



Node News

A Quarterly Publication of the Lymphoedema Association of Queensland Inc.

ABN 13602 257 202



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We welcome new members

May 2019

Welcome to the second quarterly edition of *Node News*. Since I had the honour of becoming President in November it has been a very busy and exciting time. I have been working to make our association more user friendly and updating our resource facilities.

The LAQ committee did a wonderful job in assisting me raise awareness for Lymphoedema Awareness Month in March.

Many thanks to our dedicated and hardworking committee in putting together our fantastic High Tea at the historic Hanworth House where close to a hundred guests attended.

Hanworth House owner and custodian Marisa Vecchio AM and Bianca Criaco our Social Media Officer were great guest speakers. Marisa spoke of the history of Hanworth House and her journey with breast cancer. Bianca told us about her life and the daily challenges as a young person with lymphoedema.

I was also interviewed by ABC Radio presenter Kath Feeney (*pictured*) about World Lymphoedema Day and was able to highlight our activities and speak about my Mum and my lymphoedema story.

Victoria Bridge was lit up in brilliant blue during Lymphoedema Awareness Week and we also had an Awareness Walk around New Farm Park.

Many thanks to our friends and supporters who joined us at some or all of these events. Your support is so important to us. The

Lymphoedema Association of Queensland is a small association and your membership fees, support and donations allow us to provide resources to our members. Thank you also to our trained therapists and health professionals who help our many members every day with their expert care.

Please join our support group meetings in Brisbane or Bundaberg (see page 2). Or if you would like to start your own support group closer to home, let us know and we will assist you to make it happen.

This month I also had the opportunity to meet with and lobby Hon Greg Hunt the Federal Health Minister for more funds and support for lymphoedema. I also met with the new Australian Charities and Not-for-profits

Commissioner Hon Dr Gary Johns. The sector is undergoing great challenges and changes ahead.

We continue to work closely with the Cancer Council and Breast Cancer Network Australia to provide ongoing education resources to our members and webinars.

Please don't hesitate to provide any ideas for inclusion in the *Node News* and feel free to contribute to our Facebook and Instagram posts.

Enjoy this issue of *Node News* and I hope you get some great tips.

I just want to leave you with a quote from Lena Horne. "It's not the load that breaks you down, it's the way you carry it."





- Support for those who live with lymphoedema.
- Education for the general and medical communities of the existence of lymphoedema.
- Promotion of a healthy life management around lymphoedema.

THE COMMITTEE

Uff. Hon. Teresa Gambaro
*President/Public Relations
Information Line*

Vice President (vacant)

Nerida Smith OAM
Hon. Secretary/Enquiries

Peter Halpin
Hon. Treasurer

Pam O'Connor
Newsletter/Publicity Officer

Bianca Criaco
Social Media Officer

Avon Mills
Mia Stemm
Mary Stewart
General

Hildegard Reul-Hirche
Robyn Scheer
Education Officers

REGIONAL SUPPORT GROUPS

BRISBANE: Nerida 0403 782 795 or June 3865 1195
Toowong Library closed for renovations until September.
Social meeting at Pelican's Nest Cafe, 143 The Esplanade, Wynnum, at 10am on Sunday, June 2. Further social meetings in June and July, locations to be confirmed. Stay tuned on the website, Facebook and Instagram.

BUNDABERG: Olga 4152 8507
Meets bi-monthly, 3rd Monday at 10am. Bundaberg Cancer Care Centre, Hope St, Bundaberg West (opposite Mater Hospital).

MARYBOROUGH/HERVEY BAY/PIALBA
Information session on Wednesday, October 16, 1-3pm at Maryborough Hospital K Block conference room. RSVP to Rachael Tassotti or Hayley St Ledger on 07 4325 6300.

SUNSHINE COAST: Margaret 5492 4437. Group meets socially.

TOOWOOMBA: Contact Cancer Council Queensland if you wish to be informed of upcoming educational activities on 13 11 20 or Alyce on 4690 5900.

TOWNSVILLE: Contact Libby 0439 745 716. No formal meetings.

ARE YOU A MEMBER YET?

Call 0403 782 795 for an application form.

General membership: \$30 per year

July 1 to June 30 yearly

Concession: Health Card holder/pensioner \$25 per year

Friends of LAQ: \$40 per year

Professional membership including Directory entry: \$80 per year

Membership renewals are sent out early June each year.

Donations to further our work are always welcome.

LOOKING FOR LYMPHOEDEMA TREATMENT SERVICES?

Readers can visit our website www.lymphqld.org for the current listing.
The Treatment Directory can be downloaded and printed from our website.

