



UNC
KIDNEY CENTER

Podcast Transcript:

Dr. Ron Falk

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“Why this disease should not be called Wegener’s”

No disease should be named after a person. It means we know nothing about the disease, number one. Number two – and we know a lot about this disease-if you gather ten physicians in a room, and line up ten vasculitic patients who have some of the features of what Wegener described, you will not sort those patients into a Wegener’s category or a Microscopic polyangiitis category correctly. Why? Because it’s almost impossible to do prospectively, at the time you see the person, and it’s almost impossible to do even if you have all the information--it’s a guess. In fact, it’s better to describe these diseases as small vessel vasculitis, because that’s what almost everybody sitting in this room has. Some of it is probably a proteinase 3 vasculitis, some of it is probably a myeloperoxidase small-vessel vasculitis, some of it is just vasculitis.

People have asked us to come up with another name other than Wegener’s. Wegener’s is easy to say. But here’s what I hate about that name: One, it in some individuals, implies endless therapy with Cytoxan, and those days are over.

Secondly, it doesn’t help the physician understand one iota more about their disease, and in fact pigeon-holes you into a disease category which is very difficult to define and shouldn’t guide therapy.

Thirdly, we know so much about the nature of your disease that it’s better to call your disease small- vessel vasculitis or ANCA vasculitis, and that’s a much fairer diagnosis.

Fourthly, if you knew anything about that guy, you would not want your disease named after that man. It does not provide a shred of additional information that helps you as a patient move forward.