Truth, Deception and Misinformation

August 8, 2016 By Greg Jefferys

The last couple of weeks have been rather busy for me. Because of the work load from my Hep C activities I decided to suspend my PhD studies entirely for 12 months as the combined workload was just too much. So I've been running around filling in forms and seeing people to organise the 12 months off.

Now that the PhD is on hold I am able to direct my energy back to Hep C issues, for whilst I love the topic of my PhD " Strange News; where truth and myths collide. " and enjoy the research and study I also know that the needs of people with Hep C and helping them access affordable treatment is more important than my own personal interests.

One of the big things that made up my mind about taking this path of re-focusing on my Hep C activities was news from a friend with Hep C telling me that she had just been diagnosed with a major tumor in her liver and has been given only a couple of months to live.
Of course this upset me a lot and it has taken me a while to get my head around how it must feel to get this news.
Whilst such news is hard to grasp I can relate to it by a degree because only 16 months ago my own doctor told me he suspected that I had liver cancer. So I do understand it in a small way.

Now I would like to talk about this friend, whose name is Lynne.

Lynne was diagnosed with Hep C genotype 3 earlier this year. It was about the time I was in the UK and had returned from the EASL conference in Barcelona.

Of course Lynne was shattered by the news she had Hep C because she was otherwise in very good health. So being a very pro-active person she looked at all the options and decided to go the route of generic Sofosbuvir and Daclatasvir. By far the best treatment option for Hep C Genotype 3.
When she discussed this decision to use generic Sofosbuvir and Daclatasvir with her Doctor in the National Health Service she was told in no uncertain terms that if she did the generics then they would not monitor her treatment.

(Such arrogance appalls me!)

So there was a lot of discussion about this decision (a decision which I personally think is both unethical and probably illegal) and Lynne decided to go the generic route anyway.
When the doctors heard this they then offered her a monitored treatment with Interferon and Sofosbuvir.

So, whilst it was not Lynne's preferred option, and certainly not the best option, she decided to go that way because she wanted her treatment to be monitored.

(It was however the CHEAPEST option for the NHS)

The first week of treatment was okay for Lynne but by the second week the side effects from the Interferon were getting bad, by the fourth week the side effects were a nightmare.
But Lynne pushed on because she was determined to get rid of the Hep C virus and get her life back.
She is made of stern stuff is Lynne!

But here is the thing... Interferon is a highly toxic treatment. It is a treatment from the Dark Ages of medicine. It is toxic to the liver. Yes Interferon causes significant damage to the liver and other organs. Dr James Freeman once said to me that using Interferon to treat Hepatitis C in the 21st century is like amputating an arm to treat gangrene. Sure it will cure the problem but the damage associated with the cure could be worse than the disease and there are much better options.

So Lynne completed her treatment, was pronounced virus free and then told that she had a massive tumor (which, as far as anyone was aware, was not there before she started treatment).

And she was told she had a just a couple of months to live.
So she has endured 3 months of horrendous Interferon therapy and then told she is going to die.

Now I am not saying that the Interferon caused the tumor however these concluding comments by Emeratis Professor Ronald Koretz M.D. in his excellent article about Interferon treatment entitled: ***Hepatitis C treatment (with Interferon): no benefits and possible harm*** certainly highlight the problems.

Concluding comment

Given the natural history of chronic hepatitis C, as well as what we know therapy accomplishes, it is very difficult to justify a policy for routinely treating such patients to prevent decompensated liver disease. The surrogate outcomes were not valid in the one occasion when validation information was available. The treatment has not been proven to be efficacious with regard to preventing clinically important disease, it is expensive, and it causes substantial morbidity (including death). It is an inappropriate clinical decision to prescribe a toxic therapy (especially an expensive one) that has never been shown to provide clinical benefit in properly-done randomized trials.

So Lynne's doctor prescribed a treatment that is known to be highly toxic when another, much less toxic, treatment was readily available...
Why?
The reason is simple. This doctor had either been misinformed about the effectiveness of generics by the representatives of Big Pharma or was simply in the pocket of Big Pharma.
It is a very sad and disturbing outcome and one that I sadly hear of too often.
Would the results have been different if Lynne had used Sofosbuvir + Daclatasvir? Of course we do not know however we do know that Lynne's doctor forced to take a sub-optimal treatment when a much better and safer treatment was available.

But here is another story; the opposite story.

In this next story, which I received by email today, the doctors refused to monitor the patient, refused to even see the patient if he used generic Harvoni to treat his Hep C.

But being in a country where health care is not free the doctor also could not offer the patient any alternative treatment at all. Not even Interferon.
So the patient contacted me and I assisted him to get generic Harvoni.
Here is the email:

Dear Greg,
Glad to hear from you. Florin's treatment is not completed yet; should be done by 1st of September - and then it will take another week or so until the labs results are back. As soon as I get the results will complete the attachment and email it back to you.

There is a interesting story behind this, you might want to hear it.

Greg, I'm not aware of your belief system (or lack of it) and hope you are not going to be offended by my many references to my Christian faith.

My cousin is about 10 years older than I and we grew up not particular close. In the early 80s I left Romania and rarely kept in touch. About three years ago he called me to extend his sympathy for my mom passing. After a few minutes of small polite talk I thanked him for the call and wish him good health and fortune. Them he proceeded to say that he had HepC for more than 10 years and for the majority of the time he feels quite ill - his only wish was that it was a cure for this ailment. Told him how sorry I was and that I will pray for him.

A year or so went by when I heard that FDA approved a cure for HepC. I called my cousin and give him the good news; he was aware of it and that it costs 100 times more than his annual salary. I told that I do not have that kind of money but I will keep praying for him and not to give up hope. Hung up the phone and prayed that God will find a way for him to get the medication he needed.

Months went by and I almost forgot about this issue when I came across a Bloomberg News article about India making generic Harvoni and how people are getting the medication at a fraction of its US cost. I ran a Google search and found an Australian ABC news segment about a guy (you) who was cured using the generic medication from India and who now is helping others. I quickly Googled your name, found your blog and emailed you. I pray God again that this is not a scam and you will help me help my cousin. The next morning I saw an email from you saying that you could help and explained the process. I called my cousin in Romania a told him that God just answer my prayers and how I was planning help him. I also told him not to get his hope too high as nothing is certain in life.

Few weeks went by and I never received the prescription or the copy of his ID you needed so I called to see what the delay was all about. He told me that his doctor, who offered him no hope of a treatment or cure advised him against such treatment as most likely this is a scam - when he told the doctor that these meds are being provided to him at no cost, the doctor suggested that these meds are probably fake at best, and poisonous at worst. I was really upset and did all I could to convince him that this is all legit and have nothing to fear. He finally agree to send me a prescription and ID in order to forward them to you.

Drama did not ended here - after he received the meds from India his doctor refused to monitor his health during the treatment and he needed to ask several doctors until he found one in a private practice who agreed to help for a fee.

He is taking the meds since June 1st and the only side effects were some mild headaches, insomnia and increased irritability.

He is being seen by the new doctor once a month and all his blood and liver counts are now normal. For some strange reason, the MD did not wanted him to do mid treatment virus load count Anyway, in a few weeks I will know if the treatment worked and will pass the info to you.

It is wonderful that you are helping people in need and I do not have words to express my gratitude for your selfless act!

Sorry for being so long-winded, but wanted to share this with you.

Sincerely,

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I would like to end this post with the words that Lynne said to me when I asked permission to write about her story

Yes greg you can write about my story and tell people don't wait for the NHS or for some health insurance to treat you, it may be too late. Beg or borrow the money to buy the generics .... you can use my name if u want x

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