

La Pine teen's rare disease has family struggling

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Blood disorder requires transfusions - bone marrow match the key

By Victoria Adelus, KTVZ.COM

A 16-year-old La Pine girl has a very rare disease that only affects a small percentage of the worldwide population.

It's called diamond blackfan anemia, and doctors say it can only be cured by a bone marrow transplant.

Esther Knight has been dealing with the disorder for the last nine months.

Since she was diagnosed, her family has been struggling trying to pay for her medical bills.

They recently turned to the Bend-based Sparrow Clubs for help but say it's going to take a community effort to save their daughter.

Esther has dreams like any other child her age.

"I was looking forward to being 16 and driving and getting a job," she said Tuesday. "I also play sports and I had to give that up.

February's diagnosis was a shock to the teen and her family. The disorder is typically diagnosed at birth and only affects a small portion of the world's population.

"Why do we have this?" her mother, Eilene, said of the initial question. "And then we found out 700 in the world have this, so that means one out of 10 million get it."

The family is focusing on a cure, and for Esther, that means she needs a bone marrow transplant.

They turned to the 11 million donors of the National Bone Marrow Registry.

"They tried the registry, but couldn't find a match," her mother said. "Then they upped the steroids, but it gave her migraines - watching my daughter not be able to walk."

Esther has to get blood transfusions four times a month and gets weekly blood tests.

"I have to keep doing transfusions until I find a donor," she said.

Her mother says it's been tough to stay motivated.

"I can't describe it - it's very, very hard," she said. "In the first part, I would cry and run out of the room crying, and my daughter would look at me and say, 'Mom, you can't do that. You have to be strong for me.'"



La Pine teen Esther Knight's rare disease has been challenging to her family - as have the mounting expenses

Times are tough for the Knights.

"Financially, it's unbelievable," Eileen says. "I mean, I have times when I don't have enough food."

"I even had a court order (delivery person) come to my door and hand it to my daughter to make her sign for it, because they are going after us because we can't pay."

Nevertheless, Esther, snuggling the family dog, said she's thankful to have support around her.

"My animals, and my mom has been there for me through every transfusion, sitting right there," she said. "Amy my friends, they've been a big comfort."

Esther's parents say they are worried what will happen to their daughter if they don't get help.

"We may lose her," her mother said. "My husband and I have dealt with that. We've cried."

"She doesn't complain, but I see it all in her face - the suffering, suffering, waiting to get well again."

The Knights say they already owe about \$4,000 in medical bills, and are trying to figure out how to pay for a trip to Portland, so she can undergo another procedure.

The family recently became a part of Sparrow Clubs (www.sparrowclubs.org), which will help the family pay part of their medical bills.

Anyone who wants to help can contact the organization to donate. Contributions also can be made to the Esther Knight account at any branch of U.S. Bank.