



# Everyday Super

Childhood cancer is one of the toughest challenges a family can face, bringing stress, uncertainty and painful treatment. **Susan Horsburgh** meets three courageous families and the team behind the Koala Kids Foundation, who keep little smiles coming, even on the hardest days.



Inspiring kids

# heroes



## Inspiring kids

**F**or Anna Surace, the grenade landed in her family's life one long year ago. Her then-17-month-old son, Orlando, was playing in the family kitchen on a warm January morning in 2018 when he seemed to zone out, staring into space. Anna tried to snap him out of it – and then the drooling and shaking began, his tiny hands curled into tight fists.

Panic-stricken, Anna called an ambulance as her two terrified daughters looked on, but even after the paramedics arrived, Orlando's seizures kept coming. With sirens wailing, Anna and her son sped from their Sydenham, Victoria home to Melbourne's Royal Children's Hospital, where doctors put the toddler into an induced coma to stop the convulsions.

"I can clearly remember it," says Anna. "A whole team of people around him and I just had to stand back and watch. I felt powerless. And not only did I have the worry of Orlando, I had two little girls who'd just witnessed their brother on the floor having a seizure. All I was thinking was, how am I going to fix all my children? How do I fix this?"

The next day, an MRI revealed a 10mm growth in Orlando's brain. After a week of tests, the toddler was sent home with medication to control the fits and a follow-up MRI booked. When that appointment rolled around, Anna was already anxious, but when the scan seemed to be taking too long, she knew something was wrong.

Eventually she and her partner, truck driver John Gulizia, were taken into a room and told their son had a tumour in his brain the size of a peach. Orlando needed surgery straight away.

"My whole world fell apart," recalls Anna. "You know how people say, 'My blood ran cold'? I never understood that saying until that day. I felt like I was crumbling."

A week later, Orlando was wheeled into surgery for a nine-hour brain operation and Anna sat outside the theatre for every second. "Your heart's pounding, you can't sit still," she says. "Finally, he was out and one of the nurses said Orlando was fine. I'd held everything in and the minute I knew he was okay, I could not stop crying."

When the surgeon said they'd removed the growth, Anna thought the ordeal was over, but five days later came the diagnosis: Orlando had a rare, aggressive brain cancer called a supratentorial primitive neuroectodermal tumour (PNET). "When I heard the word 'cancer', I'm pretty sure my body went into shock because I wasn't cold but I was shivering," says Anna. "I just couldn't speak any more. The surgeon said, 'Be ready for a marathon. This is not going to be a sprint.'"

Speak to parents of children with cancer and it's an oft-used analogy. Fighting the disease is an endurance test that stretches a family to its limits – physically, emotionally and financially.

One parent has to stay in hospital with the sick child, so it splits the family apart. Anna's daughters, six-year-old Zaria and Aurora, three, had to live with their grandmother and could only visit their brother when he was well enough. "Leaving the hospital," says Anna, "they'd be screaming and crying, 'Mum, why can't you come home?'"

Orlando spent 33 nights straight in hospital, with his mother sleeping beside him as he battled the brutal effects of chemotherapy. Three months into treatment, his bone marrow was so damaged and his little body so weak that doctors had to stop after only four of the recommended six rounds of chemo.

"It was like he was wondering, what are you doing to me?" says Anna. "When he could physically get up, all he'd want to do was play, but many days he'd be just lying on that hospital bed and I'd be sitting beside him in a dark room. He'd

look at you in a daze with no energy to smile or eat. To see your child go through that and not be able to do anything was so hard."

On the darkest days, a visit from the ward's Koala Kids volunteer was priceless. They'd pop in with a surprise: a colouring book and pencils, perhaps, or a bottle of bubbles. On his second birthday, they arrived with a smash cake filled with sweets, as well as gifts for Orlando, his sisters and cousins. "It lightened him up and he was happy, even if only for five or 10 minutes," says Anna. "It made you feel, 'Okay, we can keep going, we'll get through this – if he's able to smile, then we can, too.'"



### Orlando, age 2

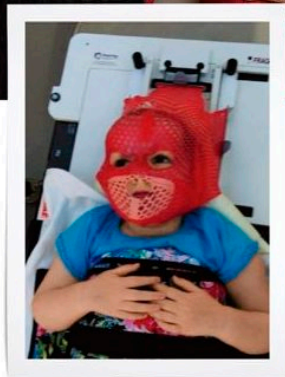
Orlando (above, with sister Aurora and dad John), who has battled a brain tumour, pretends to be Mickey Mouse with a decorated treatment mask.





