



The power of words

Leo And The Lightning Dragons is a delightful tale that will captivate young readers. **Nora McElhone** found out more about its author and the very special little boy who inspired the story

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Gill White and husband Andrew's lives were turned upside down more than those of most new parents when their son Leo arrived in 2015. After a straightforward pregnancy and delivery, Leo was rushed to intensive care at birth, at the beginning of what has been a difficult journey for the family.

"Leo suffers from Ohtahara Syndrome," explains Gill. "It's a rare and nasty form of epilepsy, characterized by intractable seizures and severe developmental delay." More than 50% of children with Ohtahara Syndrome pass away before the age of two, usually as the result of a chest infection.

Now aged three, Leo has defied those odds so far, "but every day is hard work for him, his seizures remain uncontrolled and he has had between 20 and 180 a day. He is on oxygen permanently and has a feeding tube and needs round-the-clock care, but we are fortunate to have nurses who come in three nights a week to help – without them we'd be really stuck," she says.

Leo And The Lightning Dragons is a story that Gill created when the family were going through a particularly difficult time. "I wrote the book before Leo's first birthday. He was having around 170 seizures a day, he was in pain and medication wasn't working. We were becoming very aware of just

how difficult his life was going to be and it seemed so unfair. He was fighting so hard every day – he still does – but, ultimately, his condition can't be cured and I thought he deserved a much happier end to his story, given how brave he is. So I wrote one for him, in which he gets to be the hero and all his strength and determination is rewarded."

When Gill completed the story she approached Fine artist Gilli B to bring her words to life. "I originally commissioned her to do a few illustrations but she loved the story so much she asked to

of publication hadn't entered my head. "I am blown away by the reviews," she says. "We have also had reviews from parents of children with epilepsy, saying how moved their children have been reading the story when they recognise themselves in the pages. I'm so glad that such a positive thing can come from Leo's situation – that he can help another child cope with something unpleasant they're dealing with."

The proceeds from Gill and Leo's book will go to support Chas, which she calls "an incredible organisation", adding: "Rachel House have looked after us since Leo was two months old. We have had quite a few scares with him over the past three years and Chas have been there to support us through each one. I hate to think what our lives would be like without them."

Over the coming months, Gill and Gilli B will bring their book to local children through library appearances, visits to bookshops and workshops. Leo And The Lightning Dragons has been transformed into a multi-sensory story, which Gill will take to a number of festivals thanks to funding from Parnis, which supports people with profound and multiple learning difficulties.

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illustrate the whole thing and Leo got his own 'book' for his birthday!"

Anyone reading Leo And The Lightning Dragons will be amazed that its author had never penned a story before. "I actually surprised myself quite a bit with this!" Gill admits. "It flowed really easily but I think that was because I was drawing on our experiences and it was so personal. I also didn't have any pressure, as the story was only intended as a gift for Leo, certainly the thought



Visit www.leoandthelightingdragons.com for further details.