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The Future for ME/CFS Sufferers in Australia

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1. Introduction

We are writing this statement to outline our concerns about recent proposed changes to the national ME/CFS board, and suggest a path towards the best solution for all ME/CFS sufferers in Australia.

For more than a decade now, a number of members of the Australian ME/CFS community have been working together to build *ME/CFS Australia Pty Ltd*, a company with a national board, to coordinate the interests of ME/CFS sufferers around the country. Good progress was sometimes made but some state problems created obstacles, which unfortunately have been enough to impede progress and have created significant frustration.

The Victorian society (ME/CFS Australia (Vic, Tas, NT)) has recently taken steps to attempt to circumvent these problems. While we can understand their frustration with the national board's slow progress, we believe these steps were taken hastily, without national consultation, and are not in the best interest of the nation's ME/CFS sufferers.

We believe the national board should act carefully, and be representative of all states working in harmony. We feel that unity between the states is the key to furthering advocacy of ME/CFS and providing quality service to all Australians who suffer from the condition. We therefore find the Victorian society's proposal not only divisive, but also fear that it will set back progress on a national level. Poorly conceived structures will *not* inspire confidence from government or private funding bodies. Careful steps need to be taken to build our national board's substance and credibility, in order to protect the long-term interests of all Australian ME/CFS sufferers.

2. Victorian Society Proposed Change

Over the Christmas break, the Committee of Management (CoM) of ME/CFS Australia (Vic., Tas, NT) took steps to change the landscape of ME/CFS support in Australia. They held a General Meeting and polled members about a major change in direction and name. We have particular concerns about some of what happened in that process. Our general concern is about the direction they wish to take, and the model they have proposed.

It became apparent that the Victorian CoM wishes to take over the running of ME/CFS Australia-wide and thus become the de facto national board.

3. Victorian Statements Cause Concern

There were two quite concerning statements in their message to members by ME/CFS Australia (Vic, Tas, NT) in an undated document called "Frequently Asked Questions about the Special General Meeting":

"We have a very strong, highly committed COM and staff in Victoria and believe we can undertake this role more effectively and provide improved support across the nation."

- *The proposed changes have been undertaken in consultation with the national body and various state bodies."*

While we would welcome strong management of ME/CFS support in Australia, we do not believe that what is happening in Victoria will provide a good outcome in that sense.

The proposed changes to the ME/CFS Australia (Vic., Tas, NT) constitution have NOT been "*undertaken in consultation with*" either the national body OR our (SA) state body. Given that we have been the most active state outside Victoria on the national board, we can say confidently that that second asterisked statement above is stretching the truth beyond snapping point.

4. Recent National Board Activity

Our Director for SA, Peter Mitchell, and our President, James Hackett, have both attended national board meetings over the past two years. These have been few in number (for a variety of reasons, none to do with SA) but we have always been represented and have spoken at the meetings.

A proposal was put by National Board President Mr Simon Molesworth to board members via email dated 9 August, 2013. This proposal was:

"...to appoint this [Victorian] COM to the Board of the National body together with willing members of the existing Board who would enhance its capabilities.

To distance itself from the past and to reflect the new vigour, it is proposed to change the name to eMERgeAustralia. An appropriate cost effective rebranding exercise would be undertaken. Local bodies can use the name and logo on a licence basis.

It is proposed that the organisations act in a coordinated manner to support an agreed agenda that facilitates achievement of agreed objectives. It is also proposed that the Board, Chief Executive Officer (CEO) and other key officers would be recruited by the National body and their services provided to other organisations at the local level, on a reasonable basis."

5. No Response to our Concerns

After careful and conscientious consideration, Peter Mitchell as SA director felt obliged to vote against the proposal by the national board president, mainly on the basis of concerns about its implementation as a federated body. These aforementioned concerns were detailed in a letter dated 28 August, 2013 from Peter Mitchell to the chairperson. However, Peter has never been informed of the results of that board vote, and there has been no meeting of the national board since the mid-2013 vote. As far as we are aware, there has been no correspondence to board members since August 2013.

6. Victoria Acts Unilaterally and Disingenuously

Now we find that a proposal similar to that put to the national board has been put to the Victorian members, to establish a body which seems to be similar to that which we voted against. One of the differences between what was put to the national board and this later Victorian CoM proposal is that the original proposal was for the Victorian CoM to act *with representatives from other states*, whereas the current moves by the Victorian Committee are simply for them to take over from all other states and become the de facto national board.

This puts a construction on the words "undertaken in consultation with" which is disingenuous if not profoundly misleading. That construction might suggest that the changes proposed by the chairperson were supported "nationally", but this would be false. The national board at the time of the August 2013 proposal consisted largely of Victorian directors, with one from SA and one from WA. (We are all pretty aware of the NSW situation. There isn't a ME/CFS Australia (Qld) and the ACT lost their director when she moved away from the ACT).

