

NEWS

# Leo's the hero of his very own

When Gill White penned a story to celebrate her son's incredible fight for life in his first 12 months, she had no idea it would end up being published

FEATURE

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**A** Fife mum was so inspired by her son's fight with a rare form of epilepsy that she has made him the star of his own children's book.

Just three days after he was born in September 2015, doctors switched off Leo White's ventilator and told first-time parents Gill and Andrew to say goodbye.

But Leo was determined to live and defied the odds by taking his first unsupported breath shortly afterwards.

He's been fighting ever since but it's not been easy.

At ten weeks old, Leo was diagnosed with Ohtahara Syndrome - an extremely rare form of epilepsy

which causes seizures and developmental delays.

Leo can suffer up to 180 seizures a day, he's on oxygen permanently, has a feeding tube and regularly needs suction to clear his airway.

The family feared his first Christmas would be his last, due to the recently diagnosed seizures.

His breathing had deteriorated and he was transferred from Victoria Hospital in Kirkcaldy to Rachel House in Kinross.

But Leo had other plans and, once again, fought back.

As he approached his first birthday, Gill was inspired to write a story for him.

She said: "He was having so many seizures and the medication wasn't working.

"Leo was fighting so hard every day and it just seemed so unfair.

"I wanted to write him a story in which he was the hero; he deserved that title.

"I always made up wee rhymes for him because, while he didn't understand words, rhymes seemed to soothe him."

So Leo and the Lightning Dragons was born.

Gill read it to Andrew and he loved it, so much so that he encouraged her to get it framed for Leo's first birthday.

Hoping to have a poster created for her son's room, Gill contacted Fife illustrator Gilli B - and she too fell in love with Leo's birthday present.

Gill said: "I wanted to get someone in Fife to do it so that I could meet them and have a chat to them about it.

"I found Gilli B online; her work was so innocent and whimsical. It was perfect.

"We got on like a house on fire and she fell in love with the story and asked if she could illustrate it to create

a book for Leo's birthday instead of a poster.

"So that's what she did. It was only ever meant to be a special gift for Leo though."

However, during one of the family's regular visits to Rachel House, Gill packed the book for staff to read to him. When Gill and Andrew returned to pick Leo up, she had won her first rave reviews.

Gill said: "They had all written lovely comments inside saying how much they loved it.

"They thought it was wonderful and nagged me to try to get it published."

Luckily, Gill and Andrew, who ran their own financial advisory business before Leo was born, knew author Peter Burnett - the husband of one of their colleagues.

Gill contacted him to get some advice and found another fan.

She said: "Peter knew someone at Fledgling Press and took it to them, although he warned me that they didn't usually publish children's books.

"But they fell in love with it too and were really keen to publish it."

Leo and the Lightning Dragons was published last Wednesday and a launch event will be held at Waterstones in Edinburgh's Ocean Terminal this Saturday, from 11am to noon.

Gill said: "I'm so excited; I can't believe the book is being launched at Waterstones and we've got a really fun event planned."

The in-house musician at Rachel House, Rachel Drury, has created a minstrel song for the book and will be performing it at the launch.

"I'll be reading the book and we'll have arts and crafts for the wee ones and Bucks Fizz for the adults."

"I can't believe Leo's birthday present is going to help other children."

At the heart of the story is a lesson that Leo has taught his own parents.

Gill explained: "The book encourages children to persevere and find strength in the face of adversity, even when it seems like nothing is working."

Half of children with Leo's condition do not survive past two years old.

Leo is now aged three and still defying the odds but his parents know his story may not have a fairytale ending.

Gill added: "You are always taught that if you fight and fight you can overcome anything.

"Leo is doing that but ultimately his condition can't be cured.

"He deserves a much happier ending story so I wrote him one that we can always treasure."



# book and deserves that title



Defying the odds...Leo celebrating his third birthday with his proud parents Andrew and Gill. Inset: Book in Waterstones; Gill and Gilli B and a family outing.



## Praise for NHS and CHAS

Gill and Andrew White have nothing but praise for the NHS team at Victoria Hospital in Kirkcaldy and the community team who stay at their St Andrews home three nights a week to let them get a rest.

Gill said: "We take it in shifts to look after Leo during the night as he has sleep apnea and needs round the clock care.

"We don't know what we would do without them - we'd be really stuck - so we can't praise them enough."

The family also has the support of the CHAS at Home service, run by Rachel House, which offers respite during the day so they can spend time together as a couple, away from their caring roles.

The couple met in 2001, married in 2003 and worked together for 16 years in Andrew's financial advisory firm so, luckily, were used to working as a team and spending a lot of time together.

Gill said: "CHAS has been

amazing, allowing us to spend time as a couple to remember who we are, away from being Leo's parents.

"We also go to Rachel House regularly and they work with the hospital to try to balance things to keep Leo at home as much as possible. He has an incredible team.

"Leo has a difficult time of it but we recently celebrated one year with no hospital stays.

"We are in and out quite a lot but part of the reason we can stay at home is because we have so much support."

Gill is now working with Pamis, a charity which promotes a more inclusive society, to turn Leo's book into a sensory story. She added: "I've been working with Maureen Phillip so that those with learning difficulties can enjoy the book through touch, smell and sound.

"It should be launched next month and will be toured around schools and children's book festivals."

