

His own best advocate

By Myron Goldsmith, MD | Huntington Beach, CA

The Patient from Hell: How I Worked with My Doctors to Get the Best of Modern Medicine and How You Can Too

By Stephen H. Schneider, PhD, with Janica Lane
Da Capo Lifelong Books
300 pages. \$25

In early 2001, Stanford University climatologist Stephen Schneider, PhD, was about to board a plane when he got a message from his assistant to call his doctor. After weeks of intermittently feeling an axillary lump, a biopsy had been performed and the pathology report was now in: B-cell lymphoma, what Dr. Schneider would later learn was mantle cell lymphoma. He sprinted onto the plane with moments to spare, his mind whirling. Unable to log on to the Internet to research his disease, he was in an agony of frustration. “I was literally flying blind with no relief for my left brain,” he writes.

Dr. Schneider, a MacArthur Fellowship recipient, is a professor of biological sciences and an internationally known climatologist. His equally brilliant wife is Terry Root, PhD, a senior research fellow in biology at Stanford who served as his advocate during his intense treatment. Together, they used their immense intellect to become knowledgeable about his disease and apply the decision-making tools he uses in climatology. They reached critical decisions in the face of few data about his rare cancer by working as partners with his doctors to interpret the odds and individualize his treatment.

I was struck by the differences in the care received in a world-renowned institution and that offered in most community-based oncology practices. For example, Dr. Schneider was

started on R-CHOP followed by an autologous bone marrow transplant. Initially, his doctors were reluctant to give him Neupogen during the pre-BMT phase of his treatment. The clinicians didn't seem to forewarn him about adverse events. At times, interim decisions were made by clinicians other than the primary oncologist. There were 3-week waits for test results and a described indifference by some fellows assigned to his care.

In my experience in the community setting, patients receive complete verbal and written instructions concerning side effects; patients have easier access to physicians and oncology nurses to ask questions and obtain lab reports; and orders for any change in care originate with the primary oncologist.

Advancing the field

By dint of his and Dr. Root's research and cognitive skills in problem solving and applying decision analysis, Dr. Schneider obtained care that deviated from the Stanford BMT protocols. He helped advance the therapy of mantle cell lymphoma for himself and other patients by lobbying for the 300i Isolex blood-purging machine as part of BMT treatment. In addition, he is one of the first patients with mantle cell lymphoma to be followed with serial polymerase chain reaction measurements and treated with maintenance rituximab (Rituxan) after primary therapy, a regimen he suggested

and pushed hard for.

Very few patients have the background and intellect to change their therapy as Dr. Schneider did, but many should be able to make decisions—especially when choices exist—as to what treatment they do or do not wish to receive.

I have issues with many of Dr. Schneider's medical statements, his interpretations of how doctors and nurses act and think, and some of his diatribes against the medical profession. However, the book overwhelmingly offers a positive message regarding the role of patients in treatment of their disease. His plea for advocates who can help patients with the myriad of insurance issues, treatment choices and side effects, financial issues, and Internet research is very sage.

Still, the problem remains: who will pay for the advocate if a patient doesn't have a family member, such as Dr. Root, or a trusted friend to serve in that role? If the Cancer Act of 2002 had been enacted by Congress it would have paid for what was referred to as “cancer quarterbacks”—a group of physicians who would shepherd patients through treatment. Perhaps it is time to address this need again.

Dr Schneider is to be congratulated for his many achievements. And if a national dialogue can be started on payment of patient advocates and cancer quarterbacks, that would be one more.