



UNC
KIDNEY CENTER

Podcast Transcript:

Dr. Ron Falk

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“Top Three Questions”

The number one question I get asked, I actually wrote down the questions in order of what I get asked the most, and here they are:

When you're first diagnosed, the first thing that most people want to know is, Am I going to die? That's the number one question. And the answer to that is, by the time you're in a hospital and have the diagnosis made, the most worrisome time of dying has passed. For the diagnosis and the institution of effective therapy really has tremendously, incredibly lowered the death rate. So when I first started, in these many years in the 80s, the death rate from horrible pulmonary lung-bleeding or sudden deterioration of kidney function, that death rate has dropped to the single digits with respect to percentage. And typically now, it is for people who don't come to medical attention fast enough. So that's not a matter of therapy anymore, that's a matter of education. Education of primary care providers of what these diseases look like and the need for prompt, quick institution of therapy. And that's been a wonderful result, or consequence, of 25 years of your community working on this disease. So early deaths are rare.

Here's the next question I get: Okay, If I'm not going to die, am I going to be maimed from my disease? Is my life suddenly going to change, I'm going to be alive but not really? That, too, depends on where your disease is located, but the early worries of being maimed- lung disease, kidney disease, upper airway disease-have all gotten better to a certain extent. But I would submit to you that while we have gotten okay at treating the early parts of this disease- early therapy, we've not gotten better at really helping with the chronic, the persistent manifestations of this disease, and that's why I divide that question up, and we'll talk more about that in a minute.

Here's the third most common question I'm asked. Okay, what caused my disease? Where on earth did this meteorite come from? Out of the blue, I was minding my own business, nobody ever would have set me up for this, I haven't done anything to myself that would engender this kind of disease. And it happened so fast. Well, I will tell you, that we have now learned a huge amount about what causes these diseases. This disease is no longer a disease, or group of diseases, that needs to have a name. A name of a person. In medicine, when you have a disease that's named after somebody, it means we don't know anything about that disease. For example, nobody refers to bacterial pneumonia on the basis of the original person's name of their disease. All of kidney disease at one point was called Bright's Disease. Good old Bright is long gone and we never refer to that name anymore because there's no need to, we understand the causes of many many diseases. You call a pneumonia in your lung on the basis of the bacteria or virus that causes that pneumonia.

So too, with respect to Vasculitis, we know a lot about what causes it. It's not one thing. If it was one thing, it would be easy. But it's several things. For those of you who have antibodies to Neutrophil Cytoplasmic Auto-antibodies, or did at the start of your disease, ANCA, for short, those antibodies that are supposed to

react to bacteria or toxins in the environment, react to your own white cells. And they cause those white cells to explode, releasing noxious granule constituents and bleach, essentially. That hurt tiny little blood vessels. So those antibodies clearly participate in the disease. But it's not just the antibody. It's the cell that those antibodies are causing to become activated. White blood cells. And they do things--you're supposed to have white cells that are there to chew up bacteria-get rid of things in the environment. Well now your white blood cells are affecting you--affecting your blood vessels. And, it's the combination, then, of white cells being activated, hurting your own blood vessels, and then your blood vessels not shutting down the inflammation that causes this disease.

Yes, there's a genetic propensity. Yes, there are certain genes that make your disease worse or better. But no gene that any one of us has found that causes your disease.