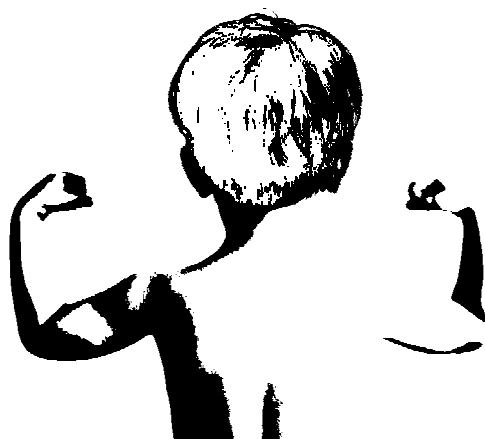


# Amber & Kaya Muscle Run



## Amber. 8 years old.

When you first meet Amber or when you see her sitting & playing with her friends, talking & laughing she appears just like any other normal happy 8yo except for one thing.

Amber suffers from a very rare neurological condition known as **Charcot Marie Tooth disease (CMT)**. Amber was diagnosed with a severe form of **CMT** known as Dejerine Stottas. It is even rarer still as Amber's DNA is different to what is typical of this disease.

**CMT** is a neurological disorder that causes damage to the peripheral nerves, which carries the signals from the brain to the spinal cord & the muscles.

Amber's nervous system is unable to feed her muscles properly which makes them hypotonic (loose). The effects of this are that her muscles are not strong enough to hold her skeletal system together & will cause Scoliosis & ongoing problems with her hips, spine, lungs, legs, feet & hands.

Since she was 3yo Amber has endured surgery to her hips, back and ankles. Amber now requires more major surgery before the end of the year to have a growth rod placed in her back to prevent further curvature of her spine.

She requires hours of physiotherapy, cannot stand or walk independently without the aid of a walker or her wheel chair. If all that was not enough, she has recently experienced the tragedy of losing a close family member to cancer.

Amber's mum says she copes amazingly well, she has a great can do attitude & never gives up. She rides horses, is a member of her local riding club & is the current state Walk Champion. She loves swimming, music & is learning the keyboard & violin at school.

Amber enjoys writing stories & dreams of being a famous author when she grows up & is very competitive often beating her mum at various board & card games.

Amber is a sociable young girl with a great circle of friends & loves going to school. Amber lives on a farm with her mum & uses her electric wheel chair to get around & take her dogs for a walk, she has even been known to help round up the cows in it. Amber is a very bright little girl who has a full life & just wants to be the same as everyone else.

For further details on **Charcot Marie Tooth disease** go to the website @: [www.cmt.org.au](http://www.cmt.org.au)

## Kaya. 8 years old

Kaya is like any other 8yo old boy who likes to play with his friends & imitate his favourite superheroes, he is a massive Spiderman fan & rarely do you see him without a smile.

However there is a harsh reality that Kaya does have to deal with that most other young boys would never imagine facing, at the age of five he was diagnosed with an extremely powerful, debilitating & incurable neuromuscular disorder, **Duchenne Muscular Dystrophy (DMD)**.

Kaya will experience the followings stages as **DMD** gradually weakens his muscles. Loss of strength & mobility causing wheel chair dependency; Scoliosis, requiring spinal curvature surgery; Heart & Respiratory function will decline causing fatigue & his immune system will deteriorate making him more susceptible to infections.

Kaya is surrounded by his loving & supportive parents, 3yo brother & extended family. Kaya's family must live with the knowledge that very few boys affected with **DMD** live past their twenties & are unable to take away the pain that he is experiencing & will continue to go through.

Kaya takes up to 14 different tablets & medications daily & as the disease progresses he will require ongoing medical intervention, surgery, physiotherapy & supportive care.

Kaya struggles with normal daily tasks that you & I take for granted, he finds it difficult to do simple things like, turning on taps or door handles, getting in and out of cars, walking up stairs, opening a packet of chips, not having enough strength to jump, skip or run or just dress himself.

**DMD** also places immense pressure on Kaya in trying to keep up with his friends in sport & social activities at school, these are things no child should ever need to worry about.

Kaya is best described as being a happy, intelligent & loving young boy, who is well liked by his friends. He loves playing video games & drawing like any 8yo boy, for now.

Kaya's family want you to know that he is a battler with a huge heart & a strong spirit & along with his precious & infectious smile, he has an inner strength that helps him to live with his everyday struggles, & what can be more inspiring than that!

For further details on **Duchenne Muscular Dystrophy** go to the website @: [www.mda.org.au](http://www.mda.org.au)

The Amber & Kaya Muscle Run is proudly presented by the Lancefield Motorcycle Run. Sunday 19 February 2012.  
All money raised will be donated directly to both Amber & Kaya. Further details [www.lancefieldmotorcyclerrun.com](http://www.lancefieldmotorcyclerrun.com)  
enq: Peter: 0417 596 621 Kristine: 0432 181 136 e: [lmcr1000@hotmail.com](mailto:lmcr1000@hotmail.com)