and indications were that it was effective in a chemotherapeutic cocktail on this type of tumour. This is the second instance

of extraordinarily fortunate timing in my life. Needless to say, the new therapy saved me, as it now saves some 70% of patients with the tumour I had.

The next few years went by without incident. The fact that I survived cancer gave me an entirely new outlook on life. Whereas, up to that point, I had more or less cruised through school and most of my activities, after the close call with death (and constantly living with the threat of relapse hanging over me), I attacked life and all of its aspects with increased determination and verve. I went back to university, determined to be the best student in the class (which didn't happen, but I tried). I became intent on going to a top-flight school to do a Ph.D. and worked single-mindedly to that end. I spent my summers working in professors' labs, and nights studying harder and harder to bring my marks to the highest level of which I was capable. I was rewarded for this effort with a spot in the physics Ph.D. program at M.I.T.

Now we get to the part of the story that is common ground for all the severe hemophiliacs in Ontario and indeed, most of North America and Europe. In my case, D-Day was December 20th, 1985. I was in Toronto for Christmas break at the end of the first term of the second year of my Ph.D. studies. I had just had a tumour marker assay and a final visit with my oncologist, and was declared cured of the terrible cancer I had contracted five years earlier. On that basis, and with that great news in hand, I proposed that morning to my then girlfriend. We had both been a little trepidatious about proceeding with marriage if the cancer issue was unresolved. Now that was behind us. She accepted my ring! Later that same day, I had what I thought was going to be a routine checkup at St. Mikes with the hemophilia team there.

Then the bomb dropped. I (and indeed virtually all of the patients of the clinic) had been infected with HIV. As many of you reading this will recall, at that time HIV was probably the most feared and loathed illness on earth. People routinely killed themselves when they found out they had it. It was universally assumed to be highly contagious and lethal in all cases. The people who had it became social pariahs, often ostracized by their communities. Young hemophiliacs all over the world were asked not to come to school. In extreme cases violence was perpetrated on HIV-positive people, including children. People's houses were burnt down (I happened to be friends with Ricky, Robert and Randy Ray, who were all campers at a hemophilia camp I volunteered at in central Florida during the eighties, and whose house was burned in an attempt to drive them out of town). People lost their jobs. People lost their lovers and spouses, and couldn't find new ones. It was a truly horrible time, as those of us who lived through it remember so well.

My fiancée decided to stay with me, which was a great relief, and we were married a year and a-half later in June, 1987. As the eighties wore on and many hemophiliacs around the country started to show the signs of full blown AIDS, I carried on with my studies, a post-doctorate, and finally landed a professor position at a major university, all the while waiting for what seemed to be the inevitable. Probably the most challenging aspect of this illness, at least for me as a seemingly healthy victim, was the necessity to keep confidential the information that I was HIV-positive. The prejudice and hysteria surrounding this disease was intense, and took literally decades to subside, even with the massive educational efforts by both governments and NGOs, followed by legislation concerning the human rights of HIV sufferers. With all the work I had put into my education and career since surviving cancer, there was no way I was willing to have my dreams and aspirations sidelined by a bigoted and ignorant public.

More and more was being learned about the virus by the researchers, and we patients who were still not sick carried on with life, monitoring CD4 levels and viral loads, and watching the newspaper obituary page for death notices of our friends. And there were many. I was lucky, in that, despite astronomical viral counts, my CD4's stayed in the 300s up until the presentation of the therapeutic alternative of AZT to the general HIV population. I stayed away from AZT for a year or so because I was still feeling very healthy and the side effects of this potent and toxic medicine were far from well understood. I eventually started taking it when I realized that the key to survival was getting the viral loads down, reducing the rate of mutation, which if left unchecked would eventually yield up a strain that was able to overcome what was left of my immune system and maybe even drug therapy in the future.

By the early 1990s, with virtually all of the severe hemophiliacs infected with HIV, and more than 75% of them dead, dying or showing signs of AIDs-related illnesses, many professionals in the field started looking to new areas in which to practice. It truly seemed that within a few more years there wouldn't be enough hemophiliacs left to support the clinics. Some giants in the field, like Dr. Peter Levine, who was a pioneer in the creation of comprehensive care clinics for the

treatment of hemophilia, abruptly abandoned their posts when their clinical patient cohort, their own lives' work, were eviscerated by this horrible "hemophilia holocaust," as I call it. At the St. Michael's Hospital clinic where I was a patient, we were luckier. Drs. Teitel and Garvey and, most importantly for me personally, Ann Harrington, stayed on station, treating, consoling, commiserating with and supporting their flocks as they shepherded them through the fires.

As for me, my life of close calls and fortunate timing continues. It is an unhappy fact that the woman I married in 1987 left me in 1994. I didn't really know why at the time, but in retrospect I think it is because she didn't want to have children with somebody who was sure to die before they grew up. Ironically, by the time this happened I was responding very well to the cocktails of drugs they were serving up, and my viral load had become undetectable. I had never had an HIV-related opportunistic infection. I was maintaining my CD4 levels. But I admit that there was a huge element of uncertainty as to what the future would hold for me. I was devastated, of course. I knew that it would be impossible to marry anyone else. Who, in her right mind, would even go on a date with a crippled HIV-positive divorced man? But I was wrong. I am always amazed at the capacity for courage and compassion that some human beings possess. I was able to start dating again, and met my soul mate, Hillary, in 1996. By this time I had abandoned my career as a physics professor, and had become a financial derivatives trader (that's another whole story) at a major bank. Hillary worked there. We were married in 1998 and were blessed with children in 2000, 2001 and 2010! I continued my work on Bay Street for another few years before the "other virus" (hepatitis C) started to work its spell on my liver. By 2003 I had had several hospitalizations for bleeding from esophageal varices, which for hemophiliacs are extremely dangerous. I knew it was only a matter of time before one of these bleeding episodes killed me. By late 2004 I had a fully decompensated cirrhotic liver and was in danger of dying from the complications of advanced liver disease directly, even if I managed to continue to dodge the internal bleeding for a while longer. I was lucky enough (and wealthy enough, something that was a direct outcome of moving from academia to finance, although that was not why I made the move originally) to get onto the liver transplant list at the University of Miami in Florida, and in May of 2005, managed to get a transplant. Curing my Hep C infection turned out to be a struggle. I was on a double dose of interferon for 18 months because the standard interferon/ ribavirin therapy had failed to clear the virus in an earlier attempt in 1999.

Those of you who have endured that particularly sinister form of chemotherapy know the hell that I was to live through. The only good thing I can say about it was that it worked.

I am now clear of Hep C, my HIV is totally under control (still undetectable viral loads and CD4s in the 400s), and wonder of wonders, my hemophilia is cured. The liver is where Factor VIII is manufactured, so when you get a new liver, you get a clotting factor factory at the same time. Too bad my poor old knee, ankle and elbow are so messed up from a lifetime of hemarthroses, or I would be perfect (lol). As my son, now 13, and older daughter, 12, settle into the monumental struggle that is adolescence, and my baby, 3, develops her full measure of toddler sass, my wife and I embrace the mundane reality of simply trying to do the best job we can at bringing up a family. Life goes on.

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