

October 27, 2016
(July Letter)

Dear Samantha,

I got your lovely typed letter this month. It was about your fall (2016) semester and you identified it as your September letter. This means I didn't get one from you for July or August since the previous one I received was for June (about your astronomy course). I hope this doesn't mean that some of your letters have been lost in the mail. It's not a big problem since I'm way behind as well.

I thought I would catch up by sending you a couple of letters about my myeloma treatments as they unfold. I hope they won't be too depressing since they are all about medical issues, but I find them interesting since they reveal some interesting things about the way in which health care has improved.

As you probably know, our bodies make white blood cells to fight infection. They are the first on the scene if a wound or infection occurs. They are made in the bone marrow of all our bones. My problem is that my body makes some of them without the infection-fighting capability of the proper white blood cells. They are not a problem if there aren't many of them - but when they become too plentiful they crowd out the good white blood cells resulting in fewer good ones to fight infection. They also produce long strings of protein that can clog up the kidneys.

They also upset the balance of bone depletion and reconstruction. Ordinarily, our bones are constantly being absorbed and reconstructed in a balance that maintains them strong and healthy. The cancerous white cells upset this balance so that more bone gets absorbed than reconstructed. As a result the bones get brittle and full of lesions (holes and abnormalities).

It used to be that the problem wasn't discovered until the kidneys failed or the bones kept breaking. Now they can anticipate the problem by checking the level of haemoglobin, long proteins (monoclonal protein), and several other markers in the blood. By diagnosing it early, they can slow down the growth of the bad white cells and avoid the kidney and bone problems that mark the advanced stages of the disease. I'm lucky that they caught it early.

The strategy for dealing with the problem is to slow down the production of the non-effective white blood cells. There are several ways that they have to do this - from the general approach of killing any fast-growing cells in the body to targeting particular characteristics of the bad cells or their production.

It used to be that the approach was to use the general chemotherapy to try and kill the fast-growing cells since cancerous cells are usually fast-growing (along with hair and fingernails). That is the approach usually taken when they don't know much about the particular type of cancer. That's also why people undergoing this type of therapy often lose their hair and their fingernails grow slower.

However, they have learned a great deal about the problem of myeloma so have developed drugs that are much more targeted to the peculiar type of cell and their production. Thus the drugs they will use for me are more effective and have fewer negative side-effects.

One of the important ways they learn about new drugs is through studies (called "trials" that are conducted with willing patients. In the trial they randomly assign the patient to one of (at least) two groups. One group (called the "control" group) is given the ordinary treatment and the other is given a special treatment with the new drug (the group called the "experimental" group). They then follow each group carefully to see if the special treatment group shows any advantage over the control group.

This way, the impacts of many other things that might affect the outcome (like gender, age, experience, size, etc.) are minimized since the various patents are randomly assigned to each group - and the effect of the treatment can be identified by comparing the overall results of the two groups. Obviously, this takes a lot of time and effort - and is one of the reasons why it takes so long for new drugs to be approved for general use.

When I was invited to participate in such a study, I was eager to do so - since I know how important it is. It also means that no matter what happens to me, I will be contributing to the accumulation of knowledge for others. At this point I do not know to which group I will be assigned, but I will find out on Nov 15th.

If I am assigned to the control group, then I will have to take oral medication for a number of months. If I am assigned to the experimental group then I will take the oral medication, but in addition I will get an infusion of the experimental drug once a week. This is provided intravenously through a tube in my arm. For both groups I will have to meet with the research team once a week to get various tests done. They monitor my body's reaction and administer a questionnaire about my responses. Since the current medication is already very effective, they will be most interested in the extent to which the treatment undermines my quality of life. They are very interested in finding out ways to improve this quality.

Other than the fact that I can't travel as easily as before, the process is very pleasant. They have given me a long list of possible side-effects related to the treatment but most of them are relatively unlikely and rather mild (like diarrhea, joint pain, or fatigue). I'm hoping that I won't be susceptible to those that will slow me down a lot. I won't know until the week after Nov 16th when the process begins.

I'll tell you a bit about the leadup to the treatment in my next letter.

Love,