

## “My baby was diagnosed with cancer. This is what I want you to know.”

**We know our babies’ gorgeous little bodies so well.**

We know every single inch – every fold of skin, roll of baby fat, spot and little mark.

New mum Kate Merry was no different – so when she noticed a strange bump while changing her son Freddy’s nappy three days after he was born, she knew [something was wrong](#).

But what happened next left her reeling.

**Q: When did you realise something was wrong?**

**A:** It was three days later [after birth] when I was up and about finally and changing his nappy for myself that I looked down. As I was lifting his bottom for a clean nappy, I thought “there’s his big bottom” but I realised it was only on one side. We realised something was out of place and [raised the alarm](#).



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**Q: Freddy wasn't properly diagnosed until he was seven months old. How did you discover it was cancer?**

**A:** At 10 days, Freddy and I were flown from Alice to Adelaide for a biopsy and MRI. Nobody knew what the problem was. They wouldn't use the 'C' word but were using terms like 'mass' and 'lesion'. We were released with a diagnosis of a non-malignant tumour that was extremely rare but generally not progressive.

**Q: Freddy was eventually diagnosed with a rare infantile fibrosarcoma. That must have felt like a kick in the guts.**

**A:** I walked out with my world falling out from under me trying to think of the words to tell my husband back in Alice. Fred was seven months old. It took me until the end of the day to make the call. None of the information was reassuring, and the description of the chemotherapy, the administering process and possible side effects was nothing short of horrific and devastating.

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**Q: How did you manage to get through Freddy's treatments?**

**A:** My family immediately offered to drop their lives and help. My sister moved to Sydney from the Cape for the first three months and we travelled that first part of the journey together with Freddy. I couldn't have done it without her companionship and sense of humour. And when my parents returned from overseas, they moved into help for the duration (18 months in total before we could come back to Alice to live). My husband, Brad, and older son, Jim, were still in Alice. My brother popped down from Darwin to lend them a hand whenever he could.



Freddy and his brother.

**Q: What were the hardest parts of his treatment plan?**

**A:** Freddy's pain, watching him deteriorate as the chemo was administered, signing off on procedures that could kill him or have irreversible long term effects, knowing it would be my signature, my permission that had given permission for a process that might kill him, just hoping that you weren't going to be the unlucky ones in the percentage where the chemo drugs or blood transfusions cause a non-curable form of leukaemia, or the blood donation is contaminated with a non-curable disease, or the long term effects of treatment create heart failure as an adult.

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*“The entire team fell in love with Freddy and his engaging personality and the support we have received from their appreciation and connection with a child benefitting from their research is considerable.”*

**Q: How did you first hear about CMRI in Sydney?**

**A:** The day after Fred's first birthday, the day we were due to be signed into a hospital bed for Freddy to start his new rounds of more brutal, possibly more lethal chemotherapy regime, we went across to the Children's Medical Research Institute for the launch of their Centre for Kinomics, which is meant to design better anti-cancer drugs with fewer side effects. I didn't know that kind of research was going on.

The entire team fell in love with Freddy and his engaging personality, and the support we have received from their appreciation and connection with a child benefitting from their research is considerable.

**Q: Freddy is now three and a half, and you've had to learn so much in that time. What advice do you want to share with parents?**

**A:** My advice to parents is 'advocate, advocate, advocate.' Make notes, inform yourself, ask questions. Don't wait. Swallow your self-consciousness, face your fear, get brave and be articulate.



*At CMRI, we work as if our children's lives depend on it. Our scientists are world-leaders in researching the causes of birth defects, cancer and genetic diseases.*

*Please visit [www.curechildhoodiseases.org](http://www.curechildhoodiseases.org) and leave a message of hope for mums, dads and little ones dealing with childhood diseases—or a note of encouragement for the team at Children's Medical Research Institute that is working so hard to find the cures we need.*

*Together, we can beat childhood diseases.*