

Petitions Committee Secretariat
Parliament Buildings
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Wellington 6160



Via petitions@parliament.govt.nz

25 August 2022

**RE: Submission to the Petitions Committee to the invitation to make a written submission relating to:
Petition of Joan Perry: Provide Stem Cell Replacement Therapy for MS Patients in NZ**

A Summary of the key information has been provided in this official response. Expanded detail is provided in Appendix 1¹.

Notes on the Submission Makers

This submission to the Petitions Department has been prepared collaboratively by the original petition submitter Joan Perry along with the national society of MS organisations in NZ, Multiple Sclerosis New Zealand (MSNZ).

About MSNZ

MSNZ is the national organisation advocating for people with MS (PwMS) and their whānau to improve their health, quality of life and wellbeing.

MSNZ has been advocating for the availability of autologous Hematopoietic Stem Cell Treatment (aHSCT) since 2017 following the undertaking of an independent evidence review². That advocacy has been driven by expressed needs of those impacted and backed by scientific evidence.

About Joan Perry

Joan Perry is the mother of a person with MS who underwent aHSCT in India in 2019. Her daughter Anne has been in remission since her treatment and returned to work as a nurse vaccinator. After seeing the life-changing impacts of aHSCT on her own family she set up this petition to help ensure other families get the same opportunity without the financial expense and mental health impacts of sending a loved one overseas for a treatment that is readily performed here in NZ.

Oral Submission

We request that:

- 1) As the petition submitter, Joan Perry be permitted to make an oral submission to the Health Select Committee *online*. Joan would like to request a Support Person, her daughter Anne Besley.
- 2) As the National patient advocacy group for the MS community, Multiple Sclerosis NZ be permitted to make an oral submission to the Health Select Committee *in person*.

¹ Expanded Information Document, Appendix 1

² aHSCT Research Review Report prepared for MSNZ - June 2017

The issue we are concerned about

Multiple Sclerosis is the most common acquired chronic, progressive neurological condition affecting young adults with the average age of diagnosis being 38 in NZ. Women three times more likely to be diagnosed.

Latest estimates based on prevalence, incidence and mortality data indicate there are in excess of 4130 people currently diagnosed with MS in NZ.³

NZIER in its *2021 Economic Burden of MS Report*⁴, commissioned by MSNZ, estimated total cost to the health system in 2021 was \$130.5m annually. This represents an average cost of \$31,607 per case of MS per year.

Eight Disease Modifying Therapies (DMTs) are currently funded by Pharmac. Only 1900 people with relapsing forms of MS are eligible⁵. Two of the most commonly used treatments, Natalizumab (Tysabri) and Fingolimod (Gilenya), have an average yearly costs per patient of \$19,915 and \$31,790, respectively. Patients potentially can remain on DMT over their lifetime, potentially 25+ years.

aHSCT is an intense chemotherapy treatment which aims to wipe out harmful immune cells and rebuild the immune system. aHSCT is a life-improving treatment halting the disease and disability in its tracks. A person receiving aHSCT will potentially need NO further treatment. Following treatment, many PwMS report improvements to mobility, cognition and fatigue. These symptoms are major barriers to maintaining employment, providing for families and contributing to the economy. Following treatment many return to paid employment.

In studies comparing clinical outcomes of aHSCT to available DMTs, aHSCT outperforms conventional treatments. Results show higher rates of improved disability, halted progression, reduced relapses, reduced brain lesion volume and overall improved quality of life. aHSCT can be a safely managed and efficacious treatment option⁶.

AHSCT is already routinely performed across NZ as a treatment for blood cancer. Despite the clinical evidence and high-level clinical support for its use⁷, patients in NZ with active relapsing MS are still being denied access to this proven, cost-effective treatment.

