



TERMS OF REFERENCE

Muscular Dystrophy Association of New Zealand Inc. (MDANZ)

Member Reference Group – Spinal Muscular Atrophy (SMA)

MDANZ aims to establish a Member Reference Group for SMA comprised of individuals and parents of children, with lived experience of SMA. This group will bring a consumer perspective to the prioritisation and implementation of SMA related activities undertaken by MDANZ.

The formation of this group reflects the MDANZ core values of Empowering/Whakamanatanga, Proactive/Kōkiritanga and Connected/Tūhonotanga.

1.0 Purpose

The purpose of this Members Reference Group is to;

- Provide a forum to address SMA related issues within New Zealand
- Identify key regional and national priorities and provide recommendations to MDANZ and its clinical advisory group
- Provide a consumer perspective into relevant projects, service planning and other MDANZ activities that relate to the SMA population
- The Consumer Reference Group may also be utilised for DHB consultation, to inform the development of care standards and service delivery to the SMA population

2.0 Membership

2.1 The MDANZ SMA will consist of up to 8 individuals with lived experience of SMA as follows;

- i. Have to be a member of MDANZ
- ii. Adult with lived experience of SMA
- iii. Parent of a child or young person affected by SMA
- iv. Geographically located in different regions of New Zealand

2.2 MDANZ will appoint a convenor for the group, who shall also be considered a member of the group and support communication with internal and external stakeholders.



- 2.3 Selecting Members
 - 2.3.1 Expressions of Interest will be called for by MDANZ to maintain membership numbers
 - 2.3.2 Members are selected on the basis of;
 - i. Group composition
 - ii. Skills required
 - iii. Availability to attend meetings (either in person or by phone)
 - 2.3.3 New members must be ratified by the Chief Executive of MDANZ.

3.0 Duration and Terms of Membership

- 3.1 Reference Group members provide their time at no cost to the organisation, however reasonable costs (such as travel to a face to face meeting) will be reimbursed by MDANZ.
- 3.2 Reference Group members will be required to adhere to a code of conduct and may promote their role affiliation with MDANZ.
- 3.3 Attendance at all meetings is not compulsory to ensure membership, however apologies in advance would be appreciated if attendance is not possible.
- 3.4 Tenure is for a three year period, reviewed annually and consecutive terms can be held.
- 3.5 The Reference Group may be disestablished by MDANZ if it is deemed the group no longer fits the purpose outlined under point 1.0.

4.0 Group Procedures

- 4.1 A designated member of the MDANZ team will coordinate meetings, perform associated administration tasks, and write and circulate Minutes of each meeting.
- 4.2 The meetings will:
 - 4.2.1 Occur approximately once every two months;
 - 4.2.2 Be of approximately two hours' duration;
 - 4.2.3 Be at a venue which is determined and communicated well in advance of each meeting, with teleconference facility available to reduce cost and impact.
- 4.3 Members of the Reference Group and MDANZ staff are able to contribute agenda items, however they should be submitted more than a week in advance of the meetings to allow time for the agenda to be prepared and circulated.
- 4.4 All members will keep confidential
 - 4.4.1 All discussions within meetings; and

- 4.4.2 All documentation related to the Reference Group; except for agreed communication to be shared with the community and stakeholder groups.
- 4.5 Group members may be asked, from time to time, to consider issues and respond outside of a meeting.
- 4.6 Between meeting discussions and outcomes that occur by email and/or telephone will be actioned as appropriate and recorded for reference at the next scheduled meeting time.

5.0 Decision making

- 5.1 Overall decision making accountability remains with the Chief Executive and National Council of MDANZ.
- 5.2 As this is a Reference Group to promote a consumer voice to support operational planning, MDANZ undertakes to respect and consider all advice and recommendations presented by the group.
- 5.3 Recommendations from the Reference Group may inform organisational priorities and/or the MDANZ Annual Operating Plan.

6.0 Minutes and Agendas

- 6.1 MDANZ will appoint a meeting coordinator who will be responsible for convening the meeting and providing administration support.
- 6.2 Following discussion of issues, the Reference Group will provide summarised, formal recommendations which are included in the meeting Minutes.
- 6.3 Minutes of Advisory Group meetings will be shared with the Chief Executive, the MDANZ Clinical Advisory Group and where relevant, with the National Council.