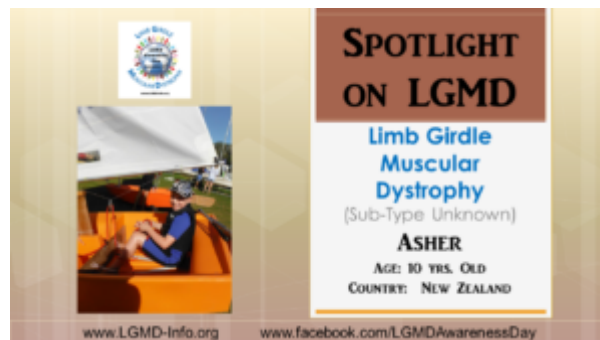


Asher

LGMD “ Spotlight Interview”

Name: Asher **Age:** 10 yrs. old



Country: New Zealand

LGMD Sub-Type: Unknown

*** (Asher’s mum Chloe assisted with the interview) ***

At what age were you diagnosed:

Asher was diagnosed when he was 5 years old.

What were your first symptoms:

He was slow to crawl, stand and walk. I noticed he struggled in comparison to his peers to use the playground equipment and run races as a preschooler and when he first started at school.

Do you have other family members who have LGMD:

Asher is the first person, we assume he has a recessive form of LGMD.

What do you find to be the greatest challenges in living with LGMD:

Asher says “My greatest challenge is that I can’t keep up with my friends and I get very tired. “

Asher's Mum says "the hardest thing for me is the uncertainty of the future and worrying that I am not making the right decisions for his health and well-being. I wish we had a complete diagnosis including subtype so I had a bit more understanding of what to expect going forward"

What is your greatest accomplishment:

Asher says "Hmmm, I'm not sure. That's deep. I have done a lot of things. I guess my greatest accomplishment is when I won an award at the National Junior Disability Games for most promising Waka Ama Athlete. That was really good"

How has LGMD influenced you into becoming the person you are today:

Asher says: "Well, I have a really cool power chair and that makes me pretty cool. My seat is more comfortable than most people's seats are – so that is pretty cool. Plus I get to do really fun stuff like disability games and adapted sport. So yeah Muscular Dystrophy is good like that"

Asher's Mum says: "having a child with a disability has changed a lot about our lives and what we had expected. It's made me more understanding and empathetic of other parents' challenges. I know what it feels like to be overwhelmed. I have signed up to be a support parent for others through an organization called parent to parent and I feel really good about that. I like the idea that we are stronger together."

What do you want the world to know about LGMD:

Asher says "I want the world to know that it is hard and people who have it feel really tired."

Asher's Mum says "I'd like people to know that it is

progressive so what people can do today they may not be able to do in the future. I think it changes the way we live our lives because we try to make the most out of every day and every experience.”

If your LGMD could be “cured” tomorrow, what would be the first thing that you would want to do:

Asher says “I would run the cross country at school and not come last.”

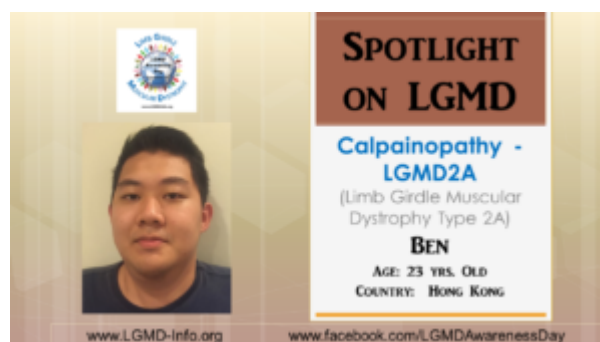
Asher’s Mum says “the first thing we would do as a family is go to a theme park and do every ride. Then we would have a bubble dance party til late and not worry about anyone being too tired”

To read more “LGMD Spotlight Interviews” or to volunteer to be featured in an upcoming interview, please visit our website at <http://lgmd-info.org/spotlight-interviews>

Ben

LGMD “SPOTLIGHT INTERVIEW”

Name: Ben **Age:** 23 yrs. old



Country: Hong Kong

LGMD Sub-Type: LGMD2A / Calpainopathy

At what age were you diagnosed:

I was diagnosed at the age of 21.

What were your first symptoms:

I developed bilateral heel cord contractures which caused toe-walking.

Do you have other family members who have LGMD:

My brother displays similar symptoms but he has not been officially diagnosed yet.

What do you find to be the greatest challenges in living with LGMD:

Right now, the greatest challenges for me include difficulty in climbing stairs and walking long distances.

What is your greatest accomplishment:

Not allowing this disease to affect my studies.

How has LGMD influenced you into becoming the person you are today:

Having LGMD has made me stronger, with a strong will and perseverance.

What do you want the world to know about LGMD:

I want the world to know that LGMD can affect people at any age – children, teens, young adults and adults. It is important that more people need to know about LGMD.

If your LGMD could be “cured” tomorrow, what would be the first thing that you would want to do:

If my LGMD could be cured tomorrow, the first thing that I would want to do is to engage in some sporting activities as LGMD currently restricts me from participating.

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