7. Our History of Support to the National Board

Over the past decade SA has consistently pushed for a better national presence to advocate for ME/CFS. We have had active and continuous membership of the national board through Dr Peter Cahalan and Mr Peter Mitchell, along with Mr James Hackett as proxy member. We have conscientiously attended phone meetings and flown interstate for every in-person meeting over that time. We have actively supported moves to develop a federal body and attempts to gain funding federally.

8. South Australia's Recent National Efforts

* To our own detriment we pushed for a national ME/CFS journal publication in 2009, believing that *Emerge* would evolve over the next twelve months or so into a truly national publication. We stopped producing our own publication and moved our members onto the *Emerge* mailing list. We encouraged our members to support the change. However, the development of *Emerge* as a *national* ME/CFS publication never happened. This was principally due to the different vision of the Victorian committee, who at that time did not see *Emerge* as evolving to a national journal, but rather remaining as a Victorian journal with inserts for other states.

It cost considerably more for us to receive a considerably lesser journal, and as a result - and with the national board's understanding - in 2010 we returned to publishing our own excellent state journal.

* In 2008 at our AGM we formally changed our name from the ME/CFS Society (SA), to ME/CFS Australia (SA) Inc. This represented our firm commitment to a national presence.

* We provided most of the members of the working group on the national website.

* Despite being totally dependent on membership fees and donations, we have always conscientiously paid our per-capita membership fee for the national organisation.

9. One State to Replace the National Board?

We have serious concerns about a proposal which basically seeks to disband the national board and replace it with a state committee. We also have well-founded concerns about a state committee running a national organisation. Those concerns are well-founded, based on experiences we have had with ME/CFS Australia Victorian staff in recent years, which were outlined to the national president.

These included:

- attempts by the (well-funded) Victorian office to charge our (completely voluntary) office for telephone support provided from Melbourne to ME/CFS patients in SA; not only conducted without our knowledge, request, or approval, but without attempt to refer the callers to our office;
- recruitment of SA callers to the Victorian Association instead of referring them to SA;
- failing to inform us when organising a medical seminar in Adelaide.
- a proposal to the Board to charge each state equally (the figure of \$15,000 per state or territory was proposed) to set up a national support line based in Melbourne. This would have been manifestly disproportionate in its impact on smaller states with smaller population and membership like ours. Also, the proposed management of the support line indicated a lack of planning and careful forethought.

10. A "National" Organisation?

And now we have the current moves by the Victorian CoM. What we should be asking is "how do we intend to proceed as a federated body? What is the model we are aiming at?" It seems that the Victorian CoM has answered those questions "by being run from Victoria, by a totally Victorian board". This is hardly a model for successful federation.

We are respectful of the success of the Victorian body in recruiting members to its CoM with successful business, accounting and legal skills, and we acknowledge that having such a collection

of skills on a national board would be important if we are to become more “professional” in our approach. Let us have a professional board with the skills to garner funds, advocacy and support from the community. But that won’t be achieved by simply allowing the Melbourne-based CoM to take over all the states.

What it lacks is a connection with other states and a connection with ME/CFS people and their carers at a local level. Providing support from Melbourne might seem to make sense in the case of states where there is no existing support group, but does it actually help them in the future?

11. Our Vision

The goal of the national body should always be to provide the best outcomes for people with ME/CFS everywhere in this nation. This means avoiding parochial state interests, and encouraging and facilitating cooperation amongst all of the state bodies

As a state society, we strongly advocate all the states working together, and we would also argue that we have the longest unbroken track record in seeking to achieve that outcome.

It must be acknowledged that the national board has been, at many times, ineffective in the past. That doesn’t mean that a national board with state representatives can’t work in the future. There are state issues to resolve, but that shouldn’t prevent us from consulting each other, discussing the issues, putting the best plan in place, and working towards the best solution. Trouble in an individual state doesn’t justify one state taking over the running of all states’ ME/CFS groups, thereby compromising the national structure already in place.


Each state must have its own committee and support groups at local level and with local knowledge. These state groups will - and should - evolve over time to have quite a different role to the national board. At the same time it is in the best interests of Australian sufferers for us to maintain the national, independent body, ME/CFS Australia. However we clearly need a restructure, a fresh start, with renewed, inclusive efforts by all to help make this work.

We believe the national board should act carefully, and be representative of all states working in harmony. We feel that unity between the states is the key to furthering advocacy of ME/CFS, and providing quality service to all Australians who suffer from the condition. We think that the Victorian society’s proposal is likely to set back progress on a national level. Poorly conceived structures and attempts by one state to “take over” another will not inspire confidence from government, or private funding bodies. Careful steps need to be taken to build our national board’s substance and credibility, in order to protect the long-term interests of all Australian ME/CFS sufferers.



Peter Mitchell

SA State Director, ME/CFS Australia Pty Ltd
Secretary, ME/CFS Australia (SA) Inc.



James Hackett

Alternate SA State Director, ME/CFS Australia Pty Ltd
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