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The Journal News - White Plains, N.Y.

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HARRISON -- For some, the end of January means the end of voting for a very important and personal cause.

Those involved with Canavan disease -- a rare genetic neurological disorder -- have been flooding the national Pepsi Refresh Project with support in an attempt to win \$250,000 for Jacob's Cure.

The nonprofit organization was founded by Jordana Holovach of Harrison to save her son, Jacob, who was diagnosed with Canavan disease when he was 6 months old. Like other Canavan patients, Jacob has been trapped in his body, unable to move or speak, and prone to seizures.

Holovach's group will not get the money. As of Monday afternoon, they were in 22nd place out of several hundred charities vying for that amount -- a strong showing, but too many votes to overcome with just hours to go.

Sarah Goshman, the assistant director of Jacob's Cure and driving force behind its application to the Pepsi Refresh Program, said she and the organization are not discouraged. "We're glad we had the opportunity to participate," she said.

Had they won, the \$250,000 would have partially gone toward a clinical trial. That process -- which involves injecting stem cells into the brains of Canavan patients -- will still move forward, just a few months later.

"We'll still see the beginning of that trial in the next few years," Goshman said. "We're still really excited about the research."

The rest of the money would have gone to a convention for Canavan families this summer. Goshman said they'll look at other ways to fund that now because connecting the families is such an important part of tackling this rare and often deadly disease.

Even though Jacob's Cure came up short, Goshman said, the Pepsi Refresh Program was very helpful in growing awareness for the cause.

"We've created a lot of local partners," she said. "We've seen our Facebook friends jump by almost 1,000."

The contest, which is controversial because of bigger charities' ability to stuff the cyber-ballots, will go through some changes as it starts its second year. Pepsi will eliminate its health, environment and \$250,000 categories as it focuses on awarding smaller donations.

"It was incredibly disappointing to hear of the changes Pepsi will be making in terms of causes that will be allowed in the future," Holovach said. "Rare diseases like Canavan always struggle to access funding that bigger causes seem to always have access to."

The remaining categories will still be voted on monthly with results updated online in real time.

The Sharing Shelf of Family Services of Westchester was also among the local groups to participate in January. The charity sought \$25,000 in an effort to distribute new and gently used clothes and supplies to kids in need, but was in 185th place Monday afternoon.

On the web

To learn more about Canavan disease or to contribute, visit jacobscore.org.

Read more about Harrison on the Sound Shore blog at <http://soundshore.lohudblogs.com>.






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Abstract (Document Summary)

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