

NZMS AHSCT Participant Questionnaire

Section 1: Information about you

What is your date of birth? (<i>Day/month/year</i>) _____
What is your gender? <input type="checkbox"/> Female <input type="checkbox"/> Male <input type="checkbox"/> Another gender. Please specify _____
What was your sex at birth (<i>For example, what was recorded on your original birth certificate?</i>) <input type="checkbox"/> Male <input type="checkbox"/> Female
Which ethnic group do you belong to? <i>Mark the space or spaces which apply to you</i> <input type="checkbox"/> New Zealand European <input type="checkbox"/> Maori <input type="checkbox"/> Samoan <input type="checkbox"/> Cook Islands Maori <input type="checkbox"/> Tongan <input type="checkbox"/> Niuean <input type="checkbox"/> Chinese <input type="checkbox"/> Indian <input type="checkbox"/> Other. Please state _____
Have you ever smoked? <input type="checkbox"/> Yes <input type="checkbox"/> No
If you are a current or ex-smoker: Over what period(s) have you smoked continuously? (<i>For example 2000-2002 and 2006-2007</i>)

What is the current combined income of your household?

This is potentially sensitive information. If you would prefer not to answer please tick prefer not to say.

- Prefer not to say
- 0-20,000 NZD
- 20,000-30,000 NZD
- 30,000-50,000 NZD
- 50,000-70,000 NZD
- 70,000-100,000 NZD
- 100,000-130,000 NZD
- 130,000-160,000 NZD
- More than 160,000 NZD

What city/town and suburb did you live in at the time of your transplant?

What is your highest secondary school qualification?

- NCEA level 1 / School certificate / other equivalent
- NCEA level 2 / University entrance / other equivalent
- NCEA level 3 / Bursary, Scholarship / other equivalent

If you have a tertiary qualification, what qualification is it?

- Bachelor's Degree
- Masters Degree
- PHD

Were you employed in work or study before being diagnosed with MS?

- Yes (full time)
- Yes (part time)
- No

Did your experience with MS impact your ability to work or study continuously for more than two months?

- No
- Yes - unable to work/study
- Yes - reduced work/study hours

Were you employed in work or study after your stem cell transplant?

- Yes (full time)
- Yes (part time)
- No

Section 2: Information about your experience with multiple sclerosis before your transplant

We have asked for consent to access your medical records. This will be the primary source of clinical information collected in the study. Your answers to the questions below will help us make sure the clinical record is complete.

If you do not know the answer to any of these questions please leave them blank.

In what month and year did you have your **first symptoms** of MS?
(This means the time that you first had symptoms, which may have occurred some time before you were diagnosed with MS. If you don't know the month but do know the year, just answer for year)

Month:

Year:

What were the first symptoms of MS that you had (tick all that apply)

- Loss of vision in one eye
- Blurred vision
- Weakness of the arms or legs
- Loss of feeling or sensory change in the arms or legs
- Bowel or bladder problems
- Other- please specify

In what month and year were you **diagnosed** with MS? *If you don't know the month but know the year, just answer for year*

Month:

Year:

Where were you diagnosed with MS? *If you were diagnosed in New Zealand, this means the hospital where you saw the specialist who first gave you the diagnosis.*

Did you have a lumbar puncture around the time of your diagnosis with MS?

Yes

No

When you were first diagnosed with MS, what pattern of MS were you told that it had?

Relapsing-remitting MS

Primary progressive MS

Secondary progressive MS (relapses and then progression)

If you were initially diagnosed with relapsing-remitting MS, were you ever told that your MS had become progressive?

If so, what year did that happen?

Yes What year was this? _____

No

How many relapses of MS did you have before your transplant? _____

In what years did these happen (some relapses may have occurred in the same year)?

What type of doctor was responsible for the care of your MS before your transplant?
Many people would have seen a number of different doctors over time. We would like to know about the doctor most involved with your care leading up to your transplant

- Neurologist
- General Physician (hospital doctor who is not a Neurologist)
- General Practitioner

Did you receive any disease-modifying medications for MS before your stem cell transplant?

Examples of these include interferon, copaxone, tecfidera, gilenya, tysabri, aubagio and ocrevus

- Yes Please list which medications:
- No

In what year did you start treatment for MS?

Do you have any other health conditions? (Please list)

Section 3: Information about your transplant

Where did you go to have your stem cell transplant done? *The most important information is the country that you went to, if you can't remember the name of the hospital that is ok*

How long in total did you spend overseas when you had the transplant?

How long did you stay in hospital for? *If you were admitted to hospital more than once please tell us about more than one inpatient stay*

Do you have any documentation about the type of transplant that you received?

- Yes
- No

*If you consent for us to have copies of this information, please send it to us.
If you do not consent for us to have this information, but are willing to share other details about the transplant, please describe below:*

Did you experience any side-effects or complications from the transplant?

- Infection
- Symptomatic side-effects (such as pain, fever, diarrhoea)
- Autoimmune (such as developing an autoimmune thyroid problem)
- Heart problems
- Kidney problems
- Allergic reaction
- Other (please state): _____

Were you re-admitted to hospital due to side-effects or complications from the transplant?

- Yes
- No

Section 4: Fertility after transplant

This section applies to people of all genders

Were your sperm or eggs collected before your transplant?

- Yes
- No

Did you experience any difficulty with fertility after your transplant? *This applies to people of all genders. It means difficulty conceiving a child without medical assistance such as in vitro fertilisation.*

- Yes
- No

Did you have a child after your transplant?

- Yes
- No

Was this child conceived via in-vitro fertilisation (IVF) following sperm, egg or embryo banking prior to your transplant?

- Yes
- No

Section 5: Financial cost of transplant

How much did your stem cell transplant cost? *Please state in New Zealand dollars if possible. If using another currency please state which currency.*

Did you receive any financial support for your transplant? *Please tick all that apply*

- Friends/family
- Crowdfunding (e.g. Give a little)
- Non-profit organisations

Section 6: Outcomes of your transplant

How do you feel your MS has progressed overall since your transplant?

Improved

Of these common symptoms of MS, which have you noticed an improvement in?

- Pain
- Sensory
- Mobility
- Urinary
- Fatigue
- Balance
- Cognition
- Vision
- Other _____

Stable

Declined

Of these common symptoms of MS, which have you noticed a decline in?

- Pain
- Sensory
- Mobility
- Urinary
- Fatigue
- Balance
- Cognition
- Vision
- Other _____

Have you had any relapses of MS since your transplant?

- Yes
- No

If you have had relapses, how many relapses have you had? _____

Which year(s) did relapse(s) occur? _____

Have you taken any medication for MS since your transplant?

- Yes
- No

If so:

- Which medication(s)?

- When did you start this medication (s):

What was your overall experience of undergoing this transplant?

Is there anything else that you would like to tell us about your transplant?