

# ms. voice



Awareness Week Special Newsletter

September 2022



**SOME OF THE MANY FACES OF MS**  
MULTIPLE SCLEROSIS AWARENESS WEEK 12<sup>TH</sup> - 18<sup>TH</sup> SEPT

*Donate to support your MS community today*

Multiple Sclerosis doesn't have one face.

**It has many faces.**

In fact, in New Zealand, it has **4000 faces**, and **2.8 million worldwide**.

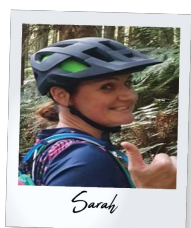
Did you know that Multiple Sclerosis is the leading cause of non-traumatic disability among young and middle-aged adults in many developed countries? In New Zealand the average age of diagnosis is 38. Usually diagnosed between 20 and 50, it's a prime time for careers, families and building a future.

You might look at a person with Multiple Sclerosis and think **"But you look fine. You don't look sick."** But what you don't see are the daily struggles, the overwhelming fatigue making daily tasks impossible, the chronic pain, the blurred vision, the spasticity or inability to lift your own hand.

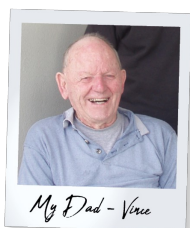
One of the most difficult parts of Multiple Sclerosis is living with the unseen symptoms.

Everyone's story and experience of MS is different. This [Awareness Week](#), we wish to share with you real stories from New Zealanders who have been impacted by this disease. These people have chosen to share their MS stories wishing to increase the knowledge and understanding and to inspire others to live well with MS.

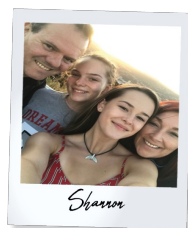
**Click on the images below to read their full stories or review all [here](#).**



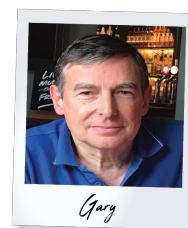
*Sarah*



*My Dad - Vince*



*Shannon*



*Gary*

"I wish to change the perception of what Multiple Sclerosis looks like and give hope to others that MS is not a death sentence and doesn't mean that you can't keep doing the things that you love."

"He died with MS, not of it and he proves that a diagnosis of MS does not always mean an early end to life. He lived a long and full life, managing his illness and carrying on anyway."

"My mum never gives up and doesn't let anything keep her down. She is so positive and inspiring. Her MS journey has not been an easy one but she always finds a way to come out on top."

"Life does change when you have Multiple Sclerosis, you can still enjoy a great life, a joyous life, a life full of love. Do not let Multiple Sclerosis define you or who you are."

Every day is different for a person with MS.

Symptoms can come and go, they might go through periods of relapse and recovery, or they can get progressively worse over time. Multiple Sclerosis is a highly complex condition and affects everyone differently. Due to this, Multiple Sclerosis is still relatively unknown and misunderstood.

MS is a chronic and life-changing condition BUT with access to support, early diagnosis, treatment and lifestyle modifications people with MS can live long, happy and fulfilled lives.

Living well with MS is possible but they need your support!

PLEASE DONATE

## MS Awareness

### What is MS?

Multiple Sclerosis is a complex disease, affecting each person diagnosed differently. To help with any unanswered questions, we have developed this introductory video.

[WATCH HERE](#)

### What is Multiple Sclerosis?

ms.



Graham, a member of our Executive Committee, a Face of MS and President for [Multiple Sclerosis Taranaki](#) was fortunate to recently feature in a [Roche Portraits of MS](#) video.

*"It's been a very interesting journey. A lot of doors closed, but also a lot of doors opened"*

[WATCH HERE](#)

### What is the Economic Burden of MS?

An important question that no one could answer. Thanks to the help of our supporters, we commissioned the New Zealand Institute of Economic Research to review the social and economic impact of Multiple Sclerosis in New Zealand. The results will support us with furthering our goal of fighting for the health and wellbeing of New Zealanders with MS and will provide the government with evidence to make informed decisions about access to vital treatment.

[WATCH HERE](#)

### What is the social and economic impact of Multiple Sclerosis in New Zealand?

ms.



### Addressing the unmet need

Currently, only approximately 1900 of the over 4130 New Zealanders diagnosed with MS are able to access funded Disease Modifying Therapies. In particular, those with progressive forms of MS, Secondary and Primary Progressive MS, have extremely limited access options.

Changes advocated for by MSNZ and approved within the last 18 months, mean some of those with Secondary Progressive MS *may* now be able to access DMTs.

[READ MORE](#)

### Progress in making aHSCT an available treatment option in NZ

aHSCT is a life-improving treatment halting the disease and disability in its tracks. A person receiving aHSCT will potentially need NO further treatment.

We recently supported Joan in her [petition to Parliament](#) to make aHSCT accessible here in New Zealand. We have since made a submission to the Petitions Committee and are calling on the Government and Health NZ to allocate the necessary resources to make aHSCT an available treatment for patients with Multiple Sclerosis.

[READ MORE](#)



## MS Awareness Events



### Understanding MS Course

'Understanding Multiple Sclerosis (MS)' is a free online course that aims to improve understanding and awareness of MS.



Sign up today and increase your knowledge of MS-related issues.

[READ MORE](#)

### Research Trust Webinars

The 2022 webinar series from the Multiple Sclerosis Research Trust continues with the Epstein-Barr virus discussion later this month and in October they delve into looking into your bodies inside and out.

#### Webinar 2 - Epstein-Barr Virus

Bookings can be made via Eventbrite following [this link](#).

#### Webinar 3 - Looking after our bodies inside and out

Bookings can be made via Eventbrite following [this link](#).



### NZBRI MS Webinar

New Zealand Brain Research Institute presents Dr Deborah Mason speaking about epidemiological studies completed recently in NZ and how they allow us to measure health outcomes for people with Multiple Sclerosis.

[WATCH HERE](#)

## Support



### Alysha's Daily September climb for MSNZ

"Help me on my journey of climbing the Eiffel tower (129 stories) everyday in September to raise money for MSNZ!"

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### Moving for MSNZ - Taupo 50km Ultramarathon

"MS symptoms have a tremendously negative impact on the quality of life for people and their friends/family living with MS. Despite these challenges, I've been incredibly inspired by some of the positive stories - a great reminder not to take my own ability to run (no matter how amateur) for granted.

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### Turn 50 cents into \$50,000

We are delighted to be one of 16 charities taking part in the 5050 Lottery, where you can support us for as little as 50 cents a ticket to have the chance to win the top prize of \$50,000 in cash.

Why not select us as your charity of choice to be in it to **WIN** it. Lottery drawn 5th October 2022.

We love to share real life stories, if you would like to **share your MS story** with the MS Community, please get in touch:

[info@msnz.org.nz](mailto:info@msnz.org.nz)

**Thank you** for your continued support, it has helped us to achieve so much to those impacted by MS.



P.S. Please check our our [Latest News](#) section on our website for updated guidelines and information.



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