Sierra trek a step in fight against rare cancer

By Jacqueline Baylon
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Hiking all 211 miles of the John Muir Trail from Yosemite to the summit of Mount Whitney is a challenge for any hiker. For Annette De Bow, the difficulty is multiplied.

De Bow, 44, has a rare, chronic blood disease called polycythemia vera, which means her bone marrow makes too many red blood cells that can set off a domino effect of health troubles if not kept in check.

In an effort to raise awareness of her disease – and money for research into polycythemia vera – De Bow will set out Friday on a “Trek for a Cure” along the John Muir Trail.

“After realizing how rare this disease is and realizing the money is not going into this specific cancer,” De Bow said, “I decided to do something.”

Because of her excessive red blood cells, De Bow’s blood is thicker than normal, which means it moves slower than it should through veins and arteries. Ultimately, that can put her at greater risk of blood clots, which can cause stroke, heart attack, blockage of an artery in her lungs or other complications.

While polycythemia vera can’t be cured, it can be treated, and patients can live with it for years.

De Bow takes a light-chemotherapy pill daily and undergoes regular phlebotomies to withdraw blood from her system and reduce the potential for clotting.

Higher altitudes can thicken the blood of any hiker, but De Bow’s condition makes this side effect more problematic. So she’s scheduled one more phlebotomy before she leaves.

During the hike, De Bow said, she’ll just hope for the best.

De Bow learned of her disease in January 2007, six months after giving birth to daughter Evan Lancet.

Two years after her diagnosis, she said, she felt she needed to act. She enjoys hiking, has always dreamed of tackling the John Muir Trail and

Bob Rosen, founder of the Chicago-based MPD Foundation said the organization has awarded about $8 million for research of myeloproliferative disorders.

“We are blessed with wonderful people who are just willing to help,” he said.

Rosen started the foundation 10 years ago, three years after he was diagnosed with polycythemia vera.

“Although these diseases are malignant, if treated properly, people can live with it for years,” said Dr. Jason Gotlib, De Bow’s doctor at Stanford University Medical Center.

There are three kinds of myeloproliferative disorders: polycythemia vera, primary myelofibrosis and essential thrombocytethia.

All three are highly uncommon. A 2003 study by the Yale University School of Medicine found 65,243 patients with polycythemia vera and 71,078 patients with essential thrombocythemia in the entire United States.

“This is a family of diseases in which the bone marrow is afflicted by a type of chronic leukemia that causes the bone marrow to make more cells than it should,” Gotlib said.

De Bow’s 211-mile hike will be divided into about eight segments, during which she will get supplies and be joined by new companion hikers. Twenty people will join her for segments of the journey.

Audrey Hicks, 46, from Boisseвин, Canada, will hike with De Bow during the third segment of the trek, and they will cover about 30 miles from Devil’s Postpile to Vermillion Valley.

Hicks was diagnosed with polycythemia vera three years ago. She said that when she read that De Bow was seeking hikers to join her on the trail, she didn't think twice.

“This is about kicking this thing in the butt,” Hicks said. “This is something we can live with.”

For more information on De Bow’s trek, go to www.trekforacure.com.

Call The Bee’s Jacqueline Baylon, (916) 321-1036.

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To view an online video with Annette De Bow by The Bee’s Jacqueline Baylon, go to videos.sacbee.com