



December 2019



Camp made possible for Kamal

Vrrrooom! The engine roars, the wheels spin, the wind is in your hair and everyone's heads turn as you drive past in your matte black Lamborghini (with yellow trims and accessories of course).

This is fifteen year-old Kamal Sadi's ultimate dream and ambition for when he grows up; to one day drive a Lamborghini. But, that's not all Kamal aspires towards. He looks forward to lots of things, like completing high school and pursuing his interests in maths and history, he hopes to continue to be a good role model for his five younger brothers, he looks forward to taking on new experiences and meeting new friends, and most of all, every year, he can't wait for Muscular Dystrophy NSW's Summer Camp!

"I look forward to camp all year. At camp, I get to see my old friends, play wheelchair soccer, go swimming, and my favourite – plan for prank wars. I plan my pranks for months, I like to come prepared. Last year, one of the camp coordinators, Mitch, got pranked with a sour cream pie to the face! It was very funny, he couldn't get the smell of sour cream out of his hair for the rest of camp."

Kamal has Spinal Muscular Atrophy (Type 2), a type of childhood motor neurone disease that primarily affects the muscles for movement and breathing.

He was diagnosed at two years old and has spent most of his childhood in and out of hospital. This year, Kamal spent four months in hospital undergoing two surgeries to straighten his crooked and unsupported spine. Now, with the support of titanium rods in his back, Kamal is in less pain, is more comfortable and can sit up straight and lean forward with ease.

But he doesn't like to dwell on the subject of his surgeries for too long, there are more important things to talk about – like camp!



Kamal loves swimming at camp



Mitch the camp coordinator

“I also love swimming at camp, it's the only time of the year I get to swim. But, won't go in without Joan (MDNSW Client Services Manager). I like the water, I enjoy the feeling of being weightless; I'm just terrified of drowning! I haven't been in the water since my surgeries, so I'm looking forward to doing it this year.”

Our Summer Camp Program provides kids with the opportunity to live new experiences, challenge themselves, be independent in their thinking and decision making and connect with their peers, all in a fun and safe environment.

Sadly, not every child gets to go to camp, due to the increasingly expensive and difficult requirements placed upon the simple, but essential, matter of transportation.



Kamal with carer



Kamal with mum and two brothers

The cost for modifying a vehicle to suit the needs of a person in a power wheelchair is in the tens of thousands of dollars, and requirements set by the NDIS, make it very difficult for most middle to low income families to be able to afford to do it. Leaving the only alternative of taxi's, which still cost hundreds of dollars per trip.

“As a full-time carer for Kamal, as well as caring for my other sons, we rely heavily on financial support from the government just to get by. We don't have modified transport for Kamal. We simply can't afford it. This is where the people at Muscular Dystrophy NSW have really gone above and beyond in their support care for us, covering the cost of transport for Kamal to and from camp, making it possible for him to go each year,” explains Kamal's mum Dalal.

Thanks to the generous donations of our supporters like you, we have been able to provide the additional service of transportation, so that every child, regardless of their socioeconomic situation, can go to camp.

A donation of \$200 can mean the world to someone, just like Kamal and his mum, by getting them to them to camp.

No transport would mean no camp for Kamal and I just couldn't bear seeing how sad and disappointed he'd be. The help we get from MDNSW thanks to peoples donations is beautiful, it's really nice, and is making a huge difference in a boy's life. You are getting these kids to a very happy place!" says Dalal.

Please, this festive season, consider giving the gift of a donation. You will be helping us to continue to provide-life changing programs and services to assist individuals and families living with Muscular Dystrophy. You can do so by completing the attached form, or by donating to us online at www.mdnsw.org.au.

Thank you for your invaluable support.

Yours sincerely



Charlotte Sangster
Chief Executive Officer, MDNSW

