Transcript: Interview with a Hep C Activist & Survivor

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Peter Staley interviews Jules Levin, an activist and survivor of hepatitis C and HIV coinfection, about the latest in HCV treatment and prevention. To see the video, click here.

Peter Staley: Welcome, this is our first interview from ICAAC in Chicago. We're here with Jules Levin, who's the Executive Director of the National AIDS Treatment Advocacy Project, NATAP, in New York. He's a tireless and renowned HIV and hepatitis treatment educator and activist. Welcome, Jules.

Jules Levin: Thank you. It's good to be here with you.

PS: We'll be talking to you about some of the latest news regarding hepatitis C [HCV] and HIV coinfection. First, let's review some of the basics. The way I understand it, nearly four million people in the US are infected with HCV, and between eight and ten thousand people die of hep C in this country every year. We also know that it is a common coinfection among people with HIV. It can cause liver disease faster in people who are infected with HIV and can be more difficult to treat. This is why hep C is considered an AIDS-related, opportunistic infection. Jules, a lot of AIDSmeds members are aware that the risk of hep C is greatest among IV drug users, when they share paraphernalia, but there is also a significant amount of research in recent years regarding sexual transmission of hep C. Can you tell us a little bit about this and what it means in terms of prevention?

JL: Well, that's a good point, and it's very current, the point that you're raising, because in the last year, and increasingly in the last few months, there have been a number of presentations at conferences for data, particularly coming out of Western Europe, showing that hepatitis C is being transmitted sexually. And some of the risk factors are, of course, unprotected sex, drinking, drug use, and anal sex, and anything, particularly with anal sex, the mucosa can be weakened by lots of rough sex. So those are a lot of the risk factors. And what was interesting was in Europe, at a recent conference, just within the last few months—I think it was in Sydney—there was a presentation, an oral presentatin from a study done identifying a network in major cities in Western Europe where thy found that- they looked at individuals' viruses that contracted hep c and they found a connection between people in the various cities, suggesting that they were giving it to each other, transmitting it to each other in cities. And they suggested that there was a network amongst men who have sex with men, and these were men, I believe, who had HIV also,

so that there was a network—people traveling amongst major cities in Western Europe, so therefore, that's the most recent data, but for the last year or maybe two years, there's been increasing amounts of data coming out of Western Europe finding that there is transmission sexually and with drug use being a factor facilitating this. And coming out of cities in Western Europe, particularly amongst people with HIV, men who have sex with men. So it's interesting that this data's been coming out of Europe and not out of the United States. This year at CROI there was presentation coming out of a doc at Mt. Sinai hospital in New York, where he's in the process of trying to establish a little network in New York, trying to get docs who treat people who have HIV to refer patients who are coming up with acute hep C to his practice so that he can try and accumulate data. And he presented that there was an increasing identification of people with HIV—men who have sex with men who had HIV who were getting acute hep C. And what he identified was—and it wasn't a well-done study so it's just a notion—what he found was that the patients who were being referred to him when he did a diagnostic test of them to identify the stage of their disease, he was finding that they were more advanced than they should have been, suggesting that it was the HIV that, right up front, was accelerating their disease, even before they had had it for a long while. So there are, as you mentioned, there's a lot going on in this field and I think that if we looked more in the US we probably would find it more.

PS: But compared to other sexually transmitted diseases, it's still considered a lot harder to transmit sexually than even HIV, correct?

JL: Yes, I believe that's true. And, you know, it hasn't been studied as well, to identify how easily it is transmitted. But traditionally and historically, amongst hepatitis C mono-infected individuals, the risk for sexual transmission has always been—traditionally it's been thought of as being very low. However, there are some exceptions to that. One is that if one of two individuals having sex has HIV, if one of two individuals having sex has an STD, those kinds of things facilitate transmission of hep C. So if somebody has HIV, if maybe they have a weakened immune system, there is increased risk. What that rate of risk is, how transmissible it is, it hasn't been studied well enough, but the risk is increased when those conditions are present.

PS: I understand there are obvious risks to the liver of having hep C, but I understand that hep C has been linked to a higher rate of diabetes. I would think that this is a serious concern, especially among HIV-positive people who already seem to face a higher risk of diabetes.

JL: And just to add to that other point: the risk for sexual transmission can be amongst men who have sex with men as well as heterosexual sex. So your question is regarding—

PS: Diabetes.

JL: And what about it?

PS: Does hep C raise the risk of diabetes?

JL: Well it seems that hepatitis C virus affects the liver. And it seems like everything that affects the liver sort of is interrelated. And it does appear as though people with hepatitis C virus—who

are hep C-positive—have higher rates of diabetes as well as insulin resistance, and that it appears that sometimes people who go on Interferon/Ribavirin therapy, diabetes may flare up and become more of an issue. Sometimes people as they go through therapy successfully, the diabetes can become less of an issue. But it does appear to be an issue.

PS: The treatment for hep C has been the same for several years now. As you mentioned, Interferon combined with Ribavirin, but for people infected with HIV and hep C, what's the current consensus regarding the best time to begin treatment.

JL: And again, let me just add to the diabetes issue. If you have diabetes or perhaps insulin resistance, your response to therapy is lower. So it's an important issue, and what's recommended or suggested is if you're considering going on hep C therapy, you should probably deal with the diabetes or insulin resistance first, and that may help you respond to therapy better.

PS: Interesting. When should we start with the traditional therapies we've got now?

