



PRAYERS AND PETITIONS

I saw my hepatologist last May and did not receive much encouragement that there was any drug or interferon-free combo available. I decided then and there that I had to do something, and that something was to get a petition going, not just for myself, but for the possible 15,000 people of Manitoba who have Hep C and those who may not know it yet. I wrote up a letter to the Health Minister and her staff to get the new drugs Sovaldi and simeprevir approved. I wanted a meeting with the Health Minister, and my doctor was willing to come to that meeting, but only with the Health Minister, not the Health Critic.

After several months of having people sign the petition and sending in the signed letters to the government, I got a reply from the assistant to the Executive Director of the Pharmacare Plans. I immediately agreed to the meeting, but my doctor was not able to be there.

The meeting was concentrated on the combo of Sovaldi and simeprevir because Harvoni was not yet much talked about, although I had read up on it at one point. I was told that simeprevir (Olysio/Galexos) was already in the Pharmacare formulary and that Sovaldi needed to be approved through the Common Drug Review (CDR). Well, when I checked the formulary, simeprevir was not included. I was very disappointed and was pretty sure that Sovaldi would also not be approved for a long time.

The executive director did comment later that my hepatologist was looking at a drug through Gilead, which was to be superior to the combo, but that the Sovaldi and simeprevir would not be approved to be given together. What a let down! Well, the petitions and the letter writing did not stop. I emailed the people involved with the CLF in Winnipeg and somehow, through that, I got an email asking for information for one of the people going to the support group. I gladly gave what info I had. This person emailed me and we have been in contact ever since. When I told him about my petition and letter writing, he joined in. Harvoni was now the drug we were asking for because it did not sound as if the other combo would ever be approved. He wrote a letter which we started handing out to people we knew. He spoke at different venues about his experience with his treatment and the high cost of the drugs. He also requested of the government (Health Minister, Premier, and Executive director of Pharmacare) to make educating the public and doctors

about Hep C a priority. The big issue here was to get doctors checking liver enzymes of all their patients once a year and follow up on those results if they were not normal.

He has spoken to a number of people as well as the regional health authorities about some of these concerns and we are hoping that they will take this seriously. The sooner Hep C can be diagnosed, the sooner treatment can begin and the drain on the health cost associated with liver disease in general can be minimized.

Among him, my husband and me, we figure perhaps 500 names were sent into the government on this issue. I also spoke with our MLA who was the Health Critic a number of years ago, and he said he would also talk to those who had clout and power to make things work.

Then in December, I received an email saying that Harvoni was under review with the CDR and should be through that by the 18th of March. So I waited, continued to hand out letters, and prayed for that drug to be approved. I was also told that once the drug was reviewed and approved, it would go to the pan-Canadian Pharmaceutical Alliance for pricing negotiations, and if that was done by May, then it would end up in the formulary possibly by the end of July. Well, now there was a glimmer of hope, but we did not let up on the sending in letters. I read an article that in the US there was a reduction of the cost of Harvoni by 47%, so I sent the Executive Director this information, that could be used for negotiating a price.

Last week when I sent an email to her asking how the review was going, it took a few days, but I got the great news that as of April 20th 2015, Manitoba Health will provide benefit coverage for Harvoni and Sovaldi, and once a person's deductible is satisfied, the eligible cost of the drugs will be paid.

Our prayers were answered, and I thank everyone who helped by signing the petitions and sending in the letters. It was a lot of work, but well worth it.