Home Sweet Home and Other Dreams

July 9, 2016 By Greg Jefferys

Well I have been back home in Tasmania for two weeks now. The first week was pretty tricky. Jet lag, culture shock, weather shock, shock shock and shock.

When we left England it was on the longest day of the year, the 24th June, and when we landed back in Tasmania it was a couple of days after the shortest day of the year.
We went from High Summer to the dead of winter in 48 hours… of course our bodies and our minds were spinning out!

Back in our little village of Woodbridge we did not venture out for nearly a week except to see our closest friends. Mostly we slept or stared out the windows over the water to Bruny Island. But tonight we went down to the local pub for dinner and caught up with the broader community, had a few drinks and a lot of laughs and some really great food.

In the past two weeks I have had a lot of time for thought, for review, for thinking about what has been done and what needs to be done.

The constant flow of emails from people with Hepatitis C has not slowed and all through my holiday I was able to keep answering people’s questions about options for Hepatitis C treatment.
Now, in the quiet of Winter, the long cold nights sitting in front of the fire are a great place for contemplation, for considering what the next step might be and reflecting on what has been done in the last few months, what I have learned.

The trips to the UK and to Spain were both interesting and productive. I learned a lot more about how things are in Europe and the UK and met with some great people doing great work.
The big lie in places like the UK and France is that they are making the new Hep C treatments available to everyone.
This is totally untrue.
The access to treatment is traiged. That is to say people have to be very ill before the national health services in the UK or France will even consider them for treatment with the new Hep C drugs.
For example in France I met a young woman who has genotype 2 (the same as I had). She was only 32 and had a good career. It would appear that she picked up Hep C from a small tattoo on her ankle she got done a few years earlier.
Whilst she was feeling the typical symptoms of Hep C like fatigue and “brain fog” her liver had no scars and so because she did not ahve any sign of cirrhosis she was told that she could not access treatment until there was some obvious damage to her liver.
Fortunately at the time I had a supply of Sofosbuvir and Daclatavir with me and was able to get that to her.
She had blood tests at 2 weeks into treatment and the Hep C viral load had dropped from 2 million to

undetected.

In the UK I met a woman who had recently learned that she had Hepatitis C genotype 3.
She did ahve cirrhosis and a swollen liver but the NHS would only give her Sofosbuvir + Interferon rather than the superior treatment of Sofosbuvir and Daclatasvir.
Not only is Sof+ Daclatasvir a better treatment it also does not have all the terrible side effects of Interferon.
A doctor once said to me that using Interferon to treat Hep C is like amputating an arm to treat grangrene ... it works but there are much better ways.
Interferon is a treatment from the Dark Ages of Hep C treatment.

The reason that the NHS offered this lady Sof+ Interferon? Interferon is **lots** cheaper!

Now I had the generic Sofosbuvir and Daclatasvir and I offered it to this woman but when she told her NHS doctor (consultants they call them in the UK) that she was considering treatment with generic Sofosbuvir and Daclatasvir the doctor point blank told her that if she used generic treatment then she would rerfuse to monitor the treatment!!!!

So she chose to do the Interferon treatment and every time I have spoken to her she was feeling worse and worse and worse.
So I hope that the treatment is worth the suffering and it cures her and that it does not do more damage to her body than the virus would have done.

I visited Hep C advokate David Crowley and his wife in Cardiff and we talked about ways of getting generic Hep C medicines to people in the UK and Europe and also about the general situation for people with Hepatitis C in the UK.
How frustrating it was for people waiting for treatment from the NHS and the frustrations of “not being sick enough” to get onto treatment with the NHS and the refusal of British doctors to monitor patients who chose to bypass the NHS and get their own generic Hep C treatment from India.

I also met up with Dr Andrew Hill and some of his post graduate students from the Imperial Collage in London. I had met Dr Hill at the Barcelona EASL conference but things were a bit hectic there and I had not had much of a chance to get to know him.
Now that we were both in London and had plenty of time we met at his home in London and we were able to discuss access to generic medicines in greater depth and also make some plans for assisting his students who are studying the issues surrounding the treatment of Hepatitis C in the UK through the use of generics.

One of the other things that was great about being in the UK was that I was able to assist people in Europe get access to generic Hep C medicines in a more direct way.

When I was in Barcelona I organised for quite a few generic treatments to reach me there and people from Italy and other European countries were able to fly to Barcelona and pick up generic Harvoni and Sofosbuvir and Daclatasvir personally from me.
It was a real treat to be able to meet people face to face instead of just organising everything through email.

When I was in the UK I was also able to organise shipments of generics to the UK and then send them on to various countries in Europe which prohibit importation of generic meds from India. The trick was that sending the meds from the UK by mail meant that the mail was treated as internal, or local, mail because of the EU treaties. This meant that I was able to get generic Hepatitis medicines sent to the UK, where there are almost no restrictions, and then forward them on to people in various EU countries like France, Latvia, Serbia, Italy and so on countries that would have blocked shipments from India. We got meds to a lot of people that way!

So as well as trekking through the Peaks District, visiting ancient castles and seeing the Loch Ness monster I was also able to get a bit of work done on my visit to the UK.