Patient Viewpoint

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

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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 terrible 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 to increase awareness and make 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 are available at http://circoutcomes.ahajournals.org

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