

WHAT MORE COULD I HOPE FOR?



I've posted my story and followed with updates a couple times. This version covers my WM journey from the beginning up to January, 2021. I am fortunate to have encountered so many excellent medical specialists. I have also had the good fortune of an incredibly supportive and understanding team that includes my wife, Nancy, my family and our friends and neighbours, and the WMFC/IWMF. Having good support makes it so much easier for a less than healthy person to achieve the "can do" attitude – an attitude that I feel really helped me in my recovery, a recovery I hope is long term.

In summary, I began to experience symptoms in 2002. A fortuitous referral to an excellent Hematologist/Oncologist in 2004 led to a bone marrow biopsy and a WM diagnosis in September of that year. I underwent chemo, (cyclophosphamide, fludarabine, ritux and prednisone), starting in April 2005. Remission allowed a return to an active lifestyle. However, symptoms returned and I required chemo again in September 2009. The cocktail this time was cyclophosphamide, vincristine, ritux and prednisone. In the Spring of 2015, some of my symptoms were returning, along with worsening lab reports. After lengthy consults with staff of the Tom Baker Bone Marrow Transplant Clinic, in Calgary, Alberta, we decided to move forward with an autologous stem cell transplant. Chemo began almost immediately and continued through the summer. Cyclophosphamide, bortezomib, dexamethasone and ritux were prescribed. A bone marrow biopsy and lab tests in the late summer indicated another remission, so stem cells were successfully harvested.

On 15 October, 2015, following the administration of melphalan to destroy all existing bone marrow, my harvested stem cells were reintroduced and I was told that at 67 I had just had my new birth day. Over the next 2 ½ months I could recognize improvement almost daily. Post-transplant I had to undergo IVIG treatments. This necessitated going to the hospital for a couple of hours every 4 weeks.

Nancy and I are avid travellers. IVIG schedules interfered with being away from home. Upon investigation we determined that in fact subcutaneous IG could not only eliminate the need for hospital visits, but it was perhaps better for my body. We took the training required to do self-infusions – and we were then free to go where we chose. Not to brag, but we have taken advantage of that freedom with numerous trips: a one-month European river cruise and an extended stay in Prague; a 5-week driving trip through Ireland, Scotland and England; a Kenyan Safari; a one-month ocean cruise from Valparaiso, Chile to the Antarctic, to Buenos Aires and then a side trip to Iguazu Falls; a Polar Bear Safari to Churchill, Manitoba; a 1 week excursion on a relatively small yacht around the Galapagos Islands followed by a trip to Machu Picchu; and a National Geographic Eco Tour of Costa Rica – coast to coast. We actually rounded the Horn of South America on my 70th birthday. Additionally,



each summer we go to our remote, lake-side cabin in North Western Ontario (1200 miles from home), where we live “off the grid” for over 2 months. Although we have installed a very small solar power system to give us a few lights and the ability to charge our devices, we cook on a wood-fired cookstove, use the outhouse and do plenty of physical work while we enjoy nature. When home, and when possible, we still try to get out on our motorcycles – a Harley and a CanAm Spyder.

We have been amazed and extremely pleased to learn that all international airports and airlines we have travelled through/with, when shown the letter from the medical authorities, had no problem with me carrying all of my blood product and administration supplies on board the plane. And the hotels we stayed at were willing to dispose of the used vials, syringes and needles. Not once was there a problem or a charge.



Following our return from watching the Polar Bears I had my regular lab work and appointment with the Doctor. The results showed that my own body was producing the necessary blood components – I no longer needed to do my weekly subcutaneous IG infusions. They were stopped in October 2019, 4 years post-transplant. Lab results since then have been “normal”. At almost 73, or over 5 since my “new birth day”, I feel great. With COVID restricting travel this winter, we’ll stay home and

attempt to stay healthy in Calgary, and plan future trips.

While I don’t think that my experience is anywhere close to being the norm, it is proof that there is hope. Just because we’ve been diagnosed with a blood cancer does not mean our days are over. Nancy and I have certainly had “bumps in the road” in our journey with WM, but we have learned to live with them, we’ve learned what is possible and what is more difficult, and learned to make the most of every moment. Nancy has become very adept at using our timeshare points to at least partially pay for trips we have made worldwide. More are already booked.

