



If he could, Boris Struk, 62, would move mountains to help his son, Ryan, and others who suffer from muscular dystrophy. Instead, he traverses them, raising hundreds of thousands of dollars along the way. He shares his story with Beverley Hadgraft

“We knew something wasn't right with our son Ryan. He had trouble walking and getting up. He wasn't following the benchmarks of our eldest son, Leon, at all.

When he was three, we received a diagnosis: muscular dystrophy (MD). “Go home and enjoy your son,” the doctor said, “because he'll be dead by the time he's 14.”

My wife, Ineke, and I were dumbfounded. We spent the

next six months in a daze.

We didn't know what to do and had no idea what was in store.

But Ryan didn't die in his teens thanks to improved treatments, from a spinal fusion to effective antibiotics. However, his physical condition continued to deteriorate. His life is spent in a wheelchair, he needs to be fed through a tube in his stomach and he can only breathe with the help of a ventilator. His lung function has



deteriorated to the stage where he can't even blow out a candle.

It's hard on him and on the family. A typical day involves lifting him out of bed, attending to his personal needs, dressing him and looking after the million other small matters most of us take for granted, such as scratching his nose, plugging in a USB stick or turning him over in bed at night. We soon forgot what an unbroken night of sleep felt like.

Although it was pre-internet when Ryan was diagnosed, I found other families in a similar situation and discovered a few were doing some fundraising for MD. Since I had a background in sales and marketing, I joined them. I did well in increasing our income, and in 1984, we formed Muscular Dystrophy Australia, to provide information and support and fund a research facility. I took on the post of executive director.

PROVIDING RESPITE

One of our most important initiatives was to start respite camps. These gave exhausted parents the chance to have a break, knowing their child was having fun with his or her peers.

We've organised 88 camps and as well as being good for families, they're excellent for training health professionals. Our carers are typically nursing or occupational therapy uni students, and over the course of a camp, they spend a full week looking after a patient.

We meet with the carers every evening. One of them once told us, "I'm totally exhausted – I was

up nine times last night."

I said, "That's pretty normal. Now imagine doing that 365 days a year." It blows their mind, but we saw for ourselves how effective our training was when, in 1996, Ryan was admitted to hospital with a bad bout of pneumonia that wasn't responding to treatment.

Eventually a physio was called. She turned out to have been his carer at a camp four years before, so she knew exactly what was required to help him shift the build-up of mucous. He was out of hospital three days earlier than doctors had predicted.

In 2006, I realised I was spending too much time behind my desk and needed to get fitter. We were doing lots of good fundraising activities such as raffling Harley-Davidsons and organising fun runs but it was never enough.

I spoke to my friend, boxing champion Barry Michael, and we decided to get fit and raise funds at the same time by cycling the length of Vietnam. By the time that project was complete, we'd been joined by another 24 riders and raised \$440,000.

It wasn't easy, I enjoy my food and had a number of locals patting my belly and observing, "Ooh, Happy Buddha." I liked the fact I wasn't just sitting there saying to sponsors and corporations, "Give us some money." Instead, I was out there tackling heat, humidity and hills and saying, "If I can do this difficult thing, surely you can sponsor me for \$50."

THE HARD YARDS

Along with other volunteers, I went on to cycle across China and Cambodia. That was followed by a trek through Nepal and a 190km expedition through the Mont Blanc region. Every time things felt hard, I thought of Ryan and how hard his life is every day.

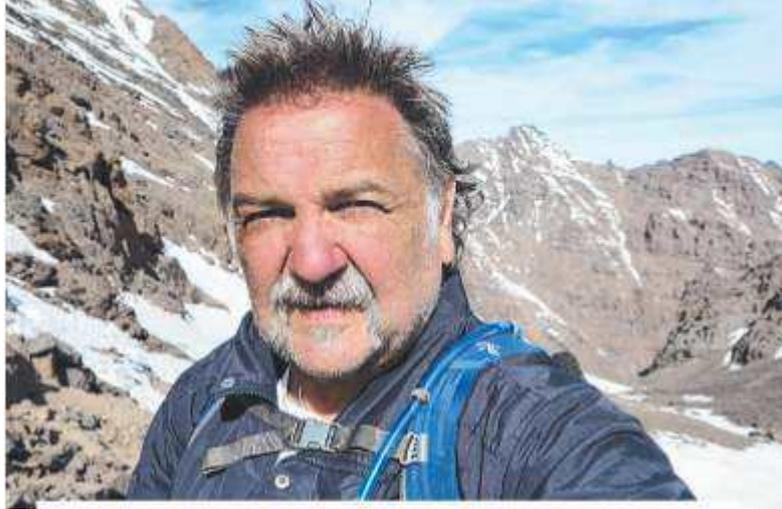
I recently returned from our latest challenge – a trek up Mount Toubkal, a 4165m peak in Morocco. It was our toughest yet and I couldn't make the final 165 metres, but many of our team did. My lungs just couldn't keep up with feeding air to my body. I thought about Ryan on a ventilator and how difficult breathing is for him. The expedition raised more than \$120,000, which will fund five camps, educate lots more carers and give dozens of families a week of restorative, unbroken sleep.

Now 33, Ryan is doing an online bachelor of arts in Middle Eastern studies at Deakin University. He's doing well but sometimes says he wishes he'd been in a car accident rather than getting a bad draw in the genetic lottery, as that way third-party insurance would have covered his medical needs; he could live in his own unit with full-time carers and we wouldn't need to save for 18 months when he needs a new wheelchair.

But that's just a wish. In the meantime, our family and others will continue climbing mountains – in every sense of the word."

For more info, visit mda.org.au





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Struk says that focusing on his son, Ryan (left), helps him get through each physical challenge