June 17, 2016
(April Letter)

Dear Samantha,

From your last letter (May), it looks like we are into sharing illnesses so I thought I would bring you up to date with mine. Mine's not as debilitating as yours (at least in the short term) – in fact, I wouldn't know it exists except for some blood tests I had as part of my doctor's search for my slight anemia. I don't notice any physical symptoms.

As part of the search for the cause of the anemia I had a number of tests over the last year or so. Eventually I was sent to a haematologist (blood doctor) who diagnosed me with Monoclonal Gammopathies of Undetermined Significance (MGUS). It is a condition where there is a preponderance of abnormal clonal plasma cells in my bone marrow. It is in the bone marrow where blood cells are made. Apparently, my bone marrow makes too many of these abnormal plasma cells.

It may be benign (causes no problems) for years, so the doctor said that he will simply monitor the condition with an eye out for the level of abnormal cells. If they become too prolific, they crowd out the haemoglobin (good cells) and produce effects such as bone lesions (abnormal growth or cracks), kidney failure, and might reduce my immunity to disease over time (since the cells that fight disease get crowded out of the marrow and blood). The critical cutoff level for treatment is 120 grams of haemoglobin per litre.

For the past many months my blood tests showed that I was above the cutoff. As is normal, I was feeling no symptoms and the only indications that things were amiss were shown in the blood test results.

At my meeting with the doctor on May 25th, he informed me that my blood test results were below the cutoff which suggested that the MGUS had moved to Multiple Myeloma and that we should consider our options for treatment. He added that there are several promising options and outlined a few – including an ongoing clinical trial taking place in Montréal. Instead of a prognosis (estimate of the likely time to death) of 12 to 18 months with full-blown myeloma and no treatment, the treatment options are likely to hold the abnormal cells at bay for many years. He sent me home to consider the options and make our list of questions in preparation for the decision.

Needless to say, it was a dramatic shift in our lives. The prognosis for managing the cancer was good but the most disappointing aspect was the limitation that the treatment would place on my mobility. It required me to be in Montréal for weekly treatments for about 3 months (depending on how I responded to them) and monthly treatments after that. The first casualty was my trip to Alaska for the ICRPS summer school. It was too soon to know what the possibilities were for our trip to BC in August so we decided to wait until we knew a bit more before passing on the news to family.

Fran and I had another meeting with the doctor on June 7th. The blood test results confirmed that my haemoglobin level (119) was below the cuttoff and we began preparations for the treatment. They started me on the many tests necessary for the screening – like a full bone x-ray scan, chest x-ray, and ECG (measures the operation of my heart). I was set up for another meeting on June 15th to finish off the screening tests, make the random selection (to see which treatment group I would be in), and perhaps begin the therapy.

I turned up at the clinic on the morning of the 15th, had my blood drawn, had a test of my lung functioning, and was invited into a room for my bone marrow biopsy (this is where they put a needle

into my hip bone to take out a sample of my bone marrow). The technician had everything set up and we waited for the doctor to arrive to take the biopsy. Instead, an assistant came in and invited me into another room. Soon the doctor came in with the news that my haemoglobin levels were now 123 – above the cutoff for treatment. Great news!

This now means we are back to monitoring my condition. I'm set up for another appointment in two months (Aug 15). At that point we will see whether I have to once again gear up for treatment or wait once more for the next assessment. According to the doctor, this is not unusual and could go on for years. It will certainly be a new feature of our lives.

Fortunately, I have been feeling fine throughout all this – other than the stress of not knowing what the long term outcome will be. It also means I will be able to travel – at least until Aug 15th. I presume that after that time my planning will be in multi-month spurts unless my blood test results once more drop under the threshold. If they do, then I will be very happy to contribute what I can to the clinical trial.

This means that I will be joining Fran for her trip to Sicamous and Victoria in July even though I have dropped out of the Alaska one. Hooray!.

This has been a difficult time for Fran and I as we rode the ups and downs – and particularly the uncertainty – of this drama. Since we were so uncertain about the situation and possible outcomes we felt it was better to wait a while until things became clearer before passing the details to family members. This good news provided a wonderful opportunity to do so. We hope that you do not find it overly stressful. I am feeling well and the prognosis for managing the potential outcomes is very good.

I was uncertain whether this type of news was appropriate for our monthly letters – but decided that it was, especially because it has such an impact on our lives and because you were willing to pass on the details of your experience with disease. Hopefully, this will not be a pattern for our future exchanges – except for the good news part of the stories!

You will also find a special something in the envelope from Fran. These finger puppets were sold at the Cirque du soleil performance of Luzia. She figured that you might appreciate it since we didn't set up an opportunity for you to attend when you were here.

I hope that your course is successful and your summer employment plans work out all right. I'm looking forward to seeing you next month!