JL: Well, that's a good question, and I feel rather strongly about this, I think it's a controversial issue. It's controversial for many reasons—one, because the therapies are hard to tolerate, and as you may know and as some people watching may know, I'm cured of hep C now. It's about five years now that I've been cured.

PS: Congratulations.

JL: Thank you. It's changed my life completely. And we can talk about this. One of the reasons I think starting therapy earlier is better, because very few people talk about the benefits and the rewards of successful therapy. And I've never felt better, I've never had more energy, I've never had more cognitive skills. And lots of other things about me that are much better than ever before. So the reason it's controversial when to begin is because—like I said I did it for two years myself, so I understand, it's hard to tolerate. And most people, most patients don't want to go on therapy because—

PS: You were on treatment for two years for it.

JL: A total of two years. The last course was 18 months with PEG Interferon and Ribavirin. Understandably, patients don't want to take the therapy, they're scared of it. And I've heard stories about some individuals who went on therapy and they were doing very well, undetectable after a couple months, and it was so hard to tolerate so they discontinued it themselves. So I understand that. But let me give you all a warning, and I think it's very important. I recommend—if you have hepatitis C and HIV—HIV accelerates hepatitis C. And it can accelerate it very quickly in some individuals. There have been a couple studies coming out of Hopkins and someplace else showing that – they looked at coinfected patients and they looked at the course of progression. And on average, they found in this study coming out of Hopkins, that coinfected people on average progressed in about three years two stages of disease. So for example, you would go from stage one to stage three, which is pre-cirrhosis—stage one is early disease—in three years. That's awfully quick progression. What that means—and I knew that even before they did this study—was

that if you have coinfection, you should do a liver biopsy, find out what stage of disease you're at, and if you're at zero which is no fibrosis at all, you may have a little window to wait. If you're at stage one, which is minimal disease, you should seriously consider going on therapy right away.

PS: And people should realize HCV like HIV has its own viral load test so you can measure viral load. How is that playing into this treatment decision?

JL: Well, that's a good question, because that's probably a source of some misunderstanding. Viral load with hepatitis C is not like HIV. With HIV, the higher the viral load, that means the more disease you have and the more likely you are to progress and get sick. And in hepatitis C, that's not at all the case. High viral load doesn't mean you have worse disease. The only way that hepatitis C viral load is relevant is people with high viral load don't respond as well to therapy. Which is something also to consider. If you find out you have hepatitis C, you should go do a liver biopsy, and a viral load. And if you are stage one, and possibly even stage zero, you should consider therapy. Certainly if you're stage two, more important to start therapy. But you're going to do a viral load test. And if your viral load is low, that's something to consider. That means you have a better chance of responding well to therapy. And that should give you more confidence that you may respond better to therapy.

PS: And let's end with what's on the horizon here: experimental therapies. It's been kind of a disappointing story over the last few years. There's a lot of development going on, but a lot of the drugs have burned out—they've been too toxic, or they haven't worked. What's on the horizon right now?

JL: Well, that's also a good question, and that's the most important thing. First of all, if you have hepatitis C and HIV, and you're thinking of, well, should I start therapy now, or should I wait for the new drugs, I think it depends on your stage of disease, because as I said, your disease could progress quickly over the course of two or three years. The first orally administered hepatitis C drug is the Vertex protease inhibitor, and it looks very good. And I estimate that it will become available in about two and a half years.

PS: That's VX-950, or Telaprevir?

JL: Telaprevir, that's correct, and I think it will progress into final stages of study and be approved, and I think that it will increase response rates to 70 to 90 percent. And amongst coinfected it may be a little lower, but right now it's 30 to 40 percent, or 40 percent at best. And so I think it will come close to doubling response rates, including among African-Americans and genotype one. So that should be coming available in about two and a half years I think.

PS: It's just entering Phase II, right?

JL: It's fully into Phase II, and they're about to start Phase III. And a very important study is starting now, and that is testing it in treatment experienced patients, patients that have failed PEG-interferon, which I think will be important data. But I think an important consideration—what people need to fully realize—is that it will be used in combination with PEG-interferon and

Ribavarin probably too.

PS: So you can get resistant to it, correct?

JL: To the Telaprevir? Resistance to hep C drugs is just as bad if not a little worse than resistance to HIV drugs. But the important point to realize is that if you thought you could get rid of the PEG and the Ribavarin, you can't. All oral agents being developed will use those drugs along with it in combination, at least for the foreseeable future, for a long time.

PS: So it's still going to be a very difficult regimen but really the only shot if your disease is progressing.

JL: Well the important thing about this, though, is that the studies are looking at the possibility of a duration of therapy of 12 weeks to 24 weeks. So as we know now, therapy particularly for coinfected people is 48 weeks at least. So there's a possibility that some people may be cured with 12 weeks, but 24 weeks looks like a good target for a course of therapy. So the benefit for the added oral agent of Telaprevir will be higher rates of cure—instead of 35 percent, it might be 70 percent. And second of all, it might be 24 weeks, perhaps 12, more likely 24 weeks instead of 48 weeks. That should encourage people to use the therapy and get treated.

PS: Thanks, Jules. That was a very good overview of HCV and HIV coinfection, and we appreciate you doing a videocast interview for AIDSmeds.com, with Chicago in the background and enjoy the conference.

JL: Thanks for asking me. And by the way, there are a dozen other oral agents further back in development.

PS: Well, it is an active pipeline. It's been disappointing up until now, but at least a lot of companies are still doing a great deal of research in this, so patients still have stuff to look forward to.

JL: Absolutely, and thanks again for asking me.

PS: Thank you.