Hard copies available from LAQ \$5 + \$2 postage.

If you do not have access to the internet please phone our information line on 0403 782 795 for direction to services or phone the Cancer Council Qld Helpline on 13 11 20.

WE NEED NEW LISTINGS!

If your treatment provider is not listed, please encourage them to contact the office for an application form. This will assist us to provide a better service to those seeking treatment.

For a listing of national lymphoedema therapists, visit the ALA website www.lymphoedema.org.au

In This Issue

3-4. March Lymphoedema Awareness Month

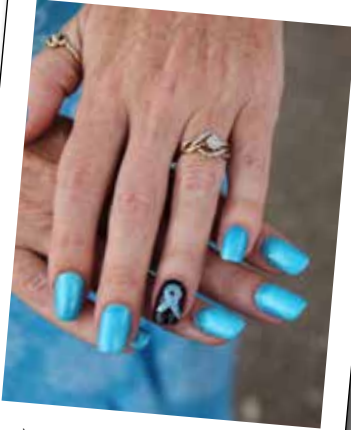
5-6. Committee profiles

7-8. Editor Says, advertising

Please Note: Information conveyed in any form (verbal or written) from the Lymphoedema Association of Queensland Inc, its officers or any branch or support group is for information only. It is not intended to be and is not professional advice and should not be relied upon by any person. Professional advice should be sought before any action is taken based on any information given, other than that given by health professionals in answer to questions asked.



Busy March raising awareness



Showing off in all forms of funky blue!



Victoria Bridge at South Bank lit up in brilliant blue on March 6 World Lymphoedema Day.



Supporters out in force for the lighting up of Victoria Bridge.



Our banner flying high on the Carindale overpass with Westfield Carindale in the background during Lymphoedema Awareness Week in March.



The Townsville support group celebrated World Lymphoedema Day with a social catch-up.



High Tea at Hanworth House



Our High Tea fundraiser on March 9 at historical Hanworth House in East Brisbane was a sizzling success attracting close to a hundred people. Pictured are President Teresa Gambaro with Secretary Nerida Smith, and Social Media Officer Bianca Criaco (above right) who was a guest speaker.



Lymphoedema Awareness High Tea East Brisbane

An elegant high tea on the lawns of Brisbane's Hanworth House made for a beautiful occasion to raise awareness for lymphoedema, a chronic swelling condition caused by a dysfunction of the lymphatic system. Coinciding with Lymphoedema Day, the event was presented by the Lymphoedema Association of Queensland and hosted by the association's new president, former federal MP Teresa Gambaro, who has the condition. Guests enjoyed champagne and an array of sweet and savoury treats with funds being raised for LAC via a charity raffle. Pictures: Pam O'Connor



Sabine Cappello and Mia Strain



Marina Vecchio and Teresa Gambaro



Carmel Woodhouse, Maryann Scott and Cath Miller



Kylie Bullock, Janet Potts and Ali Dignan

The High Tea made the social pages of The Sunday Mail's U on Sunday magazine.

March on for awareness walks



Brisbane supporters gathered in New Farm Park on March 23, proudly raising our banner high and raising awareness as they marched along the Brisbane River.



Ipswich supporters held their awareness walk on March 16.



Meet your committee

Peter Halpin Treasurer

My journey with lymphoedema began one Sunday in August 2011 when my partner Marie and I were taking our pet poodles for their usual afternoon walk.

We were attacked by a stray dog and, in defending my dogs, I was knocked to my knees and that was all that was required to cause the blockage of my lymphatic system that has resulted in my secondary lymphoedema.

It started with swelling of my left knee but I did not understand why the rest of my leg was swelling as well. After a few months, I made an appointment to see a specialist, who ordered some tests that confirmed that I had lymphoedema. Frankly, he offered no constructive advice other than to wear a knee-high stocking that he was happy to sell me.

Around this time, I had a look at the Lymphoedema Association of Queensland website and referred to the



listing of practitioners, found a practitioner and we have been working together ever since.

Treating my lymphoedema has been a long and expensive experience. I have spent thousands of dollars on all kinds of bandaging, garments and creams but still my

L-Dex reading remains at the extreme end of the scale.

I know that I will be bandaging my leg for the rest of my life, but I have learnt to live with the inconvenience of my big leg. I can still play golf (wearing a size 6 on my right foot and size 11 on my left foot) and Marie has sown material into the inside of my trouser-leg so that I can wear long trousers for more formal events. There is also no substitute for quality creams that keep the leg lubricated and as healthy as possible.

I don't think that there has been any deterioration in the condition of my leg over the last year or so, but I know that I need to be diligent in preserving and protecting it for the rest of my life.

