

## **MULTIPLE SCLEROSIS AUSTRALIA**

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# **Submission to the Senate Select Committee Inquiry on Charity Fundraising in the 21st Century regarding the current framework of fundraising regulation for charities and options for reform**

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## **About Multiple Sclerosis Australia**

MS Australia (MSA) is the national peak body for people living with multiple sclerosis (MS) in Australia. Our role is to work on behalf of all state and territory based member organisations to provide a voice for people living with multiple sclerosis across the country to support the development of:

- Research
- Advocacy and awareness
- Communication and information
- Services provided by our member organisations
- International collaboration

MSA advocates across all stakeholders, governments and communities, on behalf of our members, to represent people who are diagnosed with MS, their carers and the broader MS community.

### **Our Vision**

Is consistent with the vision of the Multiple Sclerosis International Federation – **‘A world without MS’**

### **Our Mission**

MSA will support our members and work towards meeting the needs of people with MS, their families and carers. We will facilitate a national comprehensive representation of the Member organisations through advocacy and communication.

### **Our Purpose**

On behalf of our members and people with MS, our purpose is to develop:

- **Research:**  
Supporting ongoing research to pursue further knowledge in targeting prevention, improving treatment, enhancing quality of life and ultimately, to find a cure.
- **Advocacy and Awareness:**  
Although MS impacts people differently, there are common, fundamental issues for people affected by the disease. We are steadfastly committed to giving these people a voice and remain willing and able to work with government and the Australian society to champion issues in a dynamic policy environment to bring about change to the lives of people living with MS.
- **Communication and Information:**  
Utilising traditional, contemporary and innovative channels to source information and share it with people with MS, our member organisations and our key stakeholders.
- **Support for our member organisations:**  
As MS specialists providing and facilitating high quality services that span the life-time needs of people affected by MS and other degenerative neurological conditions, their families and carers – from the point of early symptoms and pre-diagnosis, that addresses their changing needs.
- **International Collaboration:**  
Representing the MS cause and promoting collaboration with our domestic and international partners.

## **Introduction**

MS Australia (MSA) is pleased to provide a submission to the Senate Select Committee Inquiry on Charity Fundraising in the 21st Century regarding the current framework of fundraising regulation for charities and options for reform.

MSA's role is to work on behalf of all state and territory based member organisations to provide a voice for people living with MS across the country. MSA's partner organisation, MS Research Australia, has a mission to accelerate Australian research targeting prevention, better treatments and a cure for multiple sclerosis.

MSA's member organisations are:

- MSWA (covering Western Australia)
- MS SA/NT (covering South Australia and the Northern Territory)
- MS QLD (covering Queensland)
- MSL (Multiple Sclerosis Limited (covering Victoria, NSW, ACT and Tasmania)

MS Australia does not undertake any fundraising activities, though it does from time to time receive unsolicited donations. Specific fundraising activities are undertaken by the state MS organisations (to provide a range of services to people living with MS) and MS Research Australia (for research into the cause, prevention and a cure for MS).

## **Terms of reference**

Our submission addresses the terms of reference (TOR) as set out in your invitation to make a submission to this inquiry in broad terms.

## **Current problems**

The MS organisations welcome this inquiry into fundraising. Compliance with fundraising rules and regulations is a significant burden for our organisation. Whilst we understand the need for a certain level of effective regulation, we urgently need changes to the current framework to enable our organisations to focus on delivering the missions and core activities that we were formed to deliver, rather than our time and effort being subsumed by an unnecessary level of complex regulatory burden.

For our state 'service-provider' organisations, given that in recent years funding arrangements have changed significantly (i.e. block funding from the Commonwealth has ceased) and also recognising that funding via the NDIS does not cover a majority of their clients, the ability to fundraise effectively whilst minimising compliance costs is critical.

The need for a national and fit-for-purpose fundraising regulatory regime has been well documented and we have followed and supported the reform work on this issue undertaken by both Justice Connect and the Fundraising Institute Australia whose work rehearses the problems in some detail.

Overall, we urgently need a nationally-consistent, contemporary and fit-for purpose fundraising framework.

Currently, our MS organisations have to comply with seven sets of different laws, each with some significant difference from the other, including differences in definitions of 'charity', 'charitable purposes' and 'fundraising' to give but one example. Each of these sets of laws also have different exemptions and exclusion from registration, have different requirements about when a fundraising licence is needed and different reporting requirements.

It is essential that we maintain public confidence through transparency and accountability so the MS community and the wider public who are considering donating or have donated, can make informed decisions free of misinformation or coercion.

Overall, the current state/territory based laws and regulations:

- Lack consistency and uniformity causing unnecessary complexity and confusion
- Duplicate one another and other laws that otherwise regulate fundraising, causing unnecessary administrative cost
- Fail to adequately deal with new and various forms of fundraising, including fundraising through online platforms (e.g. websites, crowdfunding)
- Restrict a national approach to fundraising because of the compliance burden across multiple jurisdictions

The compliance burden, due to the complexity and inconsistency of the various laws combined with the reported lack of monitoring or enforcement of these laws, may result in organisations choosing to disregard the existing regulatory framework, through oversight or lack of understanding.

