

# Accelerated Cure Project for MS

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*Accelerating research towards a cure for multiple sclerosis*

## Richard Cohen – “Keeper of My Own Flame”

Richard Cohen’s network television news career spanned 20 years, during which he covered wars and politics for ABC News, CBS News and CNN. He received numerous awards in journalism, including three Emmys, a George Foster Peabody and a Cable Ace Award.

Richard learned that his father and his grandmother had multiple sclerosis (MS) when he was 19 years old. A few years later, he suddenly became disoriented at work and dropped a coffee pot. The same day, he tripped off a curb and his leg went numb. He learned that he, too, had MS when he was 25.

"There's an expression ‘diagnose and adios’ because really there were no treatments of any kind," says Richard. His father advised him to “suck it up and keep going.” Since his MS diagnosis, Richard has also had two bouts of colon cancer, both of which required invasive surgery.



Richard is married to journalist, Meredith Vieira, with whom he has three grown children. When he met Meredith in the early '80s, his MS symptoms were barely noticeable, except for his failing eyesight. On their second date, he told her about his condition. They decided long ago that, while MS may affect their life together, it would not define it. Their ability to look at things with a sense of humor has carried them through many hardships in their journey together with MS.

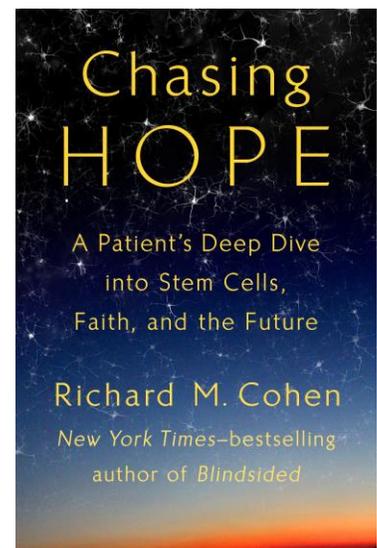
Richard and Meredith didn't tell their children about Richard's diagnosis until the night they witnessed their father fall down a flight of stairs and their oldest son started asking questions. They openly talked about MS with their children, but focused more on normal activities. In Richard's words, "We were very understated, as reassuring as we could be without being dishonest. Once you create a culture of openness in the house, they're not afraid to ask questions ... it all becomes very casual and second nature."

MS has affected Richard's vision, voice, balance, strength, and coordination. After living with MS for more than four decades, he is legally blind, has trouble walking, and difficulty using his right side. For the Cohen's, MS is a "family affair." In Richard's words, "everybody in the family is affected by MS. Everybody in the family somehow shares MS. Because it can be so limiting for the sick person, very often the rest of the family tries to help as best they can and everybody gets involved." Reflecting on the nature of chronic illness, Richard states, "it's an odd thing because, even with a loving family surrounding you... there's something very solitary about illness. I'm not contradicting myself here, it is a family affair, but there's something very lonely about being sick. It is not anybody else who is going to suffer with it, only you feel the physical effects. Only you feel the fatigue, or the pain, and in the end we really are alone with it. Having said that, it's still wonderful to have a family around you just because they become part of the battle." Now that his children are grown, Richard shares that his children watch over him. "They're just very tuned in to it ... on the one hand you don't wish it on your children, and on the other hand I really do believe that kids become better persons for growing up in a family with illness. They learn very early that life is not fair. They understand, on a very basic level, that it can be painful. They're fully aware that they are in a position to help and I think it just becomes second nature to them... So, it's not entirely just the 'down' side you've got to deal with. I think there's an 'up' side, too."

When asked how he best copes living with progressive MS, Cohen states, “There’s an inevitability to the journey because it’s a one way trip. You don’t get better and slowly get worse, so I think you’ve just got to come to grips with the fact that things are going to deteriorate. It doesn’t mean that it’s going to happen at any particular rate of speed. It doesn’t mean that tomorrow is the end of the world. It’s just a fact of life you’ve got to deal with ... You’ve got to learn to rise above the difficulties, the physical impediments that lie before you and find a way to soar ... to lift yourself up ... to be bigger than your disease ... to do something with your life ... to live gracefully ... to be a good person. This may all happen more because of the illness than anything else.” According to Richard, another aspect of MS is learning to live with how people perceive him. In his words, “I use wheelchairs at airports or very large places and people don’t want to deal with you. People don’t see us. They see the wheelchair. They don’t see the person in the wheelchair.”

Richard is the author of two New York Times bestsellers. [\*Blindsided\*](#) is a revealing memoir detailing his struggles with MS and cancer. [\*Strong at the Broken Places\*](#) follows the lives of five individuals living with serious chronic illnesses, delivering the message that we are all stronger than we think.

Even though Richard found ways to cope with and rise above illness, he rarely thought of himself as having “hope.” The lack of any meaningful treatments for progressive MS and the lack of caring physicians left him with little to anticipate other than a steady decline. In 2012, Richard and his wife hosted and chaired a stem cell conference in Rome where scientists gathered to discuss stem cell therapy for autoimmune diseases such as MS. At the conference, Richard met Dr. Saud Sadiq of the Tisch Multiple Sclerosis Center of New York. Meeting Dr. Sadiq enabled him to look at his future differently. Dr. Sadiq’s work focuses on how to utilize the potential of stem cells in trying to repair diseases like MS. He received approval for a clinical study in which stem cells would be collected from patients, transformed into brain stem cells and injected back into patients’ spinal fluid in hopes of repair and restoration of function. Richard was invited take part in the trial, which opened him up to the possibility of hope that he might get better. In the end he didn’t qualify for the trial, but he received the same treatment as those that did.



Richard shares his experiences with stem cell therapy and insights into the concept of “hope” in his new book, *Chasing Hope*. This latest work is an easy and touching read that includes interviews with doctors, scientists, and religious leaders, all with the goal of understanding the relationship between illness and hope. As revealed in the epigraph by Paul Tillich, Richard feels that hope has to be sensible, “Hope is easy for the foolish, but hard for the wise. Everybody can lose himself into foolish hope, but genuine hope is something rare and great.” In Richard’s words, “I think hope as a word is thrown around and it means a lot of things to a lot of people ... I think if you’re going to hope, you’ve got to be smart about it. You’ve got to be realistic about it and not waste your time hoping for things that will never come to be.” Richard’s close-knit family is a major source of support and hope in his life. He also makes it clear that while many find hope through faith, he does not. In his words, “I think hope is something that you have or you don’t have. I don’t much believe that it has to be tied to anything in particular ... I think hope is organic. Hope sort of feeds on itself and it’s a way of approaching life.” *Chasing Hope* delivers the strong message that, no matter what the source, it’s crucial not to lose hope. When asked how he keeps his sense of hope alive, Richard replies, “I don’t think it’s something you consciously do. I think it’s something burning inside of you. Sometimes the flame is high and sometimes it’s a low flame. Generally it endures and is not extinguished. I’m happy that I’m the keeper of my own flame.”

Richard generously allowed us to tape the interview for this article. If you’d like to listen to him share his experiences and perspective, please click [here](#). Richard also writes about his journey with MS on his blog, [Journeyman](#). When asked the reason for this title, he states, “I’m on a journey like everybody else. The drawing at the top of the blog is someone with a cane walking toward the skyscrapers of New York. That’s sort of how I see myself. I’m a member of a big city, a large community and at the same time I’m on a solitary journey.”

Chasing Hope is available now for pre-order on [Amazon](https://www.amazon.com) and will be available at bookstores everywhere on May 1, 2018.

