Big Pharma and Hep C Advocacy Groups: A Romanian Perspective

August 26, 2016 By Greg Jefferys

Over the last week I received quite a bit of about feedback about my post on the World Hepatitis Alliance, the volume really surprised me. Only one person argued against what I wrote but he was from a Hep C advocacy group in Australia that receives considerable Big Pharma funding. The rest of the responses were overwhelmingly supportive of what I wrote.

I did get one email from the UK Hep Trust explaining that they now support people following the generic treatment course for Hep C.

Below is an email I received from a person in Romania who is now cured of Hep C by generic treatment. It is a good example of how people are looking at the role of these so-called Hep C advocacy groups.

Hello Greg,

As mentioned in my previous e-mail, I am sending you this e-mail to tell you about the hypocrisy that I see regarding the HCV situation, the Big Pharma and the so called Hep C patient association in Romania:

A Couple of Points:

In Romania individual seeking to receive HCV treatment has almost no power against the healthcare system which is denying the treatment (as postponing the treatment indefinitely is in fact a denial of treatment).
Thus for people looking for support from organizations like the so-call patient's associations, these groups bring some hope to the patients that they will be able to make "a miracle" that will enable the access to treatment.

The patient association that is very active in Romania is in fact sponsored by Big Pharma companies (Roche, Abbvie BMS, Jannsen ... http://hepato.ro/sustinatori/sponsori/) and they claim they fight on many levels for Hep C patients in Romania, such as awareness about hepatitis, stigma, prevention and treatment and so on.

Of course some of the work they do is great as it is important to be active on all levels when trying to fight the curse of Hepatitis C, but by far, the treatment is the most critical one.
And of course many patients are disappointed and think it makes no sense to talk and talk about HCV and getting diagnosed as long as the healthcare system may not provide the treatment. What point the talk if there is no treatment? Or if you have to wait until you are half dead before you can get treatment?

When talking about getting treatment for the HCV patients, there are two key parameters, two critical factors: the budget of the healthcare system and the cost of treatment. For treating a high number of

patients, now that the DAAs are known to be very effective, there are 3 possible ways;
A. Increase the budget;
B. Ensure a low cost per treatment (like generic drugs or very special low prices of branded drugs);
C. A combination of A+B.

I have been monitoring several messages of this Romanian patient association and I noticed that their actions are focused on A. That is putting pressure on Romania's government to allocate more money and then publicly complaining how hard it is to negotiate with the government. Then they raise alarm signals that people are forced to proceed with "desperate actions" by buying drugs from the Internet which this so-call Hep C advocacy group claim are often "fake".
Thus this association basically ensures that point B, treatment by low cost generics, will be avoided by many patients and probably also by the government.
As I mentioned the money of this "advocacy group" comes from Big Pharma companies, so it is more than obvious why it acts like a devil disguised in an angel claiming to be concerned about the "patients safety" and "legal compliance" making a big noise about the risks of generic drugs ...

This may simply be called "hypocrisy".

Shall I believe that this patient association will ever make advocacy for HCV generic drugs? Only if I would be a naive person..... In addition to this I could argue that no government will in today's worked will be able to increase enormously their healthcare budgets which are already stretched to the limit. Perhaps all this sounds crazy, but I am convinced that within the governments there are people knowing and being aware about the cheaper generic HCV drugs. Why don't they do something?
In Latvia people power changed the government's position on generics and now in Latvia everyone can import generics as long as they get the correct documentation and can prove that the generics are licensed. It is a simple thing and saves the Latvian Health System millions and millions of euros.

Now going back to HCV generic drugs: Egypt treated already 850000 people with generics (http://www.dailynewsegypt.com/2016/07/28/hepatitis-c-patients-waiting-list-now-treated-ministry-health/) and the success rate using locally produced Sovaldi based drugs was 97% (http://news.xinhuanet.com/english/2016-07/29/c_135547944.htm). Shall we still have doubts that HCV generics really work???

So, what reasons, apart from greed and hypocrisy, might exist that the pharma companies and patient association avoid talking about the solution provided by the generic drugs and continue to make pressure on the government to increase the funds to buy the expensive branded medicines? There are no reasons for not using generics on a large scale...

So yes, thinking from this perspective, I do believe your blog about WHA is true.

with best regards
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I would like to add to the above comments that Romania has very favorable laws for the importation of generic Hepatitis medicines for personal use. When I first started helping people in Romania to import Hep C meds (more than a year ago now) the hardest thing was to find a Romania doctor who would write a prescription, which is a requirement of Romania's import laws.
However over the last year more and more Romanian doctors have heard how effective the generic Hep

C treatments are and it is getting easier for people in Romania with Hep C to get that prescription. However if the Romanian government actively assisted this process, as has happened in Latvia, many more Romanians with Hep C would be able to access treatment and this would take a lot of pressure off Romania’s health services.

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