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At the Helm: Oncologists With Cancer

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ORLANDO, Fla., May 18 - When Dr. Sandra J. Horning and Dr. David H. Johnson learned they had cancer, one immediate worry was whether the disease would end their careers as cancer specialists.

Now healthy, the two doctors have risen to a pinnacle of cancer leadership. During the meeting of the American Society of Clinical Oncology here from May 13 to 17, Dr. Horning succeeded Dr. Johnson as president of the group. They are the first cancer survivors to lead the 41-year-old society, the largest group of cancer-treatment specialists.

The two doctors said they were not chosen because they were cancer survivors, although their selection occurred at a time of growing attention to a wide range of issues related to how patients and their families adjust to life after cancer detection and treatment.

Survivors say that being cancer-free does not mean being free of cancer. Physical, psychological, social and financial needs persist, and survivors face a risk that the cancer will return, as well as the possibility that they may develop another kind of cancer.

A person is regarded as a cancer survivor from the moment the disease is detected, say federal health officials, who estimate that there are 10 million such survivors in the United States (3.5 percent of the population), up from 3 million (1.5 percent) in 1971.

Advances in treatment and increased screening to detect cancers at an earlier stage are two reasons for the increase. In one study reported at the meeting, most children cured of cancer later experienced at least one serious complication from radiation, chemotherapy and other treatments and were five times as likely as their siblings to have serious health problems later on.

A history of cancer in their immediate families influenced both Dr. Horning and Dr. Johnson in choosing their specialty, they said in interviews. The illnesses made the doctors more empathetic toward their patients and committed to helping other cancer patients and their families, the physicians said.

Dr. Horning, who practices and does research on lymphomas at Stanford, wanted to be a doctor since she was 14. Her father died of cancer when she was 21 and a medical student. Her mother has survived two types of cancer. That family experience "helped me in a way understand and perhaps be better prepared to deal with some of the emotional issues that are related to cancer diagnosis, treatment and survival," Dr. Horning said.

A diagnosis of a potentially fatal illness like cancer never comes at an opportune time. A few hours after she had been told that she had breast cancer nine years ago, Dr. Horning had to present a proposal for a federal research grant to an important committee.

"When you have a diagnosis of cancer, you think about your mortality," she said. "That is No. 1."

Dr. Horning said she felt she had to survive to care for her two sons, then 14 and 12. The cancer news

arrived when her older son was graduating from middle school and the younger was celebrating a birthday.

"But at the same time I thought about my career," Dr. Horning said. "Medicine is more than a career. For me it is a passion." As an oncologist, she was better informed than other people. Still, she said, she sought opinions from breast cancer specialists elsewhere, and she avoided directing her care.

After breast surgery, Dr. Horning continued to practice while undergoing chemotherapy for six months. She said she decided "not to hide my illness, but to have fun with it."

So she bought a wig. Her patients, friends and family, said Dr. Horning, who is a blond, "saw me as a redhead." Dr. Horning said that in caring for patients she placed communications at the top of the list. The reason, she said, is that while she was training to become an oncologist, a patient told her that whenever Dr. Saul A. Rosenberg, Dr. Horning's mentor, entered the room, his presence made that seriously ill patient feel better.

"Now, when my own patients make similar comments to me, it is one of the most rewarding aspects of being an oncologist," Dr. Horning said.

She added, "Clearly, some families have a higher level of distress than others," so "we need to partner with other health professionals like social workers and psychologists."

Dr. Horning is co-chairwoman of the oncology society's task force on cancer survivorship, which aims in part to develop guidelines for care. Another goal is to improve partnerships with psychologists, social workers and other health care professionals.

Being a cancer survivor "gives you a certain amount of credibility," she said.

Her predecessor, Dr. Johnson, is deputy director of the Vanderbilt-Ingram Cancer Center in Nashville. He said he became an oncologist because of experiences he had as a medical student, starting with his first patient, who suffered from a deadly form of lung cancer. Dr. Johnson recalled presenting the patient's case to a chest surgeon on rounds. As soon as he finished his opening sentence, Dr. Johnson recalled, the senior doctor stopped him, saying that with so little to offer the patient, there was no point in discussing the case.

Dr. Johnson said that he was speechless and that he went to the chief of surgery, "who explained that it was just the state of medicine."

The experience left him furious and filled with a desire to improve cancer care, a devotion that intensified when his mother was found to have cancer a few months later.

In 1989, Dr. Johnson developed swollen lymph nodes. He underwent a lymph node biopsy on a Friday, the day before he left on vacation with his wife and daughter, then 10, intending to wait for the findings until he returned.

But on Monday, his doctor called to say he had lymphoma. The family took the vacation, but he and his wife did not tell their daughter about the cancer until later.

At the time, Dr. Johnson said, there was disagreement about the best way to treat his type of lymphoma, and he was not eligible for a clinical trial. After colleagues had volunteered their opinions and his doctors made their recommendations, Dr. Johnson chose what then was a new treatment approach.

Before starting the therapy, he decided to stop seeing patients during the treatment period because he

thought his own illness might prevent him from focusing on crucial decisions affecting other patients.

He soon found that the therapy was "incredibly toxic." He vomited often. Swallowing was difficult. Nerve damage impaired his ability to move muscles. Skin fell off his feet, making walking painful.

The chemotherapy left him tired.

"With physical fatigue, you rest and it gets better," Dr. Johnson said. "But with chemotherapy fatigue, you rest and it does not get any better. It's very distressing."

Still, Dr. Johnson went to work each day. Instead of caring for patients, he wrote scientific papers about his research and applied for grants. That work took his mind off his own case, he said, but he erred in not talking enough about his illness with his wife and daughter.

As treatment progressed, he found that his doctors had no plan for what to do next. So, to regain strength, he developed his own.

After a diagnosis of cancer, he said: "No question, you spend the rest of your life under the sword of Damocles. You are always very wary" of minor symptoms.

Recalling a cancer patient who worried that her headaches were because of a brain tumor, not tension, Dr. Johnson said he intended to write a book, "Once You Have Had Cancer, You Can Never Have a Headache Again."