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At long last, diagnosis a relief

Monday, February 28, is New Zealand Rare Disease Day – a day for someone like Masterton woman Allyson Lock, who is one of just four people in New Zealand diagnosed with Pompe – a rare enzyme deficiency disease. She tells her story.

I was diagnosed with Type 2 Late-Onset Pompe in 2010 at age 45 after many years of inconclusive tests with a lot of different specialists.

Although it was not great to hear that I had Pompe, it was actually a relief to finally find out: What I had; that I had something; that I wasn't making it up!

I live in Masterton with my husband Steve who is in the navy, and our two sons Benjamin, 9, and Josh, 7. I have an older son James who is 23 and lives in Auckland.

We breed miniature horses, coloured sheep and a few different breeds of poultry. I try not to let Pompe stop me from doing the things I love to do.

It is my goal to have Enzyme Replacement Therapy made available in New Zealand to the people who need it – 44 other countries make this life-saving treatment available to their Pompe patients.

There are four people in New Zealand with Pompe disease that we know of.

It's hard to recall when I first noticed symptoms. I have always loved riding horses but even as a teenager was unable to vault on to a horse like everyone else did. I put it down to the fact I had a big horse and had further to go!

In my 20s I had trouble with "asthma" and medication didn't really seem to help.

In my late 20s I started to feel "heavy", even though I was slim and fit at the time. I thought maybe it was part of getting closer to my 30s.

Then climbing steps started to become a chore when previously I could run up several flights easily. I started to feel like I had weights tied to my feet. I would go to the doctor saying "I feel old".

Fast forward to 2001 and my second pregnancy. Blood tests showed elevated CK levels and although my GP said that could be because I was pregnant, she repeated the tests after my son was born – and the levels were still going up.

I was referred to several different specialists, including a neurologist who did a muscle biopsy in 2002. That showed nothing specific and he said short of sending the sample to the United States we could wait for 2 years and see him again to see if



PICTURE: KERRI BOWLING wta160211kball

A MOUNTAIN TO CLIMB: Pompe sufferer Allyson Lock, with Marty Davis, field worker from the Muscular Dystrophy Association. Allyson is one of four people in New Zealand diagnosed with the rare enzyme deficiency disease.

anything changed.

So in 2 years' time back I went – nothing much had changed and he said he had originally thought I had muscular dystrophy but because I hadn't declined since he saw me, that wasn't it.

After a lot of specialist visits and inconclusive tests I said "enough is enough, just leave me alone".

It was so depressing being shoved from one specialist to another and seeing them all throw their hands in the air and

SOME SYMPTOMS

Some of Ally's symptoms just before her diagnoses were:

- Constant chatter inside her head
- Sleeping most of the day due to a feeling of total exhaustion
- Horrific nightmares
- Cold sweats at night
- Constant headaches
- Muscle twitches — she says she could accidentally hit someone standing next to her
- Pain similar to a bladder infection, despite no infection present
- Constant pain, particularly in her lower back and legs
- Constant coughing
- Never being able to draw enough breath
- Difficulty rising from a seated position.

shrugging their shoulders.

Over time my health deteriorated, I was no longer able to run, walking up inclines, no matter how small, became increasingly difficult. My breathing became a lot worse and even on the maximum amount of asthma medication it did not improve. My joints ached, my lower back was in constant pain, I had no energy and the smallest tasks became difficult chores. I could not lie on my back without getting breathless and bending down to tie my shoes became impossible.

In 2006 we moved from Auckland to Masterton and my health was stable for a few years. I was glad to be in a new town and was hoping I could stay "under the radar" as far as being constantly tested to see if things had changed in my blood.

After a couple of years my new GP noticed my funny breathing. I agreed to further tests "as long as

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ALLY MISSES:

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