



## Stories

### **A Boy named Mitchell**

[Walkin Tall Jan 05 1.pdf](#) 240 KB



**On February 20, 2006,** Mitchell created history and became the first person ever to take his first steps on live television.

### **A Boy named Luke**

*Many times, as we Lions, Lioness and Leos work with ALCMF we meet some wonderful and extraordinary families. The Lions Clubs of Hurstville St George, Lugarno and Oatley combined to purchase a Hart Walker and ongoings for a child – a total of \$11,620. Through that donation the Lions' lives have been enriched - they met Luke and his family. Carole Powell -Trustee*

The following has been written by Luke's Mother.

Luke's Medical Condition - Immediately after Luke was born he began having 'medical emergencies' and was taken by ambulance a number of times. At 9 months Luke began having severe, unrelenting epileptic seizures. He was given an MRI which revealed that some of the grey matter in Luke's brain was in the wrong spot. His condition was given the name, Neuronal Migration Disorder, as 3 or 4 neurons had not migrated from the centre of Luke's brain to the outer rim like the other tens of thousands had done. This had occurred at 20 weeks in utero and although it was genetically caused it is not a hereditary condition. Apparently there is a tip of one or a few of Luke's genes missing (they're still looking for them!) that did not transfer correctly at conception and therefore didn't trigger the migration fully. It is very rare, but could happen to anyone at any time. It is not a syndrome and we have just as much chance of having another child with the condition as anyone else.

The Neuronal Migration Disorder has resulted in severe epilepsy which has proved somewhat drug-resistant. Although Luke's seizures are controlled throughout the day, Luke continues to suffer with sleep-induced seizures and still sleeps with me as he wakes several times throughout the night. Luke also has 'Severe Global Developmental Delay', meaning that he is both



intellectually and physically delayed, and has weak muscle tone which affects his eating and digestion. He cannot crawl, stand or walk unaided and he uses hand signs and a few basic words to communicate. Unfortunately, and unrelated to his brain abnormality, he also is allergic to milk and egg and has a life-threatening reaction if exposed to these. Recently we discovered that Luke has developed a toxic skin rash if exposed to the sun due to one of his epilepsy medications.

Having talked about all of Luke's medical problems, and despite the fact that looking after him is more than a full time job, I must say that Luke is a blessing to our family. As any parent would, I wish I could take away all of the pain and suffering he goes through, but like many children who suffer and struggle with medical conditions, they develop a beautiful heart and learn very early what is important in life and teach it to the rest of us!

Letter written to the Clubs after the Hart Walker fitting -

Dear Noel,

I just wanted to write to you and thank you for your efforts in getting our little boy, Luke, his Hart Walker. Already Luke has taken a few steps on his own and walked himself towards a toy, so progress already...Yippee!! I have included a photo of Luke in the Walker at home where he is a much happier little chappy than you witnessed last week at the Spastic Centre.

As you saw last Friday, Luke is a determined little character with a strong personality and this will serve him well in his determination to walk. I had a feeling that Luke would adjust quickly to the walker and it seems to be the case. It has come not a moment too soon, I must say. We had hit a brick wall with his development and learning because Luke has wanted to walk so much that he would refuse to do anything else. If you saw him writhe and kick to get away from the books I tried to read him you would laugh at his tenacity and stubbornness! He would not participate in any kind of sedate activity I tried with him; painting, stamping, gluing etc. Like most little 3 ½ year old boys all he wanted to do was run around and explore the world. Well, now he's on his way, thanks to you, and he is loving it – on his own terms, of course!!

I cannot tell you how much we appreciate what you, your colleagues and the Spastic Centre have done for us and for Luke, in particular. It has given Luke a whole new lease on life, and us as well, as his family. The Walker itself is an excellent machine which enables him complete independence but still challenges him at the same time. I am thrilled with it after trying for so long to hold him up in a back-breaking effort to try to give him the experience and enjoyment of being upright like everyone else. You are truly marvellous people doing great work and we feel very blessed to have benefited from your efforts in such a huge way. Please remember us if you need anything at all as we would be more than happy to help in any way we can.

