

Can you contribute to the collective voice of the Queensland Neuromuscular Community?

Muscular Dystrophy Queensland is seeking enthusiastic community members, who are keen to collaborate as a group and represent the voice that exists in Queensland's neuromuscular community.

The Community Liaison Group (CLG), will ultimately comprise of 10-12 individuals, who together will aim to provide strategic and high-level operational advice to Muscular Dystrophy Queensland's CEO and board, on matters relating to our neuromuscular community.

Specifically, we are seeking individuals who are willing to reflect upon and share their personal lived experience and knowledge, for discussion and consideration within the group, as well as listen to and consider the experiences and voices of others.

If you are keen to nominate then we would love to hear from you! Please take the time to read the below the Terms of Reference (TOR), which is then followed by the Expression of Interest (EOI) form and how to nominate for the CLG.

Terms of Reference

Purpose: The purposes of Muscular Dystrophy Queensland's Community Liaison Group (CLG) to be

the voice of Queensland's neuromuscular community and to provide strategic and high-level operational advice to Muscular Dystrophy Queensland's CEO and board on

matters relating to our neuromuscular community.

Proviso: The Community Liaison Group is a conduit for communication from community

members to the board in an advisory capacity. This feedback and communication will be valued, however Muscular Dystrophy Queensland reserves the right to make independent

decisions which benefit both the community and the organisation.

Membership: Muscular Dystrophy Queensland's Community Liaison Group will consist of the following:

- A Muscular Dystrophy Queensland Director
- Chair of the Committee
- 10 12 committee members.



During the selection process, consideration will be given to inclusion of an equitable distribution of diverse¹ segments from community members who have placed an Expression of Interest (EOI).

Members need to have lived experience of a neuromuscular condition as well as be in a position to actively contribute to committee undertakings.

Selection:

A selection panel, which will include a staff member, a board member and a community member, will be formed to select CLG Members. Nominations for CLG Membership will occur via multiple processes as follows:

- Response to an Expression of Interest
- Recommendations made by Directors, staff and others.

Decisions will be based upon:

- equitable representation from our community
- skills and experience of nominees

Decisions of the selection committee will be final. Tenure will be for a maximum of 3 years following which an entirely new selection process will be undertaken.

Financial:

At this stage, membership will be on a voluntary basis. If pre-approved costs are incurred by members, they will be reimbursed by Muscular Dystrophy Queensland.

Meetings:

The quorum for meetings is five Community Liaison Group members. Meetings will be of maximum 1.5 hours duration. Respectful collaboration is required during each meeting.

Place of meetings:

Via agreed online digital video conferencing facilities.

Frequency:

The committee will meet quarterly, with additional meetings scheduled when necessary.

Roles:

Director: This person will contribute as a full member of the group and preference will be for a Director with lived experience of a neuromuscular condition. This person will be nominated by a board member and will be appointed to the CLG for a 12-month period (which can be extended for further 12-month period as needed). It is the responsibility of the Director to report the activities and decisions of the CLG to the board.

Chair: The CLG selects a Chair from their group for a 12-month period. The Director is excluded from being the Chair. The Chair runs the meeting and ensures that each member has equitable input into the business of the meeting. The Chair will liaise directly with the Team Leader – Client Services re topics arising from the meetings or between meetings.

Gender; First Nations and cultural diversity; LGBTI+Q representative; life role and stage, for example parent of a child with a neuromuscular condition, young adult, working person, retired person; people funded under different systems, for example NDIS, aged care, unfunded; regional Queensland represented; multiple conditions; range of socio economic and other circumstances.



Secretary: The CLG selects a Secretary from their group for a 12 month period. The Secretary collects and distributes agenda items and writes and distributes minutes of the meeting after their content has been approved by the Chair. Minutes will capture key deliberations, recording options for action and recommendations for the CEO and/or board to endorse or decide upon. Minutes are distributed after each meeting and also circulated prior to each subsequent meeting, with agenda and any relevant papers.

Substitute Chair/Secretary: If the Chair or Secretary is an apology for the meeting, the group will choose a substitute for that meeting.

Community Liaison Group members: CLG members will seek to represent the entire community in a collaborative and productive manner. They will provide input to the agenda and will contribute in a positive way to the discussions undertaken in meetings.

*The CLG is not a place for the promotion of personal interests or issues for representing members

Muscular Dystrophy Queensland Support person: The Team Leader – Client Services will provide guidance and support to the CLG and will work with them and the CEO to continually improve its relevance and reach.

The Role of Muscular Dystrophy Queensland in the Community Liaison Group

Muscular Dystrophy Queensland's role is to support the committee in their independent deliberations and recommendations.

Muscular Dystrophy Queensland's role is NOT to:

- Participate actively in meetings.
- Provide personal opinions about the issues being addressed.
- Attempt to influence decisions of the group.

The Muscular Dystrophy Queensland representative is responsible for the following specific tasks:

- Induction of new committee members re the purpose and duties of the group.
- Support of the Chair and Committee Secretary in their tasks.
- Provision of a representative from the organisation to attend each meeting of the committee.
- Incidental support and communications between meetings.
- Provision of ongoing information from the sector re issues under discussion.
- Resolution of disputes which are escalated to the organisation.
- Ensuring that general administration tasks which cannot be completed by the Committee are completed.

The CEO will:

- Attend relevant meetings (if required)
- In consultation with the Director, include a summary report in the monthly CEO report to the Muscular Dystrophy Queensland board of Directors.



Work of the Community Liaison Group

The committee is representative of our community, providing advice which includes but is not limited to the following:

- Input into Muscular Dystrophy Queensland's strategic decision making, and specifically our Strategic Plan.
- Regular review of and recommendations for Muscular Dystrophy Queensland's charitable services.
- Advice re priorities in Muscular Dystrophy Queensland's operational plan and assistance with the development of any agreed new programs.
- Liaison between Muscular Dystrophy Queensland's community members and CEO/ Directors on topics of concern.
- Understanding current research priorities and making recommendations to the senior staff re research studies and clinical trials which need support.
- Providing input into Muscular Dystrophy Queensland's advocacy policies and plan.
- Input into program evaluations and providing recommendations following these evaluation reports.
- Provision of advice from the community members' perspective in fundraising and marketing programs.

It is evident that the group cannot equitably address all of the above and will provide advice to Muscular Dystrophy Queensland about their priority issues.

Adding Additional Responsibilities to the Community Liaison Group

The committee will formally approve any submissions for additional responsibilities with the following considerations to be taken into account:

- Alignment with stated purpose and priorities
- Other priorities which are being worked on at that time
- Budget limitations

Commencement

Meetings will hopefully commence in the 3rd or 4th quarter of 2022, depending on the time it takes to form and prepare the Committee.

Community Liaison Group Expression of Interest

Thank you so much for reading the above terms of reference regarding the Community Liaison Group and for looking to place an expression of interest. Please provide some further information on the specific circumstances which are relevant for your life, within the provided questions, to assist the selection panel. Please note that not all of the questions are obligatory, the types of questions which have been asked, are there to try and identify specific individuals who represent differing parts and elements of the overall community.

Expression of Interest

If you are interested in placing an expression of interest, then please complete the form online at **www.mdqld.org.au/communityliaison**

For any further enquiries contact Becky Mackenzie (Mon-Thurs) on (07) 3243 9700 or email: beckym@mdgld.org.au

We're stronger together