

# Wave of Hope to raise funds for disorder research

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THE COAST STAR

**AVON-BY-THE-SEA** — The only thing one father from Avon-by-the-Sea would like to come from a benefit held for his two daughters, is the awareness of their rare disease and donations to benefit research in finding a cure.

Jesse Le Vine, along with his family, of Avon, will be hosting the first annual Wave of Hope Holiday benefit next Thursday, Dec. 29 in order to raise awareness for Succinic Semialdehyde Dehydrogenase Deficiency [SSADH] — a disease that two of his daughters suffer from.

Amber, 22, and Haley, 20, were both diagnosed with the rare, metabolic disorder when they were toddlers, according to their father.

Finding that answer, he said, was not that easy.

"It took seven years and five major hospitals to identify," Mr. Le Vine said, noting one doctor even told the family the girls were suffering from a fatal disease.

The Le Vine's soon found themselves alone in the struggle to cope with the disorder, as the two sisters were identified as just the fifth and sixth patients diagnosed with the disease in the United States, according to Mr. Le Vine.

Since their diagnosis in

1996, approximately 350 people worldwide have been diagnosed with SSADH, Mr. Le Vine said.

People with the disorder have different reactions, from epilepsy to growth problems.

For the Le Vine sisters, growth and motor skills have been an issue, as well as walking and moving.

The girls also suffer from memory issues.

"The other thing that is really big is memory for them, both short and long term memory," Mr. Le Vine said.

Sometimes, the girls will forget something from earlier in the day, however, can remember a moment from five years ago, according to Mr. Le Vine.

The disorder has not stopped the girls from learning.

Both of the sisters attended Hawkswood School, in Eatontown — formerly School for Children — where they were able to learn at their own pace. Haley is slated to graduate in 2013, while Amber recently graduated.

Because their disorder is rare, few people have heard of it, according to Mr. Le Vine. The lack of awareness brings a lack of funding for research and potential drugs that could help lessen the girl's reactions.



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Amber, 22, and Haley, 20, Le Vine, of Avon, were diagnosed with the rare disorder Succinic Semialdehyde Dehydrogenase Deficiency. The Le Vine's will be hosting a benefit on Thursday, Dec. 29 to raise money for research for the disorder.

"The public awareness is not there," Mr. Le Vine said.

The Le Vine family decided to matters into their own hands and through a benefit to raise awareness and funding for research.

"We felt other people have done stuff, so now it is our turn to raise money," Mr. Le Vine said. "I'm trying to push this thing in a national way that is has never been before."

The Le Vine will host the Wave of Hope Holiday benefit from 7-11 p.m. at The Headliner, in Neptune.

Entertainment will be provided by The Pat Roddy Band and Paul Cilinski.

The event will also feature special drink prices and light fare by McLoone's and The

Atlantic Club. Cost per ticket is \$25 and can be purchased at The Headliner, The Atlantic Club, or through the family.

All donations will go to the Pediatric Neurotransmitter Disease Association [PND], to help find a cure for SSADH.

The PND association is a disease organization representing children and families who are affected by a pediatric neurotransmitter disease, according to the association's website [www.pndasoc.org](http://www.pndasoc.org).

For additional information regarding the fundraiser, contact Jesse Le Vine at [wavehawker@gmail.com](mailto:wavehawker@gmail.com) or visit [www.waveofhope-ssadh.org](http://www.waveofhope-ssadh.org).