I will keep in touch and let you know how Luke progresses.

Thank you again and God bless you.

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**Lions Club of Lugarno makes Hansard!**

*On 28 February 2008 Mr Kevin Greene, Minister for Community Services, made a Private Members Statement in the NSW Parliament.*

MR KEVIN GREEN (Oatley – Minister for Community Services) [4.23pm]: As many members recognise, we have the opportunity to be involved with a large number of community groups within our electorates. For the past two years I have had the pleasure of assisting Lugarno Lions Club in organising a St George sports stars breakfast with the funds raised being used to assist projects of the Lions club. Last Friday I attended that function at the home of sport within the Hurstville community, Hurstville Oval. Fortunately, this year eight international sports stars hosted tables for local business groups and others who supported this fundraiser. The Lugarno Lions Club will use the money to buy Hart Walkers. The Hart Walker program is significant for Lions clubs. The eight international sports stars who joined us were rugby league immortals, Graeme Langlands and Johnny Raper, Olympic cyclists Gary Sutton and Kevin Nichols, Australian cricketers Brian Booth and Murray Bennett, renowned

international former world record holder athlete Albie Thomas and Wayne Riley who is recognised throughout the world not only as an athlete but as an outstanding golf commentator.

This great morning raised between \$13,000 and \$14,000 to support the Lions' Hart Walker program. As the master of ceremonies, I interviewed two of the guests, Johnny Raper and Brian Booth. They certainly entertained the 100 or so gathered at the function with their stories and comments on current sporting trends both in rugby league and cricket. Well-known comedian Paul Martel generously gave of his time and also entertained us with his quick wit and stories. As I said in my introduction that morning, Paul is one of the best comedians not just in Australia but in the world. I also thank generous chefs Leo and Merren Rulishauser, who run Stapletons Restaurant, Sutherland who also gave freely of their time. I also thank Greg Lazarus and the Sydney Markets Lions Club for providing produce.

The organising committee of the Lugarno Lions Club chaired jointly by Bruce Martin and Alan Peters, current president, Ivan McKay and members, Dick Goodfellow, Noel Burchmore, Brian Anson and Keith Miller would agree with me that one of the great benefits in organising this function is the involvement of well-known local businessman and great supporter of community events, Phill Bates. Again this year Phill provided his expertise and assisted in the successful function that raised close to \$14,000. I also thank the generous business people who support the event not only by buying a ticket but by the raffle and the small number of auction items that made the day such a great success. I also thank Hurstville Council for the use of Hurstville Oval and St George District Cricket Club for the use of the Booth Saunders Pavillion, which stands so proudly at Hurstville oval. I take this opportunity to plug the trivia night to be held by Lugarno Lions Club tomorrow night at Penshurst RSL in support of Mortdale Community Services, which I will be attending together with other friends. I also plug Oatley Lions Club annual jazz in the park at Oatley on Sunday 9 March.

**MR BARRY COLLIER** (Miranda – Parliamentary Secretary) [4.27pm]: I thank the Minister for Community Services for drawing the attention of the House to the wonderful work of the Lugarno Lions Club. The Minister is well-known for his community involvement in service and sporting clubs in his electorate, and the Lions Club of Lugarno is no exception. I congratulate the club on raising \$13,000 to \$14,000 for the Hart Walker program. That is a wonderful example of how volunteers and our service clubs are making a difference to the community. I congratulate the Lugarno Lions Club. I hope its future functions, as advertised by the Minister are successful.

*The Foundation would also like to acknowledge the wonderful contribution of those people mentioned in the Hansard Report. The children and families who will benefit are indeed fortunate that we have such great Members and supporters in the Community. Carole Powell - Trustee*