



UNC
KIDNEY CENTER

Podcast Transcript:
Dr. Ron Falk
ANCA Vasculitis Treatments
“ANCA Treatments: Tests and Monitoring”

Patient: What kinds of tests or monitoring should I expect when I’m undergoing treatments?

Dr. Falk: You need to always make sure that you have tests that tell you or help your doctor tell both of you, whether you are in remission or are about to have a relapse. So, typical kinds of tests of some kind of inflammatory monitor, like a C-reactive protein or a sedimentation rate—those are very non-specific. We do follow ANCA titers, because in some individuals, a negative ANCA titer, an ANCA that goes away, really is much more correlative of remission. If the ANCA titer starts to increase again, you worry that the disease is coming back.

There are lots of patients in whom, however, the ANCA titer remains persistently elevated, and in those individuals, the ANCA titer is not as good of a test. You want to make sure that the urine has no blood in it, or few red blood cells. You want to make sure that kidney function is stable—so that would be a serum creatinine test, that then is converted to a glomerular filtration rate. You want to make sure that if you have lung disease, that lung function tests, or x-rays, are used.

The most complicated place in my mind, of monitoring, is the upper respiratory tract. Is the nose infected? Does the nose have active disease? Are sinuses infected, or is there vasculitis in the sinus? And you know that’s an incredibly complicated question for your Ear, Nose and Throat doctor to figure out. And I would hope that people listening, if they have upper respiratory tract disease, have a very careful, compassionate Ear Nose and Throat surgeon, who is going to take the time to really look in the nose, understand whether the person has infection or disease activation and, sometimes, as you know, is the combination of both, and spends the time really examining the upper airways. It’s the upper respiratory tract that is so difficult to figure out if there’s disease activity or not.

Patient: Can we talk about flares a minute since we're talking about monitoring? How do you know when you're having a flare, and what should you be doing as a patient?

Dr. Falk: Another fantastic question. I think patients know when they're flaring. I think patients are almost always correct. The problem is—for patients, and then for their doctors, is, Is the flare a little flare? A big flare? Or a consequence of diminution or reduction of the medication? Let me give you an example: You've had a disease where your joints were involved as part of the initial disease process. And now on steroids, on prednisone, your joints are feeling wonderful. Now of course, if I put most people on prednisone, their joints would feel great—every little place they hurt would nicely get better. Remember the folks that won the Nobel Prize for prednisone won it because they thought they cured Rheumatoid Arthritis. When you come off of prednisone, or the dosage has been reduced, every place that you've ever hurt before—every joint, every tendon, is suddenly going to start to hurt a bit again. That's not a flare necessarily. But that's just reduction in the dosage of medication.

So many times, the conversation I have with patients is, as we're reducing the dosage of prednisone, "Does this remind you of your disease activity? Or does this remind you of a nagging injury that you've had for years?" That's a conversation that you have to have with your physician. But again, patients know if their disease in their joints is affecting multiple joints, in the same way that it bothered them when the disease first started.

How can you tell if you're relapsing in your nose or sinuses? I think you again, can tell us as patients. Listen, this is exactly how my nose bothered me when it first started ... When you have to have an Ear Nose and Throat surgeon really look at your nose, "I'm starting to cough up blood again"—that would make me worried about disease relapse. All the things I'm telling you are recrudescence of symptoms—which patients always know earlier than their doctors.

With respect to the kidney, looking at dipsticks can tell you if blood is coming back way before you see it macroscopically. But this is where a patient-physician interaction and mutual understanding is so important. If the physician is not willing to interact with you on a regular basis, if you're worried about flare, and their response is "Oh, I'm just going to increase the dose of the medicine you're on, or "I'm going to start your prednisone back" without this kind of

dialogue, it's time to have a face-to-face, heart-to-heart chat with your physician. Because the physician should be able to say "Yes, you're right. You are having a flare. Or at least I think you're having a flare, and we should increase the dose of medicine." Or they should be able to say, "You know, let's wait for a few more days and let's see what happens, and I'll see you or I'll talk to you again." So, to me, the ability to take people off of medications, to stop all therapy, is really contingent upon my willingness and the patient's willingness to have lots of interactions by phone, by seeing each other or by e-mail. And to comfort both of us, the doctor and the patient, that we're moving in the right way together. And of course if it's a full-blown flare, that becomes pretty easy.

But you and I have talked about fatigue before. I think fatigue is a symptom that lasts for years—even if patients are otherwise in remission. You know a lot about fatigue.

Patient: I do. I know that when I am able to reduce doses of drugs, I suddenly feel this surge of energy. I think, Oh that's what that was like. Most of the time I do experience a level of fatigue, depending on various factors. So I just have to monitor my life. I think of it as an energy bank, and to make a withdrawal, you have to make a deposit. You have to take naps. You have to think about what you're going to do over a day, or in the course of taking a vacation or a business trip, you have to be self-monitoring. Also, talking about flares, I think it's really important for patients to know that they're a very important member of the care team. It's not just doctors saying this and that, it's the patient knowing his or her body, and being able to say to his or her doctors that "I think something's going on." And having that statement listened to, respected and talked through.

Dr. Falk: That's the critical nature of any chronic disease, but especially this disease where you don't have a hard and firm measure of relapse in many patients. So the dialogue you're just describing is absolutely critical. I think patients remain on drugs at higher doses, or the doses are increased, when this conversation is not a two-way street. I think that one is much more able to, as a doctor-patient relationship to come up with minimal kinds of therapy if there's good communication and both sides are listening. The people who remain on drugs forever at high doses typically have not found a doctor-patient relationship that is optimum for them.

