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KIDNEY CENTER

Podcast Transcript:

Dr. Ron Falk

Living with ANCA: Finding Support

Dr. Falk: You have, of all people, worked tremendously on support networks. You were the president of the Vasculitis Foundation, you've been very much involved locally, nationally and internationally in the support network concept. How would you then suggest to somebody who is brand-new to the whole vasculitis experience, to find support groups? To find other individuals with whom they can commune?

Dianne: The Vasculitis Foundation has all of the support groups nationally and internationally listed on their web site. They also have area contact people with phone numbers and e-mail addresses. I think it's very, very helpful.

I will tell you that I was afraid to go to a support group for a while. I was afraid to go to my first symposium, because I didn't know if I could handle it. I didn't know what I would see there. I didn't know if everybody there was going to be really depressed and look terrible and be really sick, and it would scare me to death. But I did—I went, and it was very, very helpful. I think having a support network, be it a formal support group or just talking with another patient over time, is really important because it helps you to not be isolated.

You can learn a lot. You can learn how other people cope with this disease. You can learn how other people manage symptoms. Or just learning about a symptom that you thought you had, or didn't have. Also just being with people who know what you're going through, who are going through the same thing. There's a certain comfort level there. I think it's really important. I know a group isn't for everyone, but I think having some support from another patient would be fabulous.

Dr. Falk: So, the value of the support group is the ability to know that there are others who are undergoing the same kinds of difficulties. Support groups also tend to have educational events where some

important medical topic or coping concept is usually described. It seems like that is as useful in the support group as anything else.

Dianne: It is. Some of our groups meet just to get together. Our group is really fortunate to have UNC and Duke right here. The doctors and nurses and staff, you, everyone—are very generous with your time. Another way that people have a chance to get together is at the international symposium. That’s a great way to learn everything you need to know about vasculitis and meet loads of people.

Dr. Falk: At that last international vasculitis meeting, all of us learned how to do “in the chair massage” which I must confess I have repeated on a number of occasions. That was a learning experience not just for patients, but for everybody in the audience. It was a great moment.

