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KIDNEY CENTER

Podcast Transcript:

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“What is the evidence of a relapse?”

So let me paraphrase that question, if I may: Your husband has a disease process that doesn't seem to have gone away since, for 20 years. More than 20 years. So, let me divide that question into 2 parts. At any given time, what was the real evidence that the disease was back? How do you know that your disease is back, or whether the signs and symptoms that the physician is looking at are a consequence of something else?

Let's use the example of blood in the urine. Is there blood in the urine? Let's start that way. Where's the blood coming from? Is it coming from the kidneys, and that means it's a sign of a relapse, or is it coming from the bladder, which could be a consequence of the Cytoxan. Or is the blood in the urine a consequence of the kidney stones which you just suggested that your husband had? Kidney stones have nothing to do with Vasculitis. Nothing, nothing, nothing. We live in the “stone belt”, right? I mean, holy smokes. Tons of people have kidney stones.

How sure is your physician that that relapse was a relapse, or a consequence of something else? Here's where the areas most concerning: in the upper respiratory tract, in the nose, is it disease-Vasculitis, or is it infection? Or is it a little bit of both? Boy, is the therapy different. If it's an infection, you want to slow down the immunosuppression. If it is the disease, you want to use more of an immunosuppressive approach.

So, one thing that you have every right as a patient to demand-Doctor, you're saying that I'm having a flare—and we see this all the time—What is the evidence that I'm having a flare? The physician may look at you and say “Well, the ANCA titer has gone up.” No, no, no, no. Look, we discovered Myeloperoxidase ANCA—I don't use it to guide therapy. We spend our lives thinking about proteinase 3 and Myeloperoxidase ANCA. I don't use it as a guide to therapy- I use it as a help to tell me what's going on, but not to guide therapy. In the nose, are you sure this is disease, or is this infection? And that's a question that you have every right to ask your physician.

Here's the corollary to that question: Doc, if you had this disease, how long would you be on an immunosuppressive drug? And I can answer that. One day less that I absolutely had to be on it. You have every right to ask your physician: Are you using this immunosuppressive drug—Prednisone or Imuran- because you're sure I need it, or because you think that I may relapse and you're just worried that I might relapse, and so that's why I'm on it? And then, are you worried about the complications of that drug? The Prednisone-do I really need to be on

this Prednisone? My bones are melting away. There's a risk of being on that drug. What is the absolute evidence that I need to remain on it? And, okay doc, what is the least number of milligrams of Prednisone that I must remain on? That's a very fair conversation with your physician. What's the evidence that I need the immunosuppressive drug? What's the complication? And if there's good data that I need to be on a persistent drug, then what's the lowest possible, least number of milligrams that I can be on to keep me in remission, and doc, if it were you, and you and I switched bodies, would you still be on the drug? You're saying no, and I think that is, you have every reason, right to ask that question, and if you don't get an answer from your physician, then you have the obligation to your spouse, and to yourself, to say okay, is there somebody else who will deal with me differently?