

## Registration form for the NZ NMD Disease Registry Duchenne and Becker Muscular Dystrophy [DMD\_DATA]

Thank you for agreeing to participate in the New Zealand Neuromuscular Disease Registry. Please ensure you have read and signed the Participant information sheet and consent form. To complete your registration you will need to fill in this form and return this form. You may like to complete it with the assistance of your doctor. Alternatively, if you are not certain about the answer to any question please discuss this with the registry curator.

### MANDATORY ITEMS

(For your details to be included in the global registry you must complete all of these questions.

**I am: (please tick as appropriate)**

<input type="checkbox"/>	The participant
<input type="checkbox"/>	The patient's representative

All of the following questions relate to the participant's with the condition

### 1. The participant's personal details:

Sex:	male / female (delete as appropriate)		
First name(s):			
Family name:			
Date of birth:	/	/	(dd / mm / yyyy)
Ethnicity (Do you identify yourself as . please circle the one that is most appropriate)	NZ European	Maori	Samoan
	Cook Island Maori	Tongan	Niuean
	Chinese	Indian	Other
NHI number:			
Address			
Postcode:			
Email:			
Home Phone:			
Mobile:			

**2. Please provide the name of your GP below giving us permission to contact your GP directly if we require further information to complete your registration.**

GPs Full name:	
Medical Practice Address	
Email:	
Medical Practice Phone:	

**3. If you are the participant's representative (parent/guardian), please provide your details:**

Full name:	
Address	
Email:	
Phone:	
Relationship to the participant	

**4. What is the participant's genetic test result?**

It is very important that your genetic test result is entered correctly into the registry. If you do not know your exact result, or you are not sure how to fill it in correctly, please provide the name of the hospital or doctor who requested your test. The registry curator will contact them to ask for the result on your behalf. Please include a copy of your test result if you have one.

Mutation name in DMD gene following HGVS rules (based on cDNA Ref Seq):

c. \_\_\_\_\_

**5. What is the participant's diagnosis, according to your doctor?**

<input type="checkbox"/>	Duchenne Muscular Dystrophy (DMD)
<input type="checkbox"/>	Becker Muscular Dystrophy (BMD)
<input type="checkbox"/>	Intermediate Muscular Dystrophy (IMD)
<input type="checkbox"/>	Female carrier
<input type="checkbox"/>	I don't know

**6. Current mobility (please tick the most appropriate answer):**

<input type="checkbox"/>	The participant is currently able to walk (with or without help/support)
<input type="checkbox"/>	The participant is currently not able to walk

**7. If the participant is 3 years old or more, does he/she have to use a wheelchair?**

<input type="checkbox"/>	The participant uses a wheelchair permanently (started full-time use at age: _____ years) (Uses a wheelchair any time he/she needs to get around)
<input type="checkbox"/>	The participant uses a wheelchair part-time/intermittently (started at age: _____ years) (Walks short distances and uses a wheelchair only for longer distances)
<input type="checkbox"/>	The participant has never used a wheelchair
<input type="checkbox"/>	Unknown

**8. Does the participant take steroid medication?**

	Yes, currently
	No, but previously
	The participant has never taken steroids
	Unknown

**9. Has the participant had spinal surgery for scoliosis?**

Scoliosis is a deformation or bending of the spine which may have required surgery.

	Yes
	No
	Unknown

**10. Does the participant currently take any medication for his or her heart?**

	Yes. Please give the name of the medicine:
	No
	Unknown

**11. Is the participant currently included in a clinical trial?**

	Yes, currently. Please specify:
	Previously participated in the following trial:
	No, he or she has never participated in a clinical trial
	Unknown

**HIGHLY ENCOURAGED ITEMS**

(We can still include your details in the global registry even if you can't answer all of these questions, but please answer as many of them as you can)

**12. Is the participant currently able to sit independently?**

Can he/she sit without the support of their arms or leaning against the back of the chair?

	The participant is currently able to sit independently
	The participant is not currently able to sit independently

**13. Does the participant have any signs of heart failure or weakness of the heart?**

	Yes
	No
	Unknown

If the participant has had an ultrasound scan (echocardiogram) of the heart, please fill in the result if you know it.

Left ventricular ejection fraction (LVEF):	%
Date of the test:	

**14. Does the participant regularly use a non-invasive ventilation device?**

A non-invasive ventilation device is a device to support breathing, that has not required an operation to use, for example a mask worn on the face (CPAP, BIPAP or VPAP)

	Yes, all day
	Yes, but only part-time (e.g. at night)
	No, never
	Unknown

**15. Does the participant use invasive ventilation?**

An invasive ventilation device requires an operation to use, for example a tracheostomy

	Yes, all day
	Yes, part-time
	No
	Unknown

If the participant has had pulmonary function testing, please fill in the result if you know it:

FVC (Forced Vital Capacity) % (predicted value)	
Date of the test:	

**16. Has the participant had a muscle biopsy?**

	Yes
	No
	Unknown

**17. Has the participant signed up for any other registry?**

	Yes (if yes, please specify:
	No
	Unknown

**18. Does anybody else in the participant's family have the same kind of disease?**

	Yes; if yes, please specify:
	No
	Unknown

Thank you for completing this form if you have any questions please do not hesitate in calling the Curator of the registry on **09-815-0247** or talk to your health care provider.