Along with my friend Cam Fraser, I co-facilitate the WM Support Group for Alberta. I strongly believe that a positive attitude and a healthy lifestyle have been to my benefit. Nobody likes knowing that they have an incurable disease, but I have taken the attitude that nothing is going to get in my way of striking things off my “bucket list”. I truly do enjoy talking to other patients and caregivers about our ability to continue to enjoy our lives and the retirement we saved and planned for.

Stu Boland
Calgary, Alberta.
January, 2021

The details of 2015, the year of my re-birth



- In early April, 2015 while on our way home from several weeks of hiking in Joshua Tree National Park, golfing in the Palm Springs, area, and riding the Harley in Southern California, Nancy and I found ourselves in Las Vegas.

- No – we were not to be found in the clubs or casinos, we were hiking in Red Rock Canyon and The Valley of Fire.

- I began to recognize some symptoms I was experiencing – fatigue, a dry cough, and

occasional night sweats. It had been about 5 years since the last chemo treatment.

- Immediately upon our return to Calgary I had lab tests and we visited my Oncologist for my regularly scheduled. He performed a bone marrow biopsy.
- All the test results showed elevated counts. That, coupled with how I felt, pointed to more treatment.
- My Oncologist asked if we had ever considered, or were interested in considering having an Autologous Stem Cell Transplant.
- Our quick response was: “We know a WM patient who has had a transplant, how do we get additional information?” (That person we knew is Dr. Guy Sherwood – a fellow Canadian, a Medical Doctor, a WM Patient and a very active member of the IWMMF).
- A week or so later we were meeting with the head of the Bone Marrow Transplant Clinic at the Tom Baker Cancer Centre in Calgary. Dr. Stewart, and his nurse, answered all of the questions we asked, and provided a thorough review of the process.
- Nancy and I discussed the procedure; weighed the “pros” and the “cons” and decided that the low risk and the short term “pain” outweighed the alternative – continuing chemo on a regular basis. If I was going to go through with the procedure – I had to do it before I got too much older. At 67 I was already well beyond the average age.
- We made an appointment with my Oncologist and advised him that we wanted to proceed with the transplant.
- My Oncologist and the Specialist consulted and developed a chemo protocol which began in early June.
- The chemo was taken over a 12-week period. It consisted of weekly Bortezomib (Velcade), Cyclophosphamide and Dexamethasone. Every 4 weeks I also received Rituximab.
- Once treatment had ended, I had another bone marrow biopsy and blood tests.
- The results showed complete remission.

- In mid September, after injecting myself with numerous vials of a drug to promote stem cell growth, I again visited the Bone Marrow Transplant Clinic, had a central venous catheter installed and 2 consecutive days of stem cell harvesting.
- On 13 Oct. I was admitted to Unit 57 of the Tom Baker – a unit dedicated to transplant patients.
- I received some chemo (Bortezomib) that day.
- On 14 Oct. I was given a heavy dose of Melphalan (a.k.a The Big Gun). My bone marrow was quickly destroyed.
- On 15 Oct., first thing in the morning, a large team of nurses, lab folks and my frozen stem cells arrived in my room. The process was simple, quick and painless – no matter how formal and thorough the staff was. The thawed stem cells were administered during two sessions that day.
- The team congratulated me – they told me it was my new birth day!!
- Over the next 2 ½ weeks I suffered nausea, diarrhea, fatigue, poor appetite; but these symptoms disappeared quite quickly.
- By the time I was released and home, my energy level had started to recover; and I was conscious of the need to eat well and exercise to further assist the recovery.
- By Christmas I was eating normally and walking about 5 Km (over 3 miles) a day. My weight was back to normal.
- In early/mid January I had a CT Scan and blood work, followed by an appointment with the Bone Marrow Specialist.
- GOOD NEWS!! No sign of the disease. I was being promoted back to my regular Oncologist. The Bone Marrow Clinic folks refer to me as a poster child; more than 20 years older than the average patient; but fully recovered much more quickly than most. They welcome me back to visit, but hope it will be a long, long time before I book an appointment with them.
- Nancy and I are delighted!! I say I feel completely normal – Nancy says I have never been normal! This winter, at 3 ½ months old, we'll travel by car on a long road trip. We'll hike, golf, sightsee, visit friends and relatives and celebrate!!
- We'll return in early April when I will start the process of having all of my childhood vaccines.
- Since getting our good news from the medical team we have made a purchase to use on our next motorcycle trip – a tent trailer we can tow behind the Harley. Atlantic Canada – here we come!!
- On instruction from my dietician, I am continuing with my daily dosage of 3 squares of dark chocolate – another real benefit!!