Duchenne & our child
A personal experience
In November 1990 we were blessed with a beautiful son - our first born.

He had 10 fingers and 10 toes & looked perfect. Little did we know that inside his little body there was a disease that would creep up on us and change our lives forever.....
At 17 months he started to walk on his own. A late start....possibly one of the first indicators that something may have been amiss...

When he was 3, I started to notice something wasn’t quite right........he was “tripping” on thin air. He also had a funny way of walking.....he waddled a bit.
We used to laugh about his muscular calves and say they looked like chicken drum sticks. His dad used to say, “With those legs he’ll be a front row forward one day......”. At that stage we didn’t know that this was another tell-tale sign.
On Christmas Eve 1993 we got the news that test results indicated Duchenne Muscular Dystrophy. He had a muscle biopsy and we got the definite diagnosis on New Years Eve. There was no family history of this disease.

Our world fell apart and has never been the same.
He loved to play football....
His dream was to play for Essendon.

Duchenne took that away.
He loved to ride his bike and to go fishing with his Dad & younger brother at the beach.....but now that’s impossible.

Slowly Duchenne took that away too.
He loved to run around and always participated in school sports, even though his legs wouldn’t let him run as fast as the other kids.

The water slide in the back yard, with a few mates, was always great fun on a hot summers day.

Insidiously Duchenne took that away too.
He could sit on the floor and get up by himself, in his own special way, until he was about 7. Then we had to help him to sit down on the floor and help him up again.

Now he sits in his wheelchair.
This is how he used to get up off the floor. It is the only way he ever got up off the floor. After diagnosis we learned that this is another tell-tale sign.
He got his first electric wheelchair in 2001. Duchenne had taken away his ability to walk and was gnawing away at his independence.
... he could still do the “Birdie Dance”......his arms weren't so weak then.
In August 2003 he had to have a spinal fusion done to prevent his spine from scoliosing. He had 2 titanium rods anchored to his spine. A big operation for someone so young. We were away from home for 6 weeks. It was a very trying time for all of us.
This lethal disease is like a creeping paralysis. Our son is now nearly 15. His arms are beginning to weaken. His respiratory system is weakening. Slowly bit by bit this disease is taking our boy from us.

We are but **ONE** family struggling with the effects of this devastating disease.
It affects us:
Emotionally
Mentally
Physically
Financially

Can you imagine what it is like to slowly watch your son’s independence slip away………from running around and kicking the footy to being totally dependant in his teenage years and to feel so helpless; because there's nothing you, as a parent, can do to stop this disease.
The only thing we can do is love our boys and support each other and hope for a cure.
“I’ll lend you for a little time, a child of mine,” he said.
For you to love while he lives, and mourn when he is dead.
It may be six or seven years, or twenty-two or three,
But will you, till I call him back, take care of him for me?
He’ll bring his charms to gladden you, and shall his stay be brief,
You’ll have his lovely memories as solace for your grief.
I cannot promise he will stay, since all from earth return,
But there are lessons taught down there I want this child to learn.
I’ve looked the wide world over in search of teachers true,
And from the throngs that crowd life’s lanes, I have selected you.
Now will you give him all your love, and not think the labour vain,
Nor hate me when I come to call, to take him back again?”
I fancied that I heard them say: “Dear Lord, Thy will be done.
For all the joy Thy child shall bring, the risk of grief we’ll run.
We’ll shelter him with tenderness, we’ll love him while we may,
And for the happiness we’ve known, will ever grateful stay.
But if the angels call for him much sooner than we planned,
We’ll brave the bitter grief that comes, and try to understand.”

Anon
This presentation was produced by Pam Bianchi for the benefit of all boys with DMD - to help create awareness of this type of muscular dystrophy and how it affects the lives of individuals, families and friends.

For more information contact: jpbianchi@aapt.net.au

Or the MDA in your state or Rocky Bay Inc in Western Australia.