

# Mudgee Guardian

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## Kalarny Parker and the Mudgee family saved by science



Life hasn't been easy for Kalarny Parker and his parents Lykera and Aaron, but thanks to a recent medical breakthrough, Kalarny is living a life full of love and excitement.

When he was just seven weeks old, Kalarny was rushed to hospital and treated for early heart failure. At eight weeks, he was in the operating room, and not long after that, he was diagnosed with Spinal Muscular Atrophy, or SMA.

Lykera and Aaron were told that Kalarny wouldn't make it to his first birthday, but thanks to the medical research conducted at the Children's Medical Research Institute (CMRI), Kalarny is not only still alive, but thriving.

The CMRI describes itself as a world-leader in the war against childhood disease and illness.

'The CMRI pioneered microsurgery, immunisations against lethal childhood illnesses and care for premature babies, all of which has improved the lives of countless Australian children. Today, the CMRI is the site of world-leading research in areas such as cancer, neurobiology, embryology and gene therapy,' their website says.

Lykera says the rapid timeline from birth to diagnosis and then treatment was gut-wrenching for the young family. Kalarny was diagnosed on a Monday and was receiving treatment by Friday.



"Our GP noticed he was quite floppy and wasn't doing what he should be doing. that's when we got the first tests done. Within three days of seeing our GP he was in heart failure and he was admitted to Dubbo Hospital," Lykera said.

"I remember handing him over to the anaesthetist before his operation, just sobbing because I didn't know if I was going to get my baby back in my arms or not,"

"They did MRIs and everything else you could think of. Then we got home and hadn't heard anything for two weeks. We thought 'no news is good news'. Then we got a call from a genetics counsellor saying that they would like to see us along with the paediatrician,"

The day Kalarny turned three months old is the day that he was given his SMA diagnosis. Diagnosis meant Kalarny likely wouldn't see his first birthday, it was effectively, a death sentence.

"It's taken its toll. But we're thankful to still have him. He's the happiest kid, he always has a smile on his face, he just loves life."

It's this breakthrough treatment that has literally given Kalarny and his family a new lease on life, it also allowed the family to move back to Mudgee from the Gold Coast.

"When we were first given a diagnosis we actually left Mudgee for 12 months," Lykera said.

"We were told he was going to die, so we took him back to the Gold Coast to be with our family. We did nearly lose him before his first birthday. But he's just so resilient, he just woke up one day and turned a corner."

There's no doubt the breakthrough treatment saved Kalarny's life, but it isn't all smooth sailing. Kalarny must endure a painful lumbar puncture procedure every four months as part of the treatment but Lykera says she's sure that one day he will understand how important it was.

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"He went from a kid that laid flat on a bed, unable to move his head, now he's sitting unassisted and stands up in a standing frame. He pretty much does all the things that a two-year-old does except run flat-out everywhere," Lykera said.

Thankfully for the family, the trial treatment Kalarny receives is listed on the PBS. If Lykera and Aaron had to pay out of pocket for the treatment, they'd be stung up to \$165,000 per shot, three times a year.

Kalarny has had ten shots so far and will continue to receive the treatment for the rest of his life.

"We will do everything in our power to make sure he has a great life."

A Christmas in July event, organised by the CMRI Mudgee Committee will showcase Kalarny's story in a specially produced video at Parklands Resort on July 27.

Lykera and Aaron will not only be attending, it will be their first 'night off' since Kalarny was born, a nervous time for the parents who have cared for their son so much.

"Of course there will be part of me stressing, in case something happens, but we have a great babysitter that has medical experience so I'm sure she will look after him amazingly, we're looking forward to it." Lykera said.

President of the CMRI Mudgee Committee, Alexandra Keipert-Reynolds says Lykera and her family are an inspiration and it's great to see the medical research having tangible effects on local families.

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"Since Kalarny has been born, Lykera has been coming to Bloom's [the chemist] to get advice from us since he was diagnosed,"

"The research that has been done in the last few years by the researchers at the CMRI in Sydney, one of their focuses has been SMA. They've had some incredible improvements in the last few years.

"When you donate to these charities, often the money leaves town, but we can say that while yes it is leaving Mudgee, it's going towards research that has had a life-changing effect on one Mudgee family,"

"It is helping to fund cures for kids."

The CMRI Christmas in July event will be at Parklands Resort on Saturday, July 27. Tickets are available now and can be bought at [www.cmri.org.au/christmasinjuly](http://www.cmri.org.au/christmasinjuly)