

**FOR IMMEDIATE RELEASE**

## **Time to Move with Lymphoedema March is Lymphoedema Awareness Month**

“Australia leads much of the research into the detection and management of lymphoedema world-wide” says Professor Sharon Kilbreath from the Faculty of Health Sciences at the University of Sydney. She notes that “women are still very fearful of developing lymphoedema following breast cancer and there is a belief that they need to be protective of their arms; however we want to encourage them to be physically active. Our research shows that women do not develop lymphoedema because they are active, indeed physical exercise may prevent development and worsening of the condition”. As Professor Kilbreath emphasises, “physical activity, even at the early stage, is the key - people with lymphoedema must keep moving. It does not mean that they need become a ‘weekend warrior’ – it is important to build up their level of fitness and strength”.

Lymphoedema is a condition characterised by swelling of a body part. It can be a consequence of lymph node surgery necessary to treat some cancers and can also occur as a primary genetic predisposition.

The National Breast and Ovarian Cancer Centre states that approximately 20% of breast cancer patients develop arm lymphoedema, and up to 66% of other cancer patients who have surgery and radiotherapy to their groin lymph nodes develop leg lymphoedema.

The Australasian Lymphology Association (ALA) is the peak organisation representing health professionals who treat, educate and research in lymphology. The ALA aims to improve public funding for lymphoedema services and is working to lobby the government and health funds to attract a fair rebate for costly compression garments that are an essential part of managing lymphoedema.

Liz Arctander, who suffers from arm lymphoedema after breast cancer surgery requires two new custom-made compression garments every 6 months costing a total of around \$2200 per year. She said: **“I can’t see any reason why the government cannot provide a Medicare rebate scheme similar to that available for breast prosthesis after mastectomy. Lymphoedema compression garments are not a fashion statement. People wear compression garments so that they can contain their swollen limb and avoid multiple hospital admissions for infections.”**

Currently, there is a shortage of public hospital allied health positions for staff trained in the treatment of lymphoedema. Funding for lymphoedema treatment is scarce forcing many people to pay for treatment privately. Inadequate access to lymphoedema treatment is particularly worrying in rural areas where many people live with their untreated swollen limbs, requiring frequent antibiotic treatment for severe skin infections, sometimes leading to multiple hospitalisations.

Early detection and treatment is recommended for all lymphoedema patients. President of the ALA, Penelope Sanderson says “In the past, the diagnosis of lymphoedema occurred when people presented with very large limbs and there was

already significant physical and psychological morbidity. People suffered in silence coping with the accompanying psychological burden”.

As with other clinical conditions, early detection and the initiation of appropriate treatment quickly for people with lymphoedema can assist in better responses. Dr Leigh Ward, Associate Professor at the University of Queensland says “Australia has a proud history of ground-breaking research studies in lymphoedema including pioneering the use of bioelectrical impedance analysis which provides greater sensitivity in quantifying the volume increase in limb size than more traditional ways of measurement and consequently the technology is able to provide a precise indication of lymphoedema much earlier.” As a precise quantitative measurement, the use of bioimpedance spectroscopy for lymphoedema detection can alert health professionals and the person at risk to commence treatment at the earliest opportunity.

**Marianne Taylor knows the benefit of seeking help early. “I developed lymphoedema of the arm not long after breast cancer and was referred to a clinic where I was treated and educated about the condition. After wearing a garment for many years and exercising I now have very minimal swelling and recognise the benefit of getting appropriate help early.”**

Cancer is not the only reason why people may live with lymphoedema.

**Seven year old Dallas has congenital lymphoedema of both legs and has needed compression garments and bandages since he was eight months old. This will be a lifelong financial commitment for Dallas and his family. At the moment he is very positive about it and it doesn't stop him playing his favourite sport - soccer. Dallas says “I look like you, I play like you but I need to wear compression stockings to keep healthy”.**

People living with lymphoedema in Australia have been neglected when it comes to the State and Federal health budgets. “It is time to act and provide adequate services and psychological support for both survivors of cancer and those with congenital lymphoedema. Australians need access to early diagnosis, targeted services and funding for compression in order to successfully self-manage this chronic condition” says Penelope Sanderson. As with any chronic condition, there are implications for the health system when detection and treatment of lymphoedema is delayed.

Consumers and health professionals can find the location of their nearest qualified lymphoedema practitioner by accessing the National Lymphoedema Practitioners Register ([www.nlpr.asn.au](http://www.nlpr.asn.au)). This Register is produced by the Australasian Lymphology Association to ensure and maintain the standard of lymphoedema therapy in Australia.

For more information about lymphoedema and the Australasian Lymphology Association, go to [www.lymphology.asn.au](http://www.lymphology.asn.au) or contact the President, Penelope Sanderson, at [president@lymphology.asn.au](mailto:president@lymphology.asn.au) (Mobile 0411 118 948).

**Points for journalists:**

- **Adults and children with the condition in every state are available to speak publicly about their health issues, including the people mentioned in this media release.**
- **Lymphoedema is a chronic condition affecting approximately 200,000 people in Australia.**
- **Early detection and intervention is essential for improved outcomes for Australians.**
- **Early detection of lymphoedema using impedance technology is an Australian invention.**
- **There is insufficient public funding of services for people with lymphoedema.**
- **Access to funding for compression garments is dependent on where Australians live.**
- **During March, consumer groups across Australia are meeting to raise awareness of the condition and provide information to consumers and health professionals.**
- **The National Lymphoedema Practitioners Register was launched last year and provides access to qualified lymphoedema practitioners at [www.nlpr.asn.au](http://www.nlpr.asn.au) .**

