



## MSDF Turns Knowledge into Power

Susan Rosen describes the period after her 28-year old daughter, Mary, was diagnosed with MS as “my last year . . . a time when I was literally paralyzed, unable to eat, work or exercise. I am no scientist and all of a sudden, knowing human biology so that I could understand what was happening in Mary’s body was more important to me than anything else in the world. But I couldn’t understand it. I needed somebody to ‘uncomplicate’ the science.”



Looking back on that time, Susan now sees that what was scariest was the unknown—the Big Questions for which she had no answers. What, exactly, is multiple sclerosis? What did this diagnosis mean? What impact would it have on her daughter’s future, including a brilliant career, already launched and well underway? And, most critically for a smart problem solver like Susan, what’s being done to treat and cure this awful disease?

About a year after Mary’s diagnosis, Susan forced herself to begin talking to friends and family members and networking her way to those who could teach her about the science of MS. Upon the advice of a leading geneticist, she read *Multiple Sclerosis: A Comprehensive Text*, by Dr. Henry McFarland, often referred to as “the bible of MS.” One friend, a Ph.D. scientist, introduced her to a leading MS clinician. Susan arrived to that meeting with Mary’s medical file in hand. The clinician slowly and gently walked her through the physician reports, diagnostic test results, and other data it contained.

Soon thereafter, while Googling various MS topics, Susan stumbled across the Multiple Sclerosis Discovery Forum ([www.msdiscovery.org](http://www.msdiscovery.org)), which ACP had just launched. Originally conceived as a vehicle mostly for scientists, from the start MSDF’s clearly written content spanning basic science to clinical research drew a full range of stakeholders. Susan joined a growing community of readers that includes clinicians of all stripes, medical students, bench scientists and a growing community of patients and their loved ones. Now, she logs on every day.

Without dumbing it down, MSDF makes scientific findings understandable and accessible to everyone. Its writers avoid the use of jargon that gets in the way of comprehensibility; they highlight the potential clinical impact of the research and they seek innovative ways to communicate important information to its diverse audience. Susan was hooked, and this addiction has done her good. The more she read, the more she learned and the more she learned, the more courageous she became. Today she says, “ Knowledge is power. It has helped to abate my fear and has enabled me to deal with the facts. I understand much better what I can affect and what I cannot change and that, in turn, makes me a better mom to my daughter.”