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A patient's research finds success

A woman with a tumor near her brain works with a neurosurgeon from Rhode Island Hospital to find the right treatment.

01:00 AM EDT on Wednesday, August 3, 2005

BY FELICE J. FREYER
Journal Medical Writer

By now most people have heard that when diagnosed with a serious illness, you should get a second opinion, research the options, and advocate for yourself.

A California woman took that advice to an extreme a few years ago. She spent more than eight months researching a tumor near her brain and received not just a second opinion but 40 opinions -- and rejected them all. Instead she devised her own treatment protocol, and found a Rhode Island doctor willing to give her plan a shot. It worked so well that the doctor has since used it in 40 other patients and hopes to publish a research paper about it.

The woman is Victoria Paige Meyerink, a former child actor who appeared with Danny Kaye on his weekly variety show and with Elvis Presley in the movie Speedway. Now a filmmaker, Meyerink is in New England this week and next for the Boston and Rhode Island premieres of her latest film, Finding Home. The film has nothing to do with her treatment, but she says couldn't have produced it without the care she received. The proceeds of a special screening next week will be donated to Rhode Island Hospital.

In an interview at Rhode Island Hospital

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yesterday, flanked by her husband, Lawrence David Foldes, and by the doctor who treated her, Dr. Georg Noren, Meyerink eagerly described her search for the treatment that worked for her.

In the late 1990s, Meyerink experienced muffled hearing in her right ear, episodes of tingling and numbness in her cheek, and occasional vertigo. She went from one ear doctor to another, receiving treatment for ear infections and sinus infections -- but got no relief. Finally, one doctor ordered an MRI.

The imaging test detected an acoustic neuroma, a benign tumor about the size of an apricot, located on a pair of nerves that relay sound and balance information to the brain. Such tumors press against the brain but do not invade it. But if left untreated, an acoustic neuroma can cause hearing loss and facial weakness, and eventually could even kill her if it pressed against the brain stem.

As Meyerink recalled it, her ear doctor said, "Oh, well, we found a small growth. They'll take it out. You'll be back on your feet. It's no big deal." He referred her to a surgeon, who also recommended surgery and described it as "an easy procedure," she said. In fact, the doctor pushed her to book the procedure that day.

But the more she asked questions about the surgery, the more concerned Meyerink became. The surgery, she learned, could make her deaf in one ear. It could damage a facial nerve that runs near and sometimes through the tumor, leaving half her face paralyzed. She asked about radiation, but her doctors said that radiation could cause her benign tumor to become malignant. (They didn't tell her how unlikely that was, less likely than a surgical complication, she said.)

In tears, she went home and told her husband, a writer and director. "I said, 'Wait a minute, wait a minute, wait a minute,'" Foldes recalled. They stopped the film project they were working on, and set about learning more about the options. An acoustic neuroma grows slowly, so there was time.

They talked to doctors at the major U.S. medical centers and sent her MRIs as far as Germany and England. They asked the doctors how many procedures they had done -- and how many were successful.

Meyerink and Foldes also took a step that

proved critical to the final decision: they searched far and wide for patients. Doctors referred them to their successful cases, who in turn referred them to less successful cases. They also found support groups on the Internet. They estimated that they talked to 40 doctors and 100 patients.

Those patients were not a scientific sampling, but Meyerink and Foldes were disturbed by what they heard from some who had undergone surgery. "In many cases, these people never had the life they had before," Foldes said. They met surgical patients who no longer produced tears and could close their eyelids only with surgically implanted weights.

They were leaning toward radiation therapy, although hearing loss and facial paralysis can occur with radiation treatments, too.

Once again the choice would not be simple. Radiation therapy was available in two forms. One was the gamma knife, a machine that directs 201 gamma rays through a colander-like helmet, targeting a narrow area of the brain. At the time about 30 gamma ray machines were available in the United States (now there are 89), including the one at Rhode Island Hospital. Gamma knife treatments are typically done in one large dose that destroys the target without harming surrounding tissue.

The other method was the linear accelerator, a radiation device commonly used for cancer treatment. This machine cannot focus its beam quite as precisely as the gamma knife, potentially endangering nerves located just outside the tumor. To limit the damage, doctors administer the radiation in several smaller doses over several days, called fractionating.

That gave Meyerink an idea: Why not go for the best of both worlds? Why not use the gamma knife, with its higher accuracy, but take the approach used with the linear accelerator -- fractionate the radiation in several small doses to better protect the nerves near the tumor?

There was, in fact, no reason why not. Meyerink proposed the idea to the heads of about 15 top gamma knife centers. They agreed it could work, but most did not want to disrupt their usual protocols to try it.

But when they asked Georg Noren at Rhode

Island Hospital, he said, "Yeah, OK."

Meyerink and Foldes said that Noren was the rare specialist who would really listen to them and consider their views and desires. But there were other things that they liked about him. As a neurosurgeon, he was well-schooled in the structures of the brain. But unlike most neurosurgeons, he doesn't do surgery, focusing exclusively on the gamma knife. He studied in Sweden with the gamma knife's inventor, and there he had led a team that studied using the gamma knife specifically to treat acoustic neuromas. At the time Meyerink came to him, Noren had treated 850 to 900 acoustic-neuroma patients with the gamma knife.

In May 1999, at the age of 38, Meyerink underwent five treatments over five days with the gamma knife at Rhode Island Hospital. Afterward, she said, "I went on with my life. We were having Cambodian food at Apsara the next day." She emerged with no change in her hearing, and no facial weakness. The tumor is still there, but it's not growing, and in fact has shrunk to almost half its previous size.

After his success with Meyerink, Noren offered the fractionated treatments to patients with a great need for good hearing in both ears -- a horn player, a cello player, a simultaneous translator. Eventually, he started offering it to anyone who still had useful hearing in the affected ear.

He continued to have a 95 percent to 97 percent success rate in stopping tumor growth. He continued to see no cases of facial weakness. But there was one change with the fractionated treatments. With a single dose, one in four of his acoustic-neuroma patients had suffered hearing loss. With the fractionated dosing, that number went down to 10 or 15 percent, Noren said.

One patient's success story reveals little about the effectiveness of a treatment. No doubt surgeons can also point to their individual success stories. Only scientifically designed studies involving large numbers of people can provide useful information.

But Meyerink felt strongly that surgery was not for her -- and she also felt that her preferences matter. She believed doctors underplayed the hazards of surgery and wrongly steered her away from radiation because they were accustomed to doing surgery.

That's why, she said, patients must to talk to doctors and to patients; they must ask questions, and then ask more, about the pros and cons of any treatment.

"Only you know what's right for you," she said.

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