Parents of Leeds toddler with rare condition thank public as USA drug trial continues

Zoe Lightfoot with parents Christine and Steven.

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Email

Published: 21:18 Friday 11 January 2019

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The parents of a Leeds toddler have thanked the public for helping towards treatment for their daughter who suffers from a rare and potentially fatal condition.

Zoe Lightfoot, aged three, has infantile neuroaxonal dystrophy (INAD), which usually means an affected child dies between the ages of five and 10.

Zoe Lightfoot, aged three at home in Bramley.

Since the diagnosis in April last year, Zoe has lost mobility and her speech – but the family has twice been to America since December as part of a drugs trial which they hope will curb her decline.

The toddler was one of only 15 children worldwide picked for the trial and since launching a fundraising effort, parents Christine Hamshere and Steven Lightfoot have seen people donate more than £22,000 towards treatment with the company Retrotepe’s drug in New Jersey.

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Christine, of Bramley, said: “There are some lovely people out there that deserve to know what’s happened and need to be thanked for their support because we have survived off that, really.”

The family first travelled to the USA in December and went back again this month, returning on yesterday.

“Zoe struggled when we went this time with the time difference and she didn’t really settle into American time, and none of us really got any sleep,” Christine said.

“I think she’s happy to be home.”

Zoe is taking two capsules of the drug – a type of fatty acid – each day, which will increase to three doses after 30 days.

“To give it to her we have to extract the liquid from the capsule and put it in her food and make sure it’s thick enough to swallow, because she has difficulties swallowing thin liquids,” said Christine.

The family, who attended the Goryeb Children’s Hospital in Morristown, New Jersey, will need to go to America again in six months for another half-a-year’s supply of the drug, and then again in January 2020.

In three months, blood tests will also need to be sent to America.

But Christine admitted: “In the long-term, we don’t really know where this is going.”

According to the Great Ormond Street Hospital, which specialises in care for children, INAD is a rare inherited disorder affecting the nerve axons which are responsible for conducting messages in the brain and other parts of the body.

It causes a progressive loss of vision and of physical and mental skills.

Christine said: “We’ve been blown away by the amount of support from everybody.

"We’re really grateful for it. It’s meant that we can make these trips and [pay for] hotels and travel, everything.”

To read more about Zoe’s trial, visit https://www.gofundme.com/zoes-inad-battle-fund