## Claire, age 5

Claire (above right, with dad John, mum Kerry and brother Erik) wears her Owlette mask to receive treatment (right).



The Melbourne-based Koala Kids Foundation is all about providing little things that make life a bit happier for kids and young people in cancer treatment – treats that distract them from the pain or boredom. It's a modest mission, perhaps, but one that makes a difference. When a child comes to after a lumbar puncture, for example, grumpy from the anaesthetic, they are offered a white-iced Koala Kids biscuit and a paintbrush to decorate it with food colouring. Each year the Victorian charity supplies 12,000 lollipops to hospitals across the state.

"One day at the Children's, I saw a little boy in his Thomas the Tank Engine pyjamas hooked up to his IV pole with a lollipop in each hand playing the air drums," says program director Mandy Mandie, who founded Koala Kids 14 years ago at her son's request, using the \$3000 that Nick, then 13, received for his bar mitzvah. "That's the sort of happiness we believe helps kids with cancer."

For kids undergoing radiotherapy at Melbourne's Peter MacCallum Cancer Centre, the charity supplies superhero suits, as well as individually designed masks. Radiation therapist Renae Thorson and a team of volunteer artists use special paints to create keepsake treatment masks, from Superman and Spiderman to rainbow unicorns with fluttery eyelashes.

"The delight on the children's faces – they just cannot believe it," says artist Joanna Weir, who spends up to 15 hours on each mask. "They feel empowered by it."

Radiotherapy is painless but scary. "The child is harnessed to a table which is raised metres above the floor and tipped around in different directions with the huge machines circling them," explains nurse Sarah Harms. "It's a bit like a scene from *Star Wars*."

Not only are they alone in alien surroundings, patients having radiotherapy on their head have to wear a tight mesh mask moulded to their face and fastened to the treatment table to keep them still. Younger, wrigglier patients need a general anaesthetic, so for two-year-old Orlando, that meant going under for every one of his 30 sessions – five days a week for six weeks.

Today, at *The Weekly's* photo shoot, it's more than two months since the end of Orlando's treatment, but there is still a hairless patch on the back of his head. Wearing his Mickey Mouse costume from Koala Kids and splints to support his chemo-weakened leg muscles, he's a super-cute loose cannon, popping bubbles before making a run for it.

Five-year-old Claire De Dios is just as frenetic, dancing around the studio in her Owlette outfit and playing hide-and-seek with Erik, her eight-year-old brother in a gorilla get-up. Why *PJ Masks* character Owlette? "Because she flies," explains Claire, "and fights villains."

Claire was just 18 months old, grizzly and out of sorts, when a spotty rash appeared on her bottom. Mum Kerry assumed she was just teething, maybe had a cold, but mentioned the rash to her council nurse at the toddler's check-up. A blood test the next day showed it was leukaemia. Kerry was making bread-and-butter pudding when the GP called. She hasn't made it since. "That's it – you've had your normal day and all of a sudden, pfft," says Kerry. "It's like an earthquake. Nothing's the same again."

After two-and-a-half years of treatment, Claire finally went into remission in mid-2017. "We had a big party and it was awesome," says Kerry. Doctors told her and husband John to relax, that if the cancer came back it would be picked up in blood tests. Then, in January last year, Claire started feeling sick in the morning. The next month she was cross-eyed.

The cancer was back and had caused pressure on her brain, damaging the optic nerve. "It was a bit of a kick in the guts," says Kerry. "It's sort of worse the second time, because you know what you're in for."

Claire went back into hospital and stayed for 40 consecutive nights. Erik went on camps for siblings of kids with cancer and Claire's hair fell out again. "She wants to be Rapunzel when she grows up," jokes Kerry, "so she's had a few setbacks."

Claire endured eight months of chemo, spending more time in hospital than at home. Kerry took leave from her admin job and John, a customer-service technician, went part-time. "I think it's a sign of how much my husband and I love each other," says Kerry, "that we're still married."

