



## MISSION

The Mission of the Neurological Alliance of New Zealand (the Alliance) is to lead and advocate for quality lives and appropriate investment for neurological conditions in Aotearoa New Zealand.

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## TERMS OF REFERENCE

### 1.0 Purpose

The purpose of the Neurological Alliance is to:

- 1.1 Advocate for the best outcomes for those living with neurological conditions in Aotearoa New Zealand through Government and Health Service Providers
- 1.2 Provide an external Advisory role to the Government and Health Service Providers, supporting their development of strategic priorities, health policies, white papers, research programmes and funding models to address the needs of those living with neurological conditions

The goal of the Alliance is to ensure the:

- 1 in 3 Kiwis impacted by neurological conditions in their lifetime, and the
- 1 in 5 Kiwis who will pass away as a result of a neurological condition
- get the best outcomes from health service provision and scientific research in NZ

The Alliance will do this by:

- 1.3 Providing a forum for networking for mutual benefit and for organising around and making representations on matters of common interest
- 1.4 Promoting community awareness of the needs of people with neurological conditions
- 1.5 Promoting research into neurological disorders, their prevention, treatment and cure

- 1.6 Developing a trusted partner relationship between the Alliance and the New Zealand Government and its agencies
- 1.7 Monitoring relevant policies and guidelines of the Ministry of Health and other Government agencies
- 1.8 Taking part in enquiries and reviews on matters of interest to the Alliance

## **2.0 Membership and membership fee**

### **Membership**

- 2.1 The Alliance will consist of no less than 10 organisations / members, who are a New Zealand registered charity with the Charities Services; and:
  - 2.1.1 Affiliated health and disability service providers working in the neurological field in New Zealand or,
  - 2.1.2 Providers of services to raise education, understanding and awareness of neurological conditions to New Zealanders or,
  - 2.1.3 Support the funding of neurological research, or
  - 2.1.4 A regional organisation providing one or more of the outcomes above, where the regional organisation also provides a national leadership role for advocacy to their peers.
- 2.2 Member organisations will nominate a suitable representative to the Alliance who has the decision-making ability (direct or delegated) for matters raised at the forum
- 2.3 The Alliance will be chaired by a person appointed by the group
- 2.4 Nominations for membership of the Alliance should be made in writing to the Chairperson and Secretary and will be made on the basis of;
  - i. Not for profit organisational status
  - ii. Fit with the mission and purpose of the group
  - iii. Meeting one of the criteria for membership (sections 2.1.1 to 2.1.4)
- 2.5 Nominations for group membership must be supported by a majority of members of the Alliance
- 2.6 Members are entitled to use the Alliance's logo in line with any applicable brand guidelines

### **Membership fee**

- 2.7 Membership of the Alliance is on a paid annual fee which is documented in the Membership Policy document, updated annually

### **3.0 Advocacy and advisory services**

- 3.1 The Alliance will lead advocacy and advisory services on behalf of the members, to achieve its Mission
- 3.2 The advocacy and advisory services will be provided through one of the Alliance member organisations, with the funds received from the membership fee covering the operating costs for this work
- 3.3 The scope of this advocacy and advisory work includes (but is not limited) the following areas:
  - 3.3.1 Responses to proposed NZ Government policies,
  - 3.3.2 Preparation and submission of the Alliance's response to published papers requesting public feedback through consultation processes (eg. Select Committee's),
  - 3.3.3 Briefings for Ministers of Health, Disability (as appropriate) etc,
  - 3.3.4 Briefings for Te Whatu Ora / New Zealand Health leaders,
  - 3.3.5 Supporting material, surveys, data gathering required to support key messaging from the Neurological Alliance,
  - 3.3.6 Horizon scanning of Government and Health Sector developments that may be relevant to the Alliance and its purposes

### **4.0 Terms of Membership**

- 4.1 Member organisations should provide their time at no cost to the Alliance
- 4.2 Costs of participation (such as travel to a face to face meeting) will be met by the member organisations individually, not the Alliance
- 4.3 Member organisations will be required to adhere to a code of conduct and may promote their role affiliation with the Alliance
- 4.4 Attendance at all meetings is not compulsory to ensure membership, however apologies in advance would be appreciated if attendance is not possible, substitute representatives can be nominated to stand in for the usual attendee of any member organisation
- 4.5 Membership may be reviewed to reflect the focus and alignment of the group mission

### **5.0 Group Procedures**

- 5.1 The Secretary (or another member appointed by the group) will coordinate meetings, perform associated administration tasks, and write and circulate Minutes of each meeting

- 5.2 The meetings will:
  - 5.2.1 Occur on a face to face basis, or through online meeting tools at least once every six months or as decided by the group;
  - 5.2.2 Be at a venue which is determined and communicated well in advance of each meeting, with video or teleconference facility available to reduce cost and impact; or through online meeting tools (MS Teams or Zoom)
- 5.3 A quorum for any meeting of the Alliance is representation by at least 50% of the paid up members at the time of the meeting
- 5.4 Members of the group 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
- 5.5 All members will keep confidential:
  - 5.5.1 All discussions within meetings; and
  - 5.5.2 All documentation related to the group until approved by the membership for public release
- 5.6 Group members may be asked, from time to time, to consider issues and respond out of session
- 5.7 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
- 5.8 Working groups may be formed, from time to time, to take leadership on particular topics on behalf of the full Alliance membership. Updates from these working groups will be presented back at the Alliance's regular meetings

## **6.0 Decision making**

- 6.1 As this is a working alliance, agreed goals and decisions must be supported by a majority of members of the Alliance
- 6.2 No delegated authority is given to any member of the Alliance to act for another party
- 6.3 Advocacy priorities, specific goals and action plans will be established by the group. Action plans will be implemented in accordance with group consensus and available resourcing, with goals and action plans will be reviewed annually
- 6.4 Members in attendance at meetings have the authority to progress plans related to goals that have already been determined by the group
- 6.5 Working groups can make recommendations to the full Alliance membership, they do not have delegation to act on behalf of the Alliance