

Agenda Item - Formation of a National Body to represent people living with lymphoedema

In recent times, there has been a discussion between the consumer based Lymphoedema Support Organisations in the states and territories about the advantages of forming a National body to represent people living with Lymphoedema. There are several reasons for this:

- **Our lobbying is strengthened:**
 - We speak with a stronger voice due to larger numbers, rather than each state independently. Some states do not have a formal group, significantly disadvantaging them.
 - In the past, Federal Government, the media and other funding bodies have wanted to communicate and work with a National body, rather than smaller state-based groups. Consultation requests are often made to National groups like Breast Cancer Network Australia and Australasian Lymphology Association, rather than multiple state consumer organisations.
- **Potential to reduce duplication of work:**
 - All state-based groups are trying to produce newsletters, communications, education materials, social media posts, run websites etc. There is an opportunity to coordinate this at a National level to share/reduce the workload. This also means that states without a formal structure can benefit from Nationally available material.
- **Reduce the workload on volunteers:**
 - Most states are struggling for volunteers and committee members. A National body would be able to aim to employ a staff member to take some of the administrative load, yet still support local social groups and education events.
- **Opportunity for education:**
 - There is an opportunity to provide a National platform for education, events/functions, information and digital communications such as webinars and podcasts.
- **Fundraising:**
 - National Bodies are easier to fundraise for and can be set up in a way that consumers can make donations more easily, such as at times of celebrations/special occasions or when individuals are doing a Fun Run or Marathon for example.
- **Liaising with international groups:**
 - As a National Body, we are more likely to be able to share materials and garner support from international groups such as LEARN (Lymphatic Education and Research Network), ILF (International Lymphoedema Framework) and LSN (Lymphoedema Support Network – UK based group).

The committee would like to inform members that we have been exploring this option with other states for the last year. The following is an update on each state:

- *Lymphoedema Association of Victoria* – the membership has already voted to proceed with converting their association into a National Body. They voted for this at their AGM in November 2020. The new committee's role is to facilitate this.
- *Lymphoedema Association of Queensland* – committee members have voted to roll over into a National Body in principle, although no formal AGM vote of members has occurred yet. Likely to occur at the next AGM.
- *Lymphoedema Support Group of NSW* – committee members have voted to roll over into a National Body and thus this is being presented to members to vote on at the upcoming AGM.
- *Lymphoedema Support Group of South Australia* – committee members have given support for a National body, but do not have capacity at present to facilitate such transition at this stage. This is largely due to changes regarding lymphoedema funding in the state of South Australia at the current time, and they have elected to make that their focus for 2021.
- Other states – there are no formal incorporated associations for lymphoedema in other states. However, individual representatives of informal support groups have voted to move forward and support development of a National body.

The Lymphoedema Support Group of NSW will be conducting their AGM on March 30th, 2021 at 7.00pm. This will be a virtual AGM via Zoom, which will include a power point presentation about the proposed National body for people living with lymphoedema, and will discuss the pros and cons. There will be an opportunity after the presentation to ask questions.

During the AGM, a vote will be conducted. If the vote is FOR a National body, please note that this will not occur immediately. To facilitate a smooth transition from State to National, it would be proposed to occur over a 12–18-month period to ensure that individual support groups and events in each state continue to run smoothly.

Motion to be moved:

“That the LSGNSW rolls over into a National Body to represent people living with lymphoedema”.

If the motion is seconded, there will be a vote conducted online via a poll on Zoom, with the options: Yes (in favour); No (against) or Abstain (no vote)

Only members of the LSGNSW may vote, or you can appoint a Proxy to vote on your behalf. See the attached *Form of Appointment of Proxy* for more details.