



**Senate Standing Committee on Economics**

**Senate Inquiry into the disclosure regimes for charities and  
not-for-profit organisations**

**Closing date:  
Friday 29 August**

Submitted by MND Australia via email

to: [ecomonics.sen@aph.gov.au](mailto:ecomonics.sen@aph.gov.au)

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## Background

MND Associations in Australia were formed during the 1980's to meet the varying and complex support, equipment and information needs of people living with MND their carers and their families. MND Australia was established in 1991 as a national peak body for motor neurone disease (MND). In 2008 the MND Australia network comprises of six MND Associations, representing all states and territories, and the MND Research Institute of Australia (MNDRIA).

MND Australia members work together to advance, promote and influence local and national efforts to achieve the vision of a *World Free from the Impact of MND*.

Motor neurone disease is the name given to a group of rapidly progressive degenerative neurological diseases that cause increasing and complex levels of disability leading to death, usually within five years of diagnosis. The most common form of MND is amyotrophic lateral sclerosis (ALS).

Currently around 1300 Australians are affected by MND and thousands more; family, friends and carers live daily with its effects. Each day at least one Australian dies of this cruel disease and a new person is diagnosed. Although MND was first described nearly 150 years ago there is still no known cause, no known cure and no effective treatment. Average life expectancy from diagnosis is about 27 months (Sach 2003). Average age of onset is 59 years; however, the age range of onset is 18 to 90 years.

The rapid progression of MND results in increasing support needs and reliance on a range of aids and equipment to maintain quality of life and social inclusion. Support needs can include assistance with: feeding, communication, breathing, movement, transferring, toileting and all daily activities. The social impact of MND is amplified by its complex nature, the speed of its progression and the spiralling series of losses, which pose:

- huge problems of adjustment for people who have MND;
- an escalating burden on carers and families; and
- a challenge to health professionals involved in meeting the variable and complex care needs, particularly in regional, rural and remote areas of Australia.

MND has a comprehensive impact on all aspects of living. While people of working age can remain at work after diagnosis, this is usually for a very short time, often only weeks or a few months. MND also impacts on the family carers ability to maintain employment.

During 2007/08 **493** people newly diagnosed with MND registered with MND Associations across Australia. During that period state Associations were informed of **431** people who had had lost their fight with MND. **989** people were registered with State Associations as of 1/7/08.

The motor neurone disease research institute of Australia (MNDRIA) provided \$370,000 for MND research in 2007.

## Submission

Each state Motor Neurone Disease Association is incorporated under their respective state Associations Incorporation Act. Motor Neurone Disease Australia (MND Australia) is incorporated under the *Associations Incorporation Act (Victoria)*.

As a consolidated entity the level of per annum funding to all 7 Motor Neurone Disease Associations would not exceed \$5million with NSW and Vic raising the majority, approximately \$2million each. Approximately 80% of the total funding is received through gifts, donations, events and bequests thus requiring greater transparency and accountability.

The disclosure requirements for not-for- profits, that depend on multiple funding avenues, stipulates the need to report to all stakeholders who may include:

- members,
- government funders
- ATO
- general public
- trusts and foundations

This level of reporting may be onerous but is always necessary. Reporting under state Acts is preferable to reporting to ASIC as the Australian Corporation Legislation and the *Corporations Act 2001* (Cth) focuses on the ability of the organisation to report to its shareholders or owners.

A push by some state government funders for not for profits to provide cost centred accounting, as opposed to a reporting chart of accounts as required by Australian Accounting Standards, increases cost dramatically for small organisations. Multiple accountabilities can be confusing, costly and, ultimately fraught.

In Woodward p106<sup>i</sup> conflict of interest is mentioned, as board members may represent “sectional interests”, placing them in a position of conflict under Corporations Law. Even board members volunteering, as they may have a family member being helped by a particular non profit, may find themselves in breach of ss182 and 184 of the *Corporations Act* by gaining advantage for themselves or someone else. In *R v Byrnes and Hopwood*<sup>ii</sup> found that whilst acting in the best interest of the company an ulterior motive was found. In our society seeking the best possible care for a loved one should not be considered a civil or criminal act yet under this objective interpretation of the *Corporations Act* a board member in the above situation may be deemed to have broken the law.

Recently most state and territories have taken steps to reform their respective Associations Incorporation Acts taking aspects of the *Corporations Act*.

Amendments proposed for the Associations Incorporation Acts 2008 (NSW) and similar legislation proposed in Victoria and South Australia include “to promote ethical standards the Bill imposes statutory duties of care, diligence, honesty and disclosure of interest on members of the management committee.”

## Conclusion

As mentioned not for profit organisations that rely heavily on multiple sources of funding will always have multiple reporting requirements.

However, MND Australia believes that:

- national legislation based on revised state and territory *Associations Acts* – rather than a new NFP company structure under Corporations Law - would be preferable to multiple Acts or the *Corporations Act*.
- a tiered system of reporting, depending on income as is in effect in most states and territories, should be reviewed with tiers broadened to incorporate large not for profits.

MND Australia would welcome the opportunity to provide further information.

**Carol Birks**  
National Executive Director  
MND Australia

[www.mndaust.asn.au](http://www.mndaust.asn.au)

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<sup>i</sup> Woodward, S. “Not-for-profit” motivation in a “for-profit” company law regime – national baseline data (2003) p102 Lawbook Co 21 C&SLJ.

<sup>ii</sup> *R v Byrnes; R v Hopwood* (1995) 13 ACLC 1488