

BY ALISON DALE

Talking with Richard M. Cohen

Richard M. Cohen, author of **Blindsided**, an acclaimed book about his long struggle with MS and two successfully treated bouts of colon cancer, is a journalist and former award-winning television producer. He is married to celebrity TV host Meredith Vieira, with whom he has three children.

Both Richard and I have had MS for 30 years. I was honored to speak with him the morning before he received the 2005 Dorothy Corwin Spirit of Life Award from the Society's Southern California Chapter.

How comfortable are you being a spokesperson for people with MS?

I've made it very clear that I speak for nobody. I said in **Blindsided** that I write no prescriptions. I claim no wisdom. My answer is **an** answer, not **the** answer. So I'm totally comfortable because I make very clear that I don't represent any point of view or special interest.

But I've also gotten a very clear



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reaction to the book: People with MS really want to hear from each other. I think they're tired of hearing from doctors. I think they're tired of hearing from so-called experts. I think people want to hear from real people. They want to know how did you do it or how do you do it, or what did

you do when this or that happened. I think we help each other a lot more than we realize, by just sharing.

I've been speaking around the country to pretty large gatherings of people with MS and they are really not there to listen, but to speak. What I like about these sessions is that I encourage people to talk to each other. I'm not qualified to lecture on anything. But I might be in a position to facilitate opening up lines of communication.

On the Larry King Show, you said you were going on Tysabri. What was your reaction when it was recalled?

The expectations for the drug were off the charts. People came to believe this was the wonder drug that was going to turn lives around. People with MS were devastated when it disappeared, but my attitude was I've never expected anything from drugs. Sure I was willing to try it, and I did have one treatment. It seems the jury's still out. I've talked to a lot of people, and there seems to be a consensus that Tysabri is going to come back, possibly in a matter of months rather than years.

You take one of the injectables. Do you think it helps you?

For me, it's all band-aid therapy. If you fit the center of the profile, if you're younger than I am, if you're more newly diagnosed, if you're relapsing-remitting, you may get results. But I'm older, have had MS for a while, and it's evolved into secondary-progressive—I'm on the margins of the profile. I've been taking inter-

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Richard Cohen and Meredith Vieira with their children Gabriel, Lily, and Ben in Hollywood, California.

ferons for eight years. I don't think it does a damn thing for me, I just don't. But at the end of the day, I still do it. Why wouldn't you do it?

Do you do any other therapeutic activities, such as yoga or aquatics?

My approach is I drink gin. (Laughs.) I'm not big on religion and I'm not big on the religion of what you're supposed to do, how you're supposed to live, what you're supposed to eat and drink. I think you just live your life. Like all of us, I try to do stuff that's healthy. I go to the gym two or three times a week. I believe people with degenerative illnesses that cause weakening and loss of function need to stay strong.

I can't tell you how many times I've found myself losing my equilibrium or falling, and whether I use my cane or I grab onto something, I can keep myself on my feet. I can because I'm physically strong.

I also think that going to the gym is



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important psychologically. I feel I'm staying a step ahead of the grim reaper, whether I am or not, and I feel like I'm doing something for myself.

What role should we patients have in our treatment?

There are certainly people who want to walk into their physician's office and turn over all control. Just tell me what to do and tell me I will be better. But my argument is that there are various ways of perceiving "better." They're subjective and qualitative and if you really want to find them for yourself, you've got to take a role yourself.

People should go to the doctor and hear things as opinions and suggestions, not orders. We've evolved from taking

what the doctor says as the word of God to questioning it, and becoming more proactive. Any physician who doesn't want to be questioned should be your ex-physician.

Have you found a new career in patient advocacy?

Yes, and not just with MS, but the larger sense of trying to give patients a voice. I think that's missing right now. I think there is a culture of sickness, a culture of being ill, and the patient's voice, which I would argue ought to be the loudest, is really the softest.

Between the physicians and managed care and powerful institutions, we patients can get lost in the shuffle. And partly, we allow ourselves to get lost. We're intimidated by all these huge forces.

I think patients need to become more aware of what their interests are. People not only **can** have a voice, they **should** have a voice and should be active partners in their own care. People shouldn't be asking their physicians, "What should I do?" They should be asking, "What can we do?" ■

Richard Cohen has a great deal more to say. Look for a continuation of this conversation in a forthcoming issue of **InsideMS**. Alison Dale is a California-based writer who detailed her experiences with Tysabri in our August–September 2005 issue.