# The Trial Trials

April 29, 2015 By Greg Jefferys

After a bit of Googling I tracked down some places that were running Hep C trials in Melbourne and sent off some emails to their listed contact people. I waited a week but got no replies so I sent off a few more emails and still got no replies. So I sent off another batch of emails asking (pleading actually) the recipient to please do me the courtesy of a short reply, if only to tell me that they did not want anyone for trials. This got one response from a nurse in one of the hospital research centres. She apologised to not getting back to me earlier and sent me a form to fill in and promised she would pass my details on to the head of their Hep C research team.

That seemed promising, even more so when I got an email the next day from Dr Z who asked me a whole lot of questions, which I answered and that was followed by some more questions from the good Doc, which I answered. I was now getting pretty hopeful. He asked me to scan my test results and send them to him, which I did, really feeling like I was getting somewhere. Then that was the end of communications. Despite several emails to him asking what was happening I never heard from him again??? How can people do that?

After the unanswered emails I gave up on Melbourne and went back to my mate K, who informed me that the team in Sydney was about to start another trial, specifically for Hep C genotype 2 and that I should apply pronto. He gave me all the contact details and I made an appointment with Doctor C. His secretary explained the process. I would see him as a private patient for a private consultation, he would then refer me on to the public section of St Vincent's Hospital, where I might, or might not, get on the trial. So I booked a flight up to Sydney, fortunately I have family in Sydney so the cost was only for the air fare and the consultation, more than $500 total but worth it if I could get in on the trials.

My appointment was in the afternoon and I got there early, not having any other thing to do in Sydney. The good doctor was running a bit late from at meeting at one of the Universities and arrived at his rooms in bit of a rush. There was one person before me and then I went in. His secretary had scanned the documents I had brought with me, which he skimmed through then asked me a few questions about symptoms and the CT and Ultra sound scans etc. He explained that one of the enzymes which I had at very high levels was a cancer indicator and expressed some surprise that the scans had showed no cirrhosis or tumors.

I could see he was a very sharp, no nonsense dude so we got down to brass tacks, I was there because I wanted to get on the Sofosbuvir trials. Dr C was quite frank. He said that there were a lot of people who wanted to get on those trials and that it was unlikely that I would be able to get on them because I was not sick enough. He then told me that it was likely that Sofosbuvir would be approved for the PBS with a few months and that it was probable that it would become available later in 2015.

That was the good news. Then for the bad news.

He looked me straight in the eye and told me that it was very unlikely I would be able to get Sofosbuvir even when it became available through the PBS.

He explained that, because of the high cost of the Sofosburvir, $90,000 per treatment, the government would not be able to make Sofosbuvir available to everyone with Hep C. At $90,000 a treatment, with more than 250,000 people with Hep C in Australia that would cost over $2,500,000,000 and bankrupt the health system.

The doctor told me that the government would only make the Sofosbuvir available to the sickest of people. My response was to quote the metric version of the old saying “A gram of prevention is better than a kilo of cure.”

How it this different to someone being diagnosed with cancer then being told they could not get treatment until the cancer reached an advanced stage!

The doctor shrugged and agreed with me but said that it was going to be that way and there was nothing he or I could do about it.That was how the government was going to handle the cost side of things. Bureaucrats and politicians!!! Always the quick fix rather than the long term solution.

So I flew back home the next day feeling rather disappointed: I was not going to get into the trial and I was not going to get the Sofosbuvir either. Well I would not get the Sofosbuvir until I was really, really sick.

It was very frustrating.

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