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The Shock Of Disease Leads To Foundation For Young Adults With Cancer

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Doug Ulman '99 had worked hard to get into the best shape of his life last summer. He ran, lifted weights and played soccer every day in an effort to make his sophomore season on the Brown varsity soccer team a breakthrough one. But an allergic reaction that sent him to the emergency room turned into something more serious than he would have ever imagined.

At age 19, Ulman was diagnosed with a tumor the size of a golf ball on his left side in an area bounded by his lungs, ribs and spine. Doctors advised Ulman and his parents that he could wait until after the season to have the tumor removed because 98 percent of such tumors are benign. but if he wished, they would operate.

Ulman, seriously ill for the first time in his life, found himself confused. "The doctors were talking right past me to my parents," he said. "But ultimately, because I was of legal age the decision came down to me. It was really strange. But my parents and I talked about everything."

Not wanting to postpone surgery, Ulman decided to have the tumor removed. On Aug. 14, doctors removed six inches of his seventh rib. "I just knew I couldn't go back to school knowing that I had a tumor in me," he said. Because it was late in the summer, a time when many doctors take vacation, it took several weeks and three opinions for pathologists to agree that Ulman's tumor was in fact cancerous. The diagnosis: chondrosarcoma, a rare form of cancer composed of cartilage that afflicts 300 to 500 males age 15 to 30 each year. "When I went out to find information about the disease and advice to help me with what I was going through, I couldn't find anything. I also couldn't find other people my age to talk to, because most of my friends were heading off to school. Plus, when you are my age, you're not sure how much you should tell your friends and how much they would understand," he said.

Still coping with the pain of surgery, Ulman returned to campus not only concerned that he would never play soccer again, but that his life was in danger - an overwhelming prospect for someone who had spent the majority of his life strengthening and conditioning his body to operate at its limits. Three oncologists from the Sloan Kettering Institute in New York City, Mayo Clinic in Rochester, Minn., and University of Maryland debated whether Ulman should receive further treatment, yet gave Ulman little information or attention. "When I went to New York, I met with the doctor for maybe five minutes," he said.

Finally, Dr. Alan Levine, a Brown alumnus on the staff of the University of Maryland, sat the Ulmans down for a talk. "He was the first doctor who actually talked to us," said Ulman. "He laid everything out for us. After that, we sat down as a family and decided on

a course of action." The Ulmans took Levine's advice to do nothing radical, such as removing a portion of his spine and replacing it with a metal rod as one doctor proposed. Instead, they opted for Doug to undergo periodic CAT scans, bone scans and X-rays. As of a month ago, he was free of chondrosarcoma.

Ulman returned to practice in September. A month later he was on the field, playing in a match at Loyola of Maryland, a short drive from his home in Columbia, Md. "It was probably the most emotional game of my life," said Ulman. "The doctors had told me that I might never play soccer again. So to be able to step back on that field was just incredible, particularly in front of a lot of my family and friends." Ulman acquitted himself well in his 25 minutes of play from his defender's position. But he had undergone so much and come so far that he had nothing left in him. He decided shortly after to hang up his boots for the season. "Mentally I was just so drained that I couldn't give anymore," he said. "I knew I had reached one of my goals by getting back on the field. It was time for me to take a rest."

After taking a break, Ulman soon launched himself into something potentially more draining for a 20-year-old college student: starting a foundation. After seeing an ABC "Prime Time Live" segment on cancer that featured cancer survivor Sam Donaldson describing the need for more support for cancer research and services for cancer patients, Ulman decided he needed to take action. "I called my parents and said we should do something," Ulman said. "They agreed that we knew enough people and had enough relatives that we could start a small foundation to help educate young adults with cancer, and those people my age who had relatives with cancer." He and his parents created the Ulman Foundation, a non-profit organization that provides support services for cancer patients and their families. "There are no support groups for young adults with cancer," said Ulman. "There is plenty of information for children and older adults with cancer. But there is little, if any, for young adults struggling with cancer. We want to fill that void."

As part of an independent study at Brown, Ulman has designed several pamphlets that deal with some of the issues facing young adults with cancer. He hopes to have the pamphlets distributed nationwide. Ulman is also creating a web site dedicated to young adults and cancer. Ever the ambitious Brown student, he is also writing a book that not only details his own experiences with cancer, but those of other young adults with cancer. "I am trying to include information that I wish I was told, like how to deal with fear and anger; the right avenues for information about different forms of cancer and their treatment; how to deal with the medical and insurance establishment," he said. "I was lucky that my family really came together like it did. Cancer doesn't just strike individuals, it strikes families." To kick off the foundation and raise funds, the Ulmans have planned a dinner at the Pimlico Race Course on June 21. There also will be a collegiate all-star soccer game in Maryland on Aug. 1. "I spend three to four hours a day on the phone organizing things and trying to raise money. Everybody wants to help; it is just a matter of speaking with them," said Ulman, who has enlisted the help of Donaldson at ABC. When the United States national soccer team trained at Brown two weeks ago, Ulman wasn't shy about contacting several of the players about the foundation. the

national team and several players have donated signed soccer balls and jerseys to be raffled during at he all-star soccer games.

Ulman's life has been dramatically altered since that day in August when he first went the hospital. He looks healthy, which makes it difficult to explain to others "that there was something seriously wrong with me. they see me playing soccer or walking around and they can't understand why when I first came back to campus I needed someone to carry my books," he said. "It took me a while to find others who understood." He has returned to practicing with the varsity soccer team, and recently participated in spring drills and a doubleheader against UI. "It felt good to be back out there, but I am still a long ways away from where I was before I became sick," he said. "But, you know, soccer is not as important as it once was for me." Lest Ulman forget the fragility of life, he recently received a reminder. Last week, he traveled home to Maryland to have tissue removed from his chest. That tissue was found to be cancerous. The latest cancer is unrelated to his previous illness.