

Patient leads fight for his life

He spurs research to cure rare cancer

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In the realm of rare cancers, it's rarer still when the disease strikes someone uniquely equipped to fight it.

It happened to Josh Sommer, 19, a junior at Duke University. Diagnosed last year with chordoma, a rare bone cancer, he applied his brainpower and, with a little luck, led an international charge to find a cure.

Trying to cure your own disease would be ambitious for a trained scientist, let alone a teenager who had never taken a biology class. But against the odds, Sommer has made real progress.



He learned to do laboratory research and has personally produced new findings about genes that might play a role in chordoma, which sprouts from the skull and spinal column. He has scoured the globe for cell lines cultured from live chordoma tissues, providing a vital resource for scientists testing possible treatments. And he has become an encyclopedia of knowledge about the disease, tracking every new paper published and the scientists behind them.

Working with his mother, Dr. Simone Sommer, a physician, Josh Sommer also established the Chordoma Foundation to coordinate and speed research efforts. Just a few months later, he co-sponsored the first international research meeting on chordoma, bringing together more than 50 scientists. At the Sommers' urging, National Cancer Institute researchers studying a treatment for leukemia agreed to test it on chordoma. Work the Sommers encouraged at Duke may soon lead to new trials for drugs to treat the disease.

Now, the mother-son team wants to raise \$3 million within two years to support the foundation's work.

"It is truly amazing how much work has been done," said Dr. Neil Spector, a Duke oncologist who directs the Duke cancer center's program in experimental therapies. His lab began studying chordoma at the Sommers' request and has produced findings that suggest possible treatments.

"I've never seen anything like it," Spector said, "to have this concerted an effort in this short a time."

And time is critical for Josh Sommer. There is no cure for chordoma, and few treatments are effective. The average patient survives just seven years after diagnosis.

"I feel like I'm really under the gun," said Sommer, who has maintained a full course load and an "A" average at Duke. "You just start making things happen."

A fateful choice

Over and over, the right people and resources have come to Josh Sommer at the right time. Serendipity even seemed to play a role in his decision in 2005 to attend Duke, where he has found so many physicians and others willing to help.

Duke wasn't his first choice. A born engineer who had tinkered since early childhood, Sommer dreamed of attending M.I.T. in Boston. He was accepted there, and also had offers from Stanford and Georgia Tech.

Duke, however, was the only university that allowed freshmen to come in with student-initiated research projects. Sommer and his mother were sickened by mold in the walls of their Greensboro home, and he was bent on developing a method for measuring airborne mold toxins. He accepted Duke's offer of a four-year scholarship valued at more than \$200,000. Work on his mold project continues today in the lab of a Duke engineering professor.

By winter break of his freshman year, Sommer was plagued by incapacitating headaches. A brain scan in January 2006 revealed a growth.

"The whole world was falling apart," said Simone Sommer, who trained as a family doctor and also holds a master's degree in public health.

In spring of 2006, Josh Sommer had surgery in Pittsburgh to remove his tumor, which produced a definitive diagnosis: chordoma. Sommer spent his summer recovering and reading everything he could about his cancer.

At first, he was discouraged by what he learned. Chordoma is rare, with only about 300 cases a year diagnosed in the United States. No chemotherapy drugs are effective, survival rates are grim, and just a handful of scientists in the world were even researching the disease.

But serendipity intervened again with encouraging news. One of the recent papers on chordoma was based on research in the lab of an oncologist named Dr. Michael Kelley the only researcher in the country with a current grant to study chordoma.

His location? A five-minute bicycle ride from Sommer's dormitory on Duke's West Campus.

When Sommer returned to Duke in the fall of 2006, he contacted Kelley with an unusual request. Despite his lack of scientific training, Sommer wanted to volunteer in the Duke researcher's lab.

Under Kelley's tutelage, Sommer learned to do genetic research. He now volunteers up to 30 hours a week in Kelley's lab, either growing chordoma cells or analyzing genetic data to identify the genes active in chordoma. Similar research has led to the development of drugs such as Herceptin for breast cancer and Gleevec for leukemia.

But Sommer realized that his efforts in Kelley's lab weren't going to produce results fast enough.

So Sommer and his mother approached Dr. Neil Spector after a talk he gave at the Duke cancer center. Would he start looking at chordoma in his research lab?

Spector, who led an exploratory oncology drug division at GlaxoSmithKline before taking a similar role at Duke, had never heard of chordoma. But he quickly agreed.

"When Josh and Simone came to me," he said, "the two of them were so serious and so impressive, it was hard to say anything but yes." Spector also directs a Duke center aimed at turning scientific discoveries into treatments faster.



After just a few months, Spector's lab found that chordoma has much in common with tumors in breast, lung and colorectal cancer.

Spector said those findings could pave the way for drug trials that would test existing therapies for those more common cancers in chordoma patients.

Since his surgery, Josh Sommer has been cancer-free. But he still faces a relentless push against a relentless killer. So when he recently learned that scientists at the National Cancer Institute were working with a leukemia vaccine that targets a protein also produced by chordoma tumors, he couldn't help but ask if they'd add chordoma to their tests. Their answer, of course, was yes.