

Media release 28 August 2017

New research justifies increased access to restricted drug treatments for people with MS

The Multiple Sclerosis Society of New Zealand (MSNZ) has met with senior executives of PHARMAC requesting a review of the current criteria for access to drugs that help to reduce the effects of multiple sclerosis (MS).

The current criteria were last reviewed in 2014. Since then, new research has shown that people with MS derive significant benefits from the drugs long after the disease has progressed beyond the scope of PHARMAC's current Special Authority Criteria, when funding for the drugs ceases.

"PHARMAC's criteria no longer meet international recommendations to minimise disease activity and maximise the lifelong brain health for people with MS," says MSNZ Vice-President Neil Woodhams.

"Currently people with MS in NZ experience greater restrictions accessing MS drugs than most other first-world countries. We want to work with PHARMAC to change this and ensure that New Zealand provides the best level of care for people with MS based on the growing evidence available."

In late June MSNZ presented PHARMAC with a report on the current research showing recommended changes to the current drug approval criteria which would enable more people to access life-changing treatments. Following the meeting an official submission was made to PHARMAC's Pharmaceutical Technical Advisory Committee (PTAC) in July 2017.

"We are pleased that PHARMAC has agreed to listen to our recommendations. In the past three years four new treatments have been made available by PHARMAC which are helping more people to stay in the workplace and stay off benefits. The treatments are dramatically reducing the disabling effects of MS. We want to help more people access these benefits earlier and for a longer time than the current criteria allows."

The current criteria require people with relapsing remitting MS to have had a confirmed diagnosis of MS with a relapse or second recorded episode. "While we understand the restrictions around not putting people on treatment until diagnosis is confirmed, which is often after a second relapse of symptoms, there is a select group of people with MS who would benefit from immediate access to treatment. Delay puts these people at further risk of irreparable disability and potentially means that they will not qualify for treatment at a later stage," says Woodhams.

In addition, MSNZ wants to work with PHARMAC to review the system used to assess treatment success. Currently only one measure is used which measures ambulatory disability, or difficulty with mobility. Research shows the profound effect that these treatments are having on people's cognitive function and in minimising fatigue, factors which can often be the main barriers to people with MS working or engaging in social activities.

"We want to keep people in the workplace, engaged with their communities, and supporting their families. People should be supported to live the best life possible and MSNZ wants to help them do that," says Woodhams.

"MS doesn't just affect the person diagnosed but also their children, partners and carers."

(continues on pg 2)

The costs of MS in NZ are not well understood but overseas studies have shown that overall costs increased markedly as the disease progresses.

“MS is a chronic condition which people can live with for 30 years or more. Most of the costs, particularly in later stages of the condition, fall on the individual, family, and community.

“We believe that the information received from multiple studies worldwide clearly demonstrates the need for changes to the current criteria. We have met with PHARMAC and made a formal submission which we understand will be reviewed at the September PTAC meeting. We look forward to working with them to improve access to life-changing treatments for hundreds of people in New Zealand who could benefit from access right now and those who are yet to come.”

ENDS

Media enquiries:

Neil Woodhams

MSNZ

Email nbw@xtra.co.nz

Ph 021 531 654

Multiple Sclerosis Awareness Week:

Multiple Sclerosis Awareness Week takes place this 28th August – 3rd September 2017. The Multiple Sclerosis Society of New Zealand (MSNZ) is a non-profit organisation that advocates for systemic change so people with MS in New Zealand have access to first world treatment, resources and services to improve their well-being and quality of life. The work of MSNZ aims to reduce the burden of MS on those diagnosed, their carers and families. MSNZ provides support, information and educational resources to 18 independent Regional Societies supporting people living with MS in their communities.

Please consider giving generously this MS Awareness Week online and to Street Collectors to help MS Organisations continue to provide support and advocacy to people living with this life-long and life-changing condition.

For more information about MSNZ please email info@msnz.org.nz, call the 0800 MS LINE (67 54 63) or visit www.msnz.org.nz

About Multiple Sclerosis:

- MS is a progressive disease of the central nervous system, for which there is no cure at present
- MS affects 2.3 million people worldwide
- There are approximately 4,000 people living with multiple sclerosis in New Zealand
- 134 people are diagnosed with MS on average every year
- More women than men have MS, with a global ratio of three women to one man
- Diagnosis of MS is generally between 20 and 40 years of age, although onset may be earlier
- MS attacks the nervous system. Symptoms can include sight loss, pain, fatigue, incontinence and disability
- Early diagnosis and treatment are important
- MS is unpredictable - one day you can be fine, the next you might lose your sight or be unable to move