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Podcast Transcript:

Dr. Ron Falk

Living with ANCA: Managing Your Disease

Dr. Falk: When you were first diagnosed with ANCA Vasculitis, the first positive measure that you took was to learn how to manage your disease. Let's talk for a while now about what strategies you've learned about how to manage your disease.

Dianne: Well, I was lucky because I was at a renowned vasculitis center. I think patients need to search for doctors who know vasculitis, who know this disease and who treat it often. Either by establishing themselves as a patient at that facility, or by having their physician consult as needed with the Vasculitis Foundation medical consultants. That is really, really important. I think it starts you on a good path to getting good therapy, to doing all of the things you need to do to take care of yourself.

The second thing that I did was to ask lots of questions. Have those questions ready before each of your medical visits. Get copies of your test results. Keep a notebook of your doctor visits, and what was said. Sometimes when I'm on a lot of prednisone, I have a very foggy memory and I can't remember, so the notebook is especially useful then. Also, by having that notebook you have more of a sense of continuity of your disease, it gives you some reassurance that yes, here's this disease, I have all of my information in one place. It gives you—as if you ever have—some sense of control of this disease.

To me, it was also important to be a part of my care team. You, and the team at UNC, and most physicians anywhere who are treating vasculitis, know that quite often, it is the patient who is the "canary in the mine" when a flare is coming on, and it's important that there's really good communication and trust among all of the care team members.

I also try to keep up with the science. That keeps me hopeful. There's a lot of information on the Vasculitis Foundation web site,

and other web sites that post current research on ANCA. So those are just some of the strategies.

Dr. Falk: You've done a remarkable job of taking charge of your health, but you have all sorts of individual "Dianne Shaw strategies" that I've witnessed over the course of time. How did you figure out about what those various tests meant, for example?

Dianne: Well, I did a lot of searching on the web. I also asked you about them. I also talk to other patients when I go to support group meetings or to the international symposia. There's a lot of emphasis given to what is an ANCA test, what does it mean, what is normal, and what is normal for you—because not everybody measures the same way, and it doesn't mean the same thing for each patient. So that's important, to know what those test results mean.

Dr. Falk: What about reactions to medications?

Dianne: Well, you really have to know your body. You have to know how you are with a certain drug. For instance, when I'm on steroids, we know that if we start me really high, that I just flip out and I'm gone for days. So we try to start it at a rational dose for me. And it took time to moderate and learn that dose, but knowing that is really important. And now when I'm having surgery and they want to give me a taper of steroids, I say, "Let's start here" because that works best for me.

Dr. Falk: For you, that has worked out wonderfully. What advice would you give somebody who wants to help their physician figure out the best prednisone dose, for example? How would you suggest that that patient interact with their physician so as to get their physician not to come up with a cookbook prescription, but rather a patient-friendly, individualized dosage?

Dianne: I think that it's noticing what happens to you. I think the first few times that you have steroid tapers, you'll see at a certain dose you can start sleeping at night. At a certain dose, you don't have to peel yourself off the ceiling every morning. And note that in your notebook. So that when I'm at 28 milligrams, I can do this. If it's under 16 milligrams, I can sleep through the night.

And noticing those things means that the next time you go and get a prescription for steroids, you can say "The last few times I've had it, here's what I've noticed. I've noticed that the symptoms diminish without a huge dose and maybe we can start here. And then if we need to, we can go up, but what about starting at this dose?"

Dr. Falk: So now of course we're at the point I just do whatever you tell me to do with respect to the dosage!

You're a full-time, employed individual, so what do you do to help your co-workers learn about your disease and learn about how you may have reacted to these medications?

Dianne: I have been pretty open with people in my office about my vasculitis. And they are uniformly supportive. I know that I'm very, very lucky. Some people choose to tell only a few people at work. I tell people when I'm on steroids—I say it jokingly: "I just want you to be aware that I'm starting a steroid taper at a high dose, and when I'm at this dose, if you ask me something, I will tell you. I will try to keep myself under wraps, but just know that it's going to be rocky for me for a few days until I get to a rational dose. "

Dr. Falk: What would you advise people who are not as willing to be as open with their co-workers? There are a lot of patients who really don't want to share anything about what they're going through with anybody in their working environment—which perhaps has a benefit of shielding the patient from too many prying questions, but, on the other hand, has a downside of not allowing individuals in a supportive environment to weigh in at times, when you or other patients, really need them to weigh in. How would you help patients get over that? It's almost a hurdle, of wanting to open up.

Dianne: It is, because when you're first diagnosed you feel so weird. You feel like you're now living on a different planet. You have a disease that nobody's heard of, nobody knows what it is, how it affects you, what the therapies are. So you tend to pull yourself back and pull inside. I think that talking with people you know can talk with about something like this, is a good start. If you don't feel you can tell people at work, then you need to make a plan for yourself so that if you're on a huge taper of prednisone and you need to go home and sleep for the afternoon, then get your stuff done during the morning and take time off in the afternoon. Say you have a medical appointment or something, and go home and sleep.

Try to do things that will help you move along in your illness, but also stay at work as long as you can.

Dr. Falk: You, almost invariably, tell me a joke or two when you come to visit. What role does humor play in how you've managed your disease?

Dianne: Humor for me plays an enormous role. I feel like it deflects pity in some people. I think it shows that I have dealt with this and that I'm moving on. I am not just a person who has vasculitis, that I'm a person with a sense of humor, that I'm a person in a job, that I'm a person. I'm not a sick person, necessarily.



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