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What About CUP Patients?

BY KATY HUMAN

Cancer of unknown primary isn't exactly rare—an analysis of National Cancer Institute data shows that more than 30,000 new cases are diagnosed annually in the United States, about the same as for pancreatic cancer. But unknown primary cancers are neither well-known nor well understood, which can be frustrating for patients seeking information and support.

It can be disorienting to have cancer yet not belong to a group supported by an annual 5K or other fundraiser. “It’s just bizarre,” says Lori Young, 39, from New Market, Alabama, who was diagnosed two years ago with cancer of unknown primary (CUP). “You can’t just say, ‘Oh, it’s breast cancer, it’s colon cancer. You have to instead go through this whole process of explaining, ‘It’s in my liver, but it’s not liver cancer. They don’t know where it came from’ People just look at you like you’re making it up.”

Young, who is undergoing a second round of chemotherapy, couldn’t find an in-person support group focused on CUP. “Online turned out to be my best resource, finding other people on blogs and cancer sites,” she says. It can be a relief to talk with someone who “understands the language. It helps to not feel like you’re speaking a foreign language.”

Byron Holstine, Jr., 37, who lives in Thornton, Colorado, says he also turned to the Internet for information from the National Cancer Institute (www.cancer.gov), the American Cancer Society (www.cancer.org), and others such as Cancer.net. Support and information are also available through Jo’s Friends (www.cupfoundjo.org), a nonprofit started by a man in England who lost his wife to CUP.

Holstine was diagnosed with CUP in 2004, after four brain surgeries to remove what his doctors assumed was a benign pituitary tumor that kept growing back. Eventually, radiation knocked back the tumor in his brain, but now Holstine is fighting off unidentified metastases scattered around his chest wall. He’s been through bouts of radiation, chemotherapy, more surgeries—and a divorce in the middle.

“For me, some friends have been my support group, and my parents, my mom

especially,” Holstine says. For more support, he carefully follows news about promising cancer treatments. “I know there are some phenomenal things coming to a head now in terms of treatment. You focus on that, and you focus on saying, ‘This is not a death sentence.’ ”