



Muscular Dystrophy New Zealand

999999

Mr A B Sample
Sample Street
Sample Suburb
Sample City 9999

The day our **BUBBLE BURST**

Dear <Salutation>

Every family remembers its major milestones – weddings, births of children, first days at school and the special triumphs that bind us together.

There are other types of milestones as well. They're the painful ones that make us feel as though the bubble we've been living in has burst.

For me and my whānau, that bubble burst in July last year when Lance Jr., the youngest of our seven children, was diagnosed with Duchenne muscular dystrophy. As a doctor living and working in Kaitaia, I've spent many hours talking with patients and their families at some of their most desperate moments. But nothing had prepared me for being on the opposite side of the fence, and the absolute pain of being told our son has a progressive, life limiting condition that currently has no cure.

Tracy and I had noticed traits about Lance Jr. that were different to our other children, but we figured that with six older siblings on call, it wasn't surprising



Lance Jr. on the rugby field;
me and my boy at the beach.

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Muscular Dystrophy
New Zealand

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Our whole whānau; taking cover with the family; Lance Jr. celebrating a win.

he constantly wanted to be carried. As he began primary school, he didn't seem able to do things the others could. When his teacher mentioned he was always last off the mat, we realised we needed to investigate.

Fast forward a year and a bit since the eventual diagnosis and the O'Sullivan whānau has regrouped and started a new journey. At first there was a real sense of hopelessness, but out of that dark and gloomy place has come a sense of hopefulness.

It's from that position of hope that I write today. We are lucky to live in a very supportive community in the Far North and have the loving support of an extended whānau. We're proud to have now joined another supportive community – the whānau of the Muscular Dystrophy Association (MDA). As we have moved through this painful experience, we have learned about this supportive organisation.

I hadn't realised how vulnerable this group of people was, but having experienced it first hand, I now realise the need is so great. The MDA provides a community of support to reduce isolation and help with day to day needs. It is an independent voice advocating for the best care and access to resources for people living with degenerative neuromuscular conditions. Through their research arm and strong clinical networks across the globe, the MDA is striving to offer hope for the future treatment of these rare and incurable conditions.

And that's why I'm sharing my story with you today. I've pledged my support to the MDA, and we need your ongoing help to make a difference and offer hope for the future.

Our whānau continues to mark milestones. Some days are harder than others – receiving Lance Jr.'s first wheelchair was one of those hard days. And while things have changed, one thing that hasn't is the love we have for our son. We now realise the bubble didn't burst, it just changed shape and we had to look at it a different way.

Ngā mihi

Dr. Lance O'Sullivan

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Thank you very much for your support

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