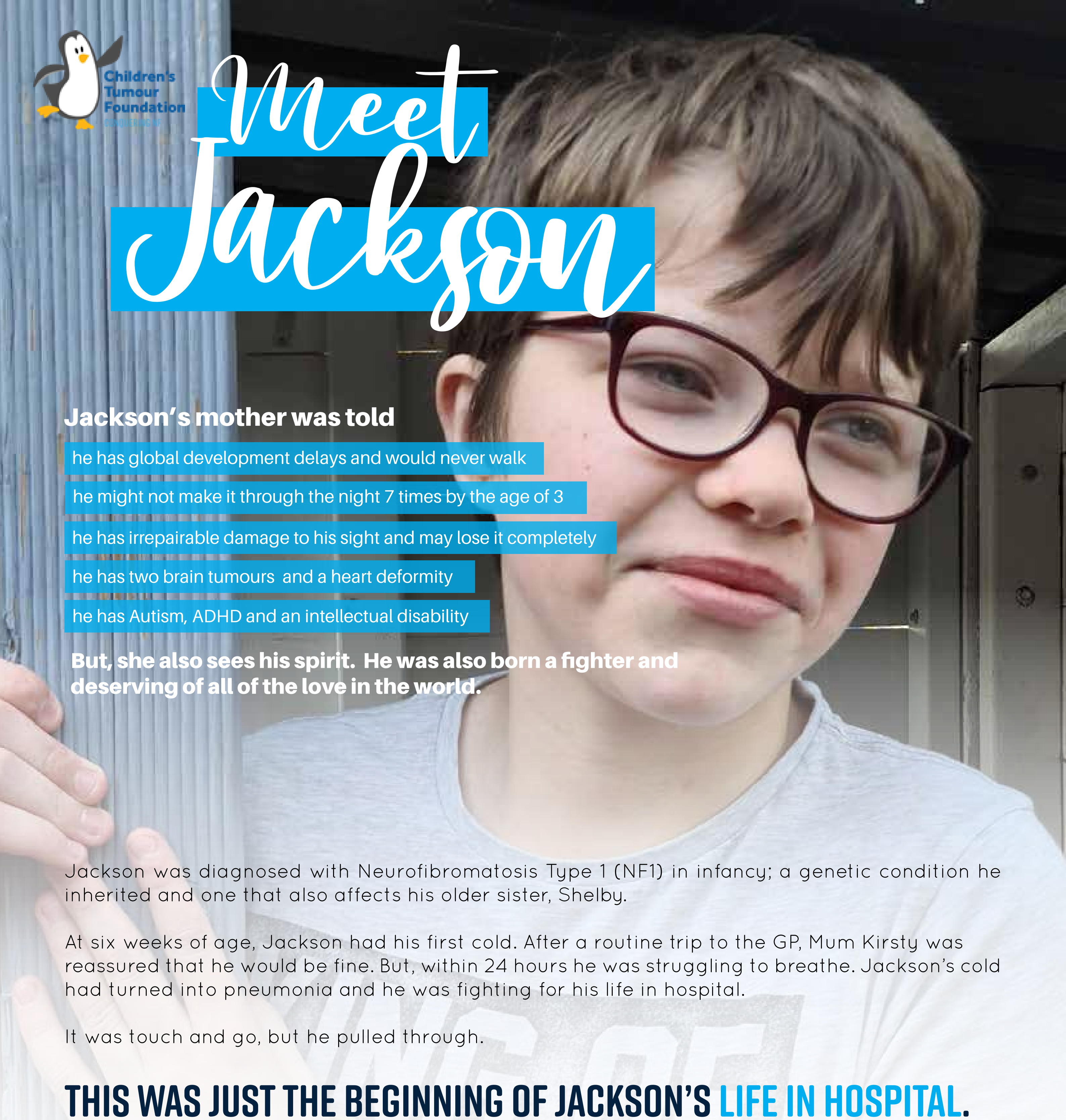
Children's Tumour Foundation



Meet Jackson

Jackson's mother was told

- he has global development delays and would never walk
- he might not make it through the night 7 times by the age of 3
- he has irrepairable damage to his sight and may lose it completely
- he has two brain tumours and a heart deformity
- he has Autism, ADHD and an intellectual disability

But, she also sees his spirit. He was also born a fighter and deserving of all of the love in the world.

Jackson was diagnosed with Neurofibromatosis Type 1 (NF1) in infancy; a genetic condition he inherited and one that also affects his older sister, Shelby.

At six weeks of age, Jackson had his first cold. After a routine trip to the GP, Mum Kirsty was reassured that he would be fine. But, within 24 hours he was struggling to breathe. Jackson's cold had turned into pneumonia and he was fighting for his life in hospital.

