



Terms of Reference for the Dystonia Network of Australia Inc. (DNA) Advisory Board, December 2014.

To be posted, renewed and examined for any necessary amendments annually by the Advisory Board in consultation with the DNA committee.

Background

The Dystonia Network of Australia Inc. (DNA) is a new national association set up for adults and children with all types of dystonia. It has been registered as a not-for-profit organisation, and a charity, and will be run completely by volunteers. The principal objectives are as follows.

1. To provide appropriate, well-researched information and educational literature for adults and children with dystonia, their carers, families and interested health providers.
2. To increase community awareness of the condition by continued dissemination of information on dystonia.
3. To ultimately fund seminars and assist in research into dystonia.

Purpose

The purpose of the Advisory Board is:

1. To provide expert advice and guidance to the DNA committee on all matters concerning dystonia, in particular new treatments and research results.
2. To offer guidance on strategic planning and direction of the association.
3. To comment on and critique educational literature e.g. brochures and web site copy within the time frame requested by the DNA committee.
4. To support the association committee and members in the organising and delivery of educational seminars.
5. To advise the association on appropriate research projects.

Confidentiality

The contents of all documents, copy and booklets must be treated as confidential until published.

Structure

The Advisory Board will consist of up to 25 members and will include:

Movement Disorder Neurologists, Movement Disorder Paediatric Neurologists, Neurologists, a Geneticist, Neurosurgeon, General Practitioner, Physiotherapist, Neuroscientist, Pharmacist, Speech Pathologist, Specialist Movement Disorder Nurses, Occupational Therapist, Neuropsychologist and 3 Patient Advocates - 2 people living with dystonia and a carer of a child with dystonia.

New members will be appointed by the association committee in consultation with the Advisory Board. A chairperson will be elected by nomination from within the Advisory Board with majority agreement and will have a tenure of two years. Any disputes within the Advisory Board will be heard by the chairperson and an office bearer from the association.

Tenure

Tenure for Advisory Board members is renewed biannually with automatic renewal unless otherwise directed by the Advisory Board member or the association. Resignation of a member at any time during tenure requires one month's notice or by mutual agreement of the member and the association committee.

Advisory Board Meetings

A meeting will be scheduled annually to coincide with either the Movement Disorder Society of Australia Meeting or the Australia & New Zealand Association of Neurology Meeting. In general, communication between Advisory Board members and between the association and the Advisory Board members will be conducted via email with all communications copied to the Chairperson.

NB. The Advisory Board plays no role in the governance of the association, and the association committee is not required to act in accordance with any advice from or recommendation of the Advisory Board.