




Speech By
Jessica Pugh

MEMBER FOR MOUNT OMMANEY

Record of Proceedings, 16 March 2022

ADJOURNMENT

Scleroderma; Motor Neurone Disease; Usman Khawaja

 **Ms PUGH** (Mount Ommaney—ALP) (7.24 pm): What a start to 2022! In between COVID and then the floods that have hit Queensland I had the opportunity to meet with a couple of fantastic advocates for some rare health conditions, and I want to shine a light on these today. First, I met with Rose, a Mount Ommaney local, who has a condition called scleroderma. The word scleroderma comes from two Greek words: 'sclero', meaning hard and 'derma' meaning skin. As well as the skin being affected, the internal organs and joints can also be involved. It is a complex disease, it is often difficult to diagnose and the symptoms can range from mild to very serious.

My father had a cousin who was diagnosed at a relatively young age with this awful condition. Alison was an amazing woman who had very severe symptoms for as long as I knew her. What I did not realise before meeting Rose was the variability of symptoms that people with scleroderma could experience, although some could experience relatively normal lives. I really appreciated the opportunity to meet with Rose because I learned something really important that day.

People with scleroderma really love living in Queensland because of our warm weather. The cold weather is terrible for people with the condition. It makes it painful and uncomfortable. For that reason Queensland has a high proportion of the overall number of Australians with the condition because if they are not born here they often end up settling here, as was the case for my dad's cousin who came to Melbourne from New Zealand before moving to Brisbane. There are 30,000-odd people in Australia with scleroderma and many of them live here in Queensland. I am also informed that Cairns in particular is a very popular location to move to for people with the condition. I ask every member in the House to take five minutes to learn about it if they have not heard of the condition. If I had not had a family member with it, I certainly would not know about it. It is something for us all to think about.

I also want to highlight the amazing work of Mount Ommaney local Wayne Cooper on his recent completion of the Tassie Overland trek, raising funds and awareness for motor neurone disease and Me Foundation. Shortly before he left, I met with Wayne, who is a member of our local RSL, and some fantastic advocates for motor neurone disease so they could tell me about their plans. Sadly, I expect most members of this House will have met someone who has or has had motor neurone disease. It is a cruel condition; it cuts young lives short. The motor neurone disease foundation, with the help of amazing volunteers and advocates like Terry, is aiming to change this by raising funds for a cure.

In the time remaining I want to reflect, which is unusual for me, on the stellar run that Usman Khawaja has had in the cricket this summer. We all know our mate Duncan Pegg was a massive 'Uzzie' fan; he had a picture of him in his room. When 'Uzzie' made it to the Ashes team, I realised that Duncan's time in heaven had been very well spent designing his ideal cricket team. When 'Uzzie' made his first ton this summer, I am not ashamed to say that I cried because I knew Duncan was up there watching, too.

Duncan was a huge advocate for health. He would want me to remind everybody that having a good relationship with your GP is vital because whether it is scleroderma, motor neurone or cancer, early detection is key.