Reading the perspective written by Dr Young about her experiences with fibromuscular dysplasia (FMD) filled my mind with the faces of literally dozens of patients like her whom I have had the privilege to meet as they came to grips with their diagnosis of FMD and with what it would mean for them and their families. Dr Young’s experiences and observations, although clearly informed by her being an experienced physician, are nonetheless quite like most people who find themselves not only threatened by the seriousness of this diagnosis but isolated in a real way by the rarity of FMD, and the confusion the diagnosis can cause.

There are 4 special challenges for us as we help our patients face rare, serious diseases. Dr Young describes them eloquently. One is the time that passed from the initial onset of her symptoms to a diagnosis. Second, she also shared the fright that comes from realizing that many of her physicians were unfamiliar with either diagnosing or treating her medical problem. Even a horrible diagnosis usually comes with some assurance that the problem is understood. Third, this is further compounded by a sense of loneliness and isolation, when she discovered no comrades in arms or even familiarity with FMD in her community—even among her physician colleagues. Unlike heart disease, and many more common maladies, FMD is sufficiently uncommon that one’s friends will have no reference for one’s experience, and sufferers will likely find no fellow victims with whom to commiserate. And finally, she refers to the Damocles’ Sword with which patients having FMD must live. All 4 of these challenges: delays in diagnosis, physician inexperience, absence of community support, and a sense of doom from an unknown prognosis, call for a concerted effort in understanding and making sure all patients and providers work to solve the puzzle of FMD, we should also work to increase awareness and make sure all patients and providers have access to the current state of knowledge and the opportunity to make FMD less of a mystery.

One of the greatest services I feel I have to offer my patients is information and support. I often say my main profession is really teaching. Not just the teaching of students and trainees, but sharing what I know with my patients. Knowledge is the greatest weapon in the battle we all wage for our health and well-being. We all crave understanding of what we face in the future, of what we can do to improve our condition and prognosis, and of what is actually going on inside the bodies that carry us through this existence. FMD in 2016 provides me and my patients with a huge challenge. I lack the weapons I take for granted in my work with patients having other problems such as coronary artery disease. I look my FMD patients in the eye and see them looking back at me with a fear of the unknown which we all share, but which in the FMD patient’s case I can do little to assuage.

For most conditions, usually I can offer patients a current understanding of their disease process, which helps them understand what is happening. Furthermore, for more common diseases, I can offer at least some idea of treatment options, and the likelihood of improvement with treatment. Whether my patient’s problem is dire and insolvable, mild and treatable, or something in between, they can at least leave my office better armed to face the future informed. FMD, like so many rare diseases, robs caregivers and patients alike of that solace. Even though the vast majority of patients with FMD have a smooth course after diagnosis, as Dr Young has, facing the journey without a compass is daunting.

I salute the courage and forbearance Dr Young has shown in plotting her journey and sharing it so forthrightly. I also share her gratitude for the FMD Society of America, and the tremendous service they offer for sufferers of this disease. As we work to solve the puzzle of FMD, we should also work to increase awareness and make sure all patients and providers have access to the current state of knowledge and the opportunity to make FMD less of a mystery.

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Clinical Commentary on "My Life With Fibromuscular Dysplasia: A Sword of Damocles"

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