Podcast Transcript:
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"How does the patient and the physician determine whether you're in remission?"

How does the patient and the physician determine whether you're in remission? On a regular basis, we gather and go through the records of patients who are in our registry. And the question that we ask, with all of the patient's information sitting in front of us, is: is the patient in remission, are they in remission on therapy, have they had a flare, and when's the flare over? So, we actually have the information at the time of the event and we have longitudinal information in both directions. And we've done this, now, on 550 some-odd patients in this very rigorous way. Incidentally, it's wonderful to participate in patient registries—not patient lists—patient lists are "I have your name and you have this disease." A patient registry, which many of you are in, allows us to go over your record repetitively over time.

And so, in fact, I will tell you the best way of the patient and physician knowing whether you're in remission. It's to start at the beginning of the disease, follow the course of the disease, and you know only retrospectively if the person is truly in remission. That is, there are no signs or symptoms of the disease for a prolonged period of time—months. That's when you're in complete remission. There's no evidence from the patient, from symptoms or clinical signs, there's no evidence of Vasculitis in the upper respiratory tract, there's no evidence of new pulmonary disease. There are no red cells in the urine. The kidney function is stable. There's no new rash. There's no new arthritis. The neuropathy, if there is one, is stable. And it has been for a while. The ANCA test may or may not be negative.

Okay, clinically, and from available laboratory and physical exam or x-ray findings, you have no evidence of disease activity, and that has now persisted for more than a day. In other words, that there is some period of time in which the disease activity has dissipated. That's easier to do, if you are in fact able, you as a physician and a patient, to look at that longitudinally. How do you decide that sitting in an exam room? Patients know better than doctors. Look, doc, my ear nose and throat-there's nothing going on up there. Is there blood in my urine? No, okay, cool. My lungs feel good, my energy level is back. It's not back all the way, I'm still tired. You're probably right, you're probably in remission. And the next time you see the person, you ask that same question: Am I still in remission? Okay, yes I am. And then you have an enduring remission. And some people are in remission for 20-30 years.

I now have a long term remission. The next question is, Am I in remission on therapy? Or, can I come off? And, in fact, in our hands, we're constantly trying to take people off. Some people, we can, some people, we can't. But that question of when you're in remission, and then how long you remain in remission, is this attention to where the disease process was, and is there evidence that it is still in whatever organ system that it was to start with?

I think you know when you're in remission. Better than your physician. Other than urine, because there can be blood in your urine and you just don't know, you have to look. But that's the critical question. And then if you're in remission for a long time, or any period of time, do I have to be on a drug to remain in remission, or can I come off? That requires a neurotic patient and a neurotic physician. Do you dipstick your urine, if you've had blood in your urine? If you have a flare, or you think you're flaring, do you feel comfortable

calling your doc and saying, “Hey you need to see me, because I think I’m flaring now.” If you don’t have that relationship, then, in fact, there’s a much greater chance that your physician is going to want you to stay on some immunosuppressive drug, because in fact that’s their way of preventing the disease from coming back. But most of you know, sometimes you relapse on immunosuppressive therapy. So a good doctor/physician relationship is critical. Critical short-term and critical long-term.