Currently PwMS are privately raising between \$70-\$120,000 to pay for overseas treatment. Going overseas places undue mental, physical and financial pressures on PwMS and their whānau. The cost of delivering aHSCT in NZ has been calculated to be \$50,000 per patient⁸. The Cost Benefit analysis done by the Northern Region Clinical Working Committee shows that the cost is less than the cost of DMTs for two years.

What would we like Parliament to do?

We are calling on the Government and Health NZ to allocate the necessary resources to make Autologous Haematopoietic Stem Cell Transplantation (aHSCT) an available treatment option in NZ for patients with multiple sclerosis.

³ Economic Burden of MS Report 2021, New Zealand Institute of Economic Research, Appendix 2

⁴ Economic Burden of MS Report 2021, New Zealand Institute of Economic Research, Appendix 2

⁵ OIA Response from Pharmac Provided to MSNZ 31 August 2021. Available on request.

⁶ Expanded Information Document, Appendix 1, Pages 2-4

⁷ Relevant page (P146) from an OIA Response from MOH provided to MSNZ regarding aHSCT, received 31 August 2021, Appendix 4

⁸ OIA Response from ADHB Provided to MSNZ regarding aHSCT, 1 July 2021, Appendix 3

How would this resolve the issue?

- aHSCT has been shown it can be a safely managed and efficacious treatment option, outperforming currently available DMTs in multiple studies⁹.
- Clinical experts in NZ have already reviewed the evidence and expressed support for aHSCT for appropriate patients.¹⁰
- A DHB initiated cost-benefit analysis has demonstrated a payback within two years compared to the cost of DMTs.¹¹
- aHSCT is already widely performed in NZ for blood cancers.
- NZ has the capabilities to perform aHSCT for MS¹².
- Making aHSCT an available treatment option in NZ has clinical benefits for patients and cost benefits for the health budget.

Clinical Support

At the recent MS Neurologists Meeting held in Queenstown on Friday 12th and Saturday 13th August 2022, the MS specialists and neurologists in attendance discussed aHSCT for PwMS. There was general discussion acknowledging that aHSCT is a recognised treatment for patients with aggressive active multiple sclerosis.

It has been proposed that a committee of NZ Neurologists be formed to review cases which fit an agreed NZ criteria. With agreement of the Committee they should be put forward for treatment. While some DHBs have the capabilities and capacity, the concern is around equity of access nationally. Chair of this Committee Dr Jennifer Pereira, Auckland DHB Consultant Neurologist, is happy to discuss this further.

Also in support are Dr Deborah Mason and Dr John Mottershead, Consultant Neurologists and MS Specialists at Canterbury and Southern DHBs, respectively. Both are also willing to speak to their support of aHSCT for appropriate MS patients if required.

Thank you for considering our submission. Should you have any questions or require any further information we would be happy to supply these where available. We hope to be able to answer any further questions at an oral submission.

Yours faithfully,



Neil Woodhams, ONZM
MSNZ President



Joan Perry
Petition Submitter



Amanda Rose
MSNZ National Advocacy Manager

⁹ Expanded Information Document, Appendix 1, Pages 2-4

¹⁰ Relevant page (P146) from an OIA Response from MOH provided to MSNZ regarding aHSCT, received 31 August 2021, Appendix 4.

¹¹ OIA Response from ADHB Provided to MSNZ regarding aHSCT, 1 July 2021, Appendix 3, Page 8

¹² OIA Response from ADHB Provided to MSNZ 1 July 2021, Appendix 3, Page 1



Multiple Sclerosis
New Zealand

Appendices

Attached to this submission for reference are 6 items:

- 1) Expanded Information Document prepared by MSNZ
- 2) Economic Burden of MS Report 2021, New Zealand Institute of Economic Research
- 3) OIA Response from Auckland DHB regarding aHSCT provided to MSNZ 1 July 2021
- 4) Relevant page (P146) from an OIA Response from MOH provided to MSNZ regarding aHSCT received, 31 August 2021
- 5) aHSCT Research Review Report prepared for MSNZ - June 2017
- 6) Letter of Support from Dr John Mottershead