It was touch and go, but he pulled through.

THIS WAS JUST THE BEGINNING OF JACKSON'S LIFE IN HOSPITAL.

By the time he was one, Jackson still wasn't walking, crawling or even sitting up. His Mum, Kirsty was told he was just a bit behind in his development, but after lots of physio appointments, a specialist even questioned whether he would walk at all.

But Kirsty was determined to do everything in her power to get Jackson up and walking.

Each day she would do a little physio with him until he started to move on his own. She spent hours and hours on the floor with him; moving his arms and legs to encourage him to roll over.

Jackson took his very first steps at 18 months and proved his doctors wrong. Today he runs just about everywhere.

FOR THE FIRST THREE YEARS, JACKSON SPENT COUNTLESS NIGHTS IN HOSPITAL. BUT THERE WERE NO ANSWERS AS TO WHY HE WAS GETTING SO SICK.

While other Mothers were celebrating their children's milestones, Kirsty was learning to read Jackson's cues.

She could tell when he was starting to get sick when he started to use the wrong muscles to breathe, and she knew the exact moment it was time to get him to hospital.

By chance, one doctor noticed an abnormality in his breathing and sent him off for some tests. They discovered a leaky valve in his one of his lungs which was causing him to aspirate.

This meant anytime he ate or drank, there was the potential for some of the fluid to enter his lungs, and the cause of his continuous infections.

Surgery was on the agenda, but thankfully simply thickening Jackson's fluids and sitting him upright was all that was needed and he simply grew out of it.

When Jackson was three, a passing comment was made to their GP that he had "chameleon eyes". He was immediately sent to an Ophthalmologist who reassured them that everything would be fine, but ordered an MRI to be on the safe side.

> *I went into the appointment feeling positive. It was only precautionary, and it was unlikely they were going to find anything. That was the first and last time I ever walked into an appointment to get results with such a positive outlook," said Kirsty.*

When Jackson was three, a passing comment The MRI results showed a thickening of the optic nerve and confirmed that a tumour had started growing.

Thankfully, he would not require chemotherapy at this stage, but did have surgery on his eyesto straighten them.

But, in the same year he was rushed back to hospital after suffering a violent seizure. His family watching on helplessly as they wheeled in a crash cart.

Not long after, Jackson was rushed to hospital again struggling to breathe. As they pulled him out of the car, he stopped breathing all together.

The hospital became their second home.

At just three years old, Jackson had fought for his life seven times.

By this time, Jackson had also added:

- **Autism Spectrum Disorder**
- **ADHD**
- **Sensory Processing Disorder**
- **Global developmental delay**
- **Chronic asthma; and**
- **Scoliosis to his growing list of health issues.**

As Jackson reached the age of 9, he had started running into things and was mistaking objects.

An MRI revealed a brain tumour; an optic glioma in the middle of his brain (chiasm) that would require constant monitoring.

If the brain tumour grew or changed in any way, he would require immediate chemotherapy. However, chemo has only limited success in shrinking these types of tumours.

If at any point a biopsy was required, this would involve cutting into his scull from ear to ear and lifting his brain out to take a sample from underneath.

He risks complete blindess or worse in every scenario.

RESEARCH IS KEY TO FINDING MORE EFFECTIVE TREATMENTS FOR KIDS LIKE JACKSON.

In 2017, Jackson's previously mild scoliosis was upgraded to moderate. His spine is now at a 38-degree curvature and twisted the wrong way. It is likely he will require surgery to place rods in his spine to straighten it.

Jackson also has a heart deformity that increases his risk of having a heart attack or stroke. At some stage, he'll also require surgery for this.

Earlier this year, Jackson received the news that he has yet another tumour that is enhanced on his right optic nerve; meaning he now has two optic nerve gliomas that are being monitored on that side.

In October, the potential benefits of chemotherapy seemed to outweigh the risks of doing nothing. It is a decision Jackson's oncologist will need to make soon, despite evidence that it is has only limited success.

> *“Words cannot express how I feel. Our journey is far from over. In fact, we are just starting a new chapter of unknowns, the biggest unknown is I do not know how long I will have my baby for.”*

On top of all this, Jackson also has an intellectual disability, which means cognitively, he probably won't develop much further than a five-year-old. He struggles to make friends and is constantly picked on at school because he just doesn't understand.

He tries to befriend kids of his own mental age (5), but to them, Jackson seems big and scary. He is about to transition into high school which presents another set of challenges as his peers start to develop into adulthood.

> *“Jackson has a huge heart and so much love to give, but he is often misunderstood, and feels alone and isolated. A Mum's hug only goes so far and recently it hasn't been enough for him”.*