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Mr. Dean Sutherland,
President
Speech Therapy Org. NZ
University of Canterbury
Private Bag 4800
Christchurch 8140

Dear Mr. Sutherland,

I am writing on behalf of the NZ Dystonia Patient Network and enclosing information on Dystonia. One of our members recently sat with a student Speech Therapist on a plane. The young man had never heard of Dystonia so our member who has Spasmodic Dysphonia was able to tell him all about it.

I am attaching an article written by one of our members describing the onset of spasmodic dysphonia and the impact on his life.

We thought this information would be valuable as a teaching tool at the grass roots level and we could also offer a chance for a student to interview a Dystonia patient if one wanted to study this as a project.

**Article from Dave Mitchell, new Auckland area
Executive Committee Member**

"Hi, I'm Dave Mitchell and I have spasmodic dysphonia. I live in Auckland and my story starts almost 10years ago when I started to develop an occasional strange sensation in the throat area which halted my speech mid sentence. At first this only happened from time to time, but it became more frequent and developed to the point of being a daily occurrence so my friends and family thought I should get this unusual condition investigated. At this point I was concerned that it was the precursor to something more sinister which is probably why I hadn't had it checked out sooner – a typical male response some would say!

By this stage my voice fairly quickly progressed into halting speech although not too severe. My current doctor at the time was unsure as to what the condition was and gave me three specialists to choose from. I chose to consult the first on the list, Jim Bartley, an otolaryngologist who diagnosed 'muscular tension dysphonia' but also referred me to speech therapist Jeanette Gillibrand. Jeanette was sure I had spasmodic dysphonia and this was later confirmed to be the case. This all happened within a month or so from the initial contact with the specialist so I was very lucky indeed to be diagnosed so quickly compared to some of the horror stories I have heard and read.

Jeanette suggested speech therapy lessons which I began, and found to be of great benefit to me. At this stage my voice was still not too severe and it was considered to be a mild case of SD. Some weeks later, it was as though a switch had been turned on and my voice suddenly changed to a raspy choking sound and I struggled to make myself heard and understood. I was in a customer services role at the time and experienced great difficulty, especially in using the phone. I continued with the

speech therapy and developed various techniques over the following months to get by. It was like learning another language and I had to think about what I wanted to say beforehand and take deep breaths prior to getting a sentence out.

At the same time, I investigated various natural treatments which I also feel helped me greatly. I am now almost back to where I started where my voice is halted only occasionally unless I am under stress and then it is full on again. I realize that this condition can come and go in some cases but I am of the mind that this will not happen.

All the while I have had tremendous support from my friends and family and the NZ Dystonia Patient Network, and I would urge anyone who may be reading this or knows of someone with any dystonia-related condition who has previously not made contact with a group such as ours, to come forward and share their story and enjoy support from a very friendly and caring group of people – we also know how to have fun!"

We hope this information will be of some help to your students for the future. As always we are aware that with a rare disease diagnosis can take a long time. The impact on people's lives is huge. Most of our members with spasmodic dysphonia have had to change jobs.

We are happy to provide more information if needed.

Yours sincerely

A handwritten signature in black ink, appearing to read 'P. Hooper', written in a cursive style.

Philippa Hooper
Network Manager.