Most charities in Australia rely on donations and fundraising activities from the community to meet their missions; some may depend more on this source of income than others. In doing so, the community has the right to request accurate and transparent reporting on how these funds are raised and used by the charity. All charities need to be accountable and transparent regarding of the levels of funding and how these funds are used. The current reporting requirements by State regulators are not consistent and there are no reporting standards set-up at a national level. As a result, readers of financial information provided by charities such as donors, fundraisers or the government are unable to accurately and consistently compare the financial performance of one charity to another. A wide range of advocates have been seeking improved accountability and transparent financial reporting by the sector however these improvements are yet to be achieved.

### **Proposed solutions**

The work undertaken by Justice Connect to identify the current problems and recommend solutions is supported by a significant number of organisations and individuals working and operating within the charity/NFP sector. The solutions resulting from this work, in essence, recommend that the Federal Government take the lead in addressing the problems through a strengthening of Australian Consumer Law to apply to fundraising activities, repeal the existing regime of the various state and territory laws and develop a core, mandatory code to be enforced under Australian consumer law.

These solutions, for implementation no later than mid-2019, could be summarised as follows. Federal, State and ACT governments to:

1. initiate amendments to the Australian Consumer Law to ensure its application to fundraising activities for and on behalf of charities (and other not-for-profit organisations) is clear and broad;
2. repeal existing fragmented State and ACT (there are no such laws in the NT) fundraising laws; and
3. work together as Australian Consumer Law regulators, and with the Australian Charities and Not-for-profits Commission, self-regulatory bodies and sector intermediaries to draft and consult publically on a core mandatory code to be enforced under the Australian Consumer Law multi-regulatory framework.
4. develop a National Reporting Framework across the sector to include a clear set of definitions and standardise reporting templates. Incorporating the National Standard Chart of Accounts (NSCOA) in this framework could be a step forward.

5. implement new National Guidelines on Fundraising to assist charities. Referencing other fundraising guidelines implemented in other countries such as New Zealand, Canada, the United States of America or various European countries may be helpful.

We support Justice Connect's belief that these solutions will deliver 'Stronger, Smarter, Simpler' laws to support charities, fundraisers and donors by:

- Stronger: Using the Australian Consumer Law (supported by a conduct code) to put protection of all donors at the heart of all fundraising regulation across the nation regardless of method used to fundraise;
- Smarter: Principles based regulation (backed by a national process for reform) is more likely to capture innovation and changes to methods of fundraising, without territorial limitations
- Simpler: Creating a truly national system of regulation by removing duplicate and burdensome requirements for registration (licensing) and reporting, allowing for ethical conduct to be central to all fundraisers and fundraising activity.

We understand that the FIA Fundraising Institute Australia (FIA) is also recommending a series of solutions to assist the Federal and State Governments to address the current need to work together to provide charities and other not-for-profits and the donating public with a national fundraising regulatory regime. These proposals, which we believe further support and enhance those proposed by Justice Connect, could be summarised as follows:

1. All Australian governments should commit to harmonise fundraising regulation within an agreed time limit of two years.
2. Restore fundraising reform and charity/NFP issues to the COAG agenda, including re-establishing the COAG NFP Working Group to elevate fundraising regulation reform.
3. Provide for a greater role for the ACNC Charity Portal to facilitate alignment and harmonisation of fundraising regulation.
4. Overall responsibility for fundraising issues at Commonwealth level be centralised under one senior minister.
5. Recognise the key role of FIA's and other sectoral codes and complaint handling mechanisms as an integral part of the regulatory framework.

The solutions proposed in this and other submissions, and their consequences if and when implemented, must be considered carefully and be well supported by the sector. It would be terribly disappointing if, as a consequence of systemic overhaul, fundraising activities were made more difficult or compliance more onerous.

MS Australia is pleased to have been given the opportunity to provide a submission to this inquiry.

**KEY FACTS:**

- Multiple sclerosis (MS) is a neurological condition affecting the central nervous system (brain and spinal cord) that affects more than 25,600 people throughout Australia
- It is the most common chronic neurological condition diagnosed in young adults.
- MS is most commonly diagnosed between the ages of 20 and 40
- 75% of people diagnosed are women.
- MS varies significantly from person to person. For some people, it is a disease that comes and goes in severity with periods of unpredictable relapse and remission. For others it means a progressive decline over time. For all, it is life changing.
- Symptoms vary between people and can come and go; they can include severe pain, walking difficulties, debilitating fatigue, partial blindness and thinking and memory problems.
- There is no known cause or cure.
- MS causes significant and chronic disability to people in the prime of their lives and therefore has a substantive health burden and economic cost to the Australian health system.
- The direct and indirect costs to the Australian community are increasing and now exceed \$1.9 billion every year. Nearly 50% of this figure is through the lost productivity of Australians living with MS and their carers.

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