Adds John, "You do feel like you're separated. It's not all bad, though. You see how tough your kid is and the whole extended family pulls together. It's one of life's tests and you realise, as you go through it, that you've got this." →



## Inspiring kids

The first time around, Claire had been a compliant patient. “She was like one of those clowns at the show,” says Kerry. “She’d open her mouth for any medicine.” But the second time she was more resistant. Radiotherapy, though, was fun because she could transform into her favourite cartoon alter ego. With her Owlette cape on, she’d play chasey in the Peter Mac waiting room among the adult patients, then swan in and tell the radiation therapist what colour she wanted her “invisible medicine” to be.

“She got the red-carpet treatment,” says Kerry, “and on the way out she got to pick a treat from the Koala Kids treasure chest. They just made it such a positive thing for her. When you’re four or five, you don’t have control over many things in your life, so feeling like you’re the centre of the universe is pretty special.”

Now legally blind, Claire finished radiation in December and is in the maintenance phase. It’s more than four years since Claire’s original diagnosis and Kerry admits, “I’m a bit tired.”

Quick with a joke, Kerry seems the stoic, optimistic type, not given to bouts of self-pity. In fact, she talks about her family’s ordeal for an hour and gets emotional only once – when asked about Koala Kids. “It’s sometimes harder to take the nice things people do for you than [to take] the bad news,” she explains. “Maybe it’s the veneer you put up because you get so used to washing bad news off and trying to think positive. It’s pride as well. I’ve always tried to do things for other people, but [I’ve decided] it’s a bit unfair for me to push things on other people if I’m not willing to accept them myself. That’s been a real revelation: I do need help.”

Since her son Lochlan was diagnosed with leukaemia last year, Cass Howcroft has appreciated all the offerings from Koala Kids – from the parent lunches and kids’ pizza-making lessons, to the toiletry packs and cookies in the kitchen. “When you’re given small things to make things easier for you, that’s all you need,” says the sales and marketing account manager, “because the big things you can’t think about.”

Arriving from a hospital appointment, Lochie dons his Iron Man outfit and, with a shy smile, moves through his repertoire of superhero poses. Lochie picked the character because “he’s just normal – he doesn’t have a superpower”. It seems an apt choice from an ordinary boy who has proved his extraordinary resilience over the past year,

facing chemo, radiation and countless medical procedures. “He has more empathy,” says Cass, “than some of the adults I know.”

The first sign of his blood cancer came at the start of 2018, when one side of Lochie’s face drooped and he was misdiagnosed with Bell’s palsy. The facial paralysis was actually the leukaemia in his central nervous system and it was only discovered when an exhausted Lochie started complaining of headaches and putting himself to bed at 2pm. A pediatrician insisted Lochie was fine, but Cass took him to emergency in late January. “Cancer was the furthest thing from my mind,” she says.

Aged seven at the time, Lochie started chemo the day after diagnosis and didn’t leave the hospital for 98 days. Meanwhile, Lochie’s little brother, Aidan, started prep and his dad, business manager Andy, cut his work week down to three days to share the hospital duty with his wife.

Lochie had Philadelphia-positive acute lymphoblastic leukaemia, which meant a more punishing protocol than the standard treatment, so he spent almost all of 2018 in hospital on a cocktail of heavy drugs, having chemo or battling side effects such as ulcers along his digestive tract.

Yet whether it was an MRI or a finger prick for the steroid-induced diabetes he developed, Lochie accepted it. “He knows that this is how it has to be,” says Cass. “Having your seven-year-old say to you, ‘Mummy, am I going to die?’ and having to explain to him, ‘No, but I need you to do everything I tell you to do’ – that just breaks your heart.”

So what has pulled her family through? “You have to get through – you just have to,” says Cass. “There’s no going, ‘I give up, I don’t want to do this anymore.’ A lot of parents say to me, ‘I could

never do what you do.’ Yes, you could and you would – because it’s your child. I’m willing to do whatever it takes to get him better.”

Now in maintenance, Lochie has been at home since Christmas and will stay on oral chemo until next February, but the Howcrofts are hopeful the worst is over. “We don’t know what the future is for us,” says Cass. “I’m hoping it’s bright, but in the back of my head there’s still that worry of relapse. I just have to hold onto the fact that he is well now, embrace every moment that we have, and know that we are, at this very point in time, one of the lucky ones.” **AWW**



### Lochie, age 8

Lochie (above, with mum Cass) is as brave as his favourite character Iron Man, having spent the last year fighting leukaemia.