While my lymphoedema is an uncomfortable inconvenience, I know that there are more invasive conditions and illnesses than lymphoedema and I count my blessings that it can be managed effectively, allowing me to enjoy a full and active life.

2019 | 2020 Entertainment Memberships are here!

An Entertainment membership is a gift that keeps on giving with discounts for dining, travel, shopping and activities. Purchase a membership and you will also support the Lymphoedema Association of Queensland. To order click here: <https://www.entertainmentbook.com.au/orderbooks/22150q0>



Meet your committee

Mia Stemm General Member

My name is Mia. I am a wife and mum and a chatterbox. I was diagnosed with vaginal cancer in February 2015 and went on to have pelvic surgery. This surgery included removal of all of my pelvic lymph nodes to stop the spread of this disease. (So far so good!) However, I have ended up with some lymphoedema in my left leg, lower pelvis, patches on my right leg and genitalia.

So starts another quest for knowledge, and me joining Lymphoedema Association of Queensland and then becoming a committee member. The LAQ members are a wonderful source of knowledge and practical support. You just have to ask questions, chat and share.

So with that in mind I thought I could toss in some of my tips and hints that have worked for me in dealing with lymphoedema in my life.



Mia's handy tips

- ◆ When purchasing new compression garments make sure you are measured correctly by a lymphoedema specialist. That ensures the best fit and efficiency.
- ◆ Use a marker pen to put a date on your garments to track their age. I have several pairs of stockings and pants on the go.
- ◆ I wash my garments in a lingerie bag in cold water in the machine with my undies. Seems to work for me. I tend to hang the stockings by the toes in the shade to dry.
- ◆ When travelling carry a lingerie bag and a skirt hanger to wash and dry the garments. Roll the garments in a towel and stand on them to squish the water out.
- ◆ Deep breathing. Breathe in to make a fat tummy. Everyone I have spoken to reminds me of this, and I am happy to be reminded of this frequently.
- ◆ Lymphoedema does make your skin feel different - like satin. I think that is because the skin is tight. I have also experienced a slight loss of sensation on the skin.
- ◆ I keep all my bandages and associated gear rolled and ready to go in a basket. Easier to keep organised.
- ◆ Manual lymphatic drainage and use of external compression pump occur each night. I set myself up in bed with comfy pillows and TV for entertainment.



Editor Says

I hope you enjoy reading this edition of *Node News*.

As you can see on pages 3-4, a busy schedule of Lymphoedema Awareness Month activities during March meant there was plenty of positive news to report!

Meet a couple more of our committee members and their lymphoedema stories on pages 5-6.

As this new-format *Node News* continues to evolve, we would like to hear more of our members' stories, tips, recipes and activities.

If you would like to see something published or to give us feedback, get in touch by sending us an email at info@lymphqld.org

Happy reading!

Pam O'Connor



General committee member Mia Stemm spritzes a supporter with cool water in a spray bottle during the Awareness Walk at New Farm Park on March 23. It was a scorching hot day as supporters marched along the Brisbane River, raising awareness and holding our banner high. Spritzing is a fantastic way to stay cool in the hot and humid summer, even over the top of compression garments. Read more of Mia's handy tips and her lymphoedema story on page 6. Send us your handy tips to info@lymphqld.org

JM REMEDIAL THERAPY & LYMPHOEDEMA CLINIC

The clinic services include quality, comprehensive treatments for people living with lymphoedema and venous insufficiency:

- Manual lymphatic drainage massage
- Compression therapy
- Education for long-term self-management

Early treatment equals low cost



3 Jupiter Court

Eatons Hill, Qld 4037

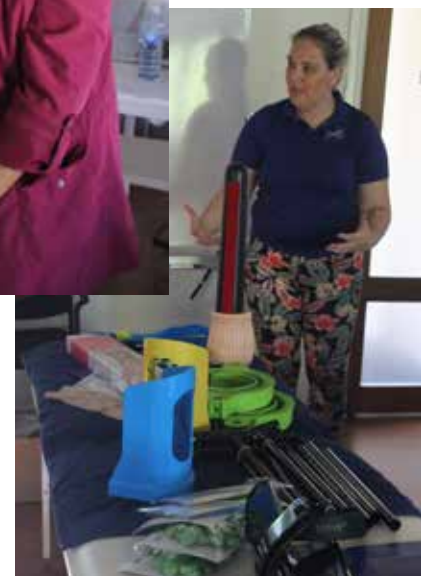
Email: mewburnj@bigpond.net.au

URL: www.jmremedialtherapy.com.au



Lymphoedema therapist Emily Muldoon (below) held a Living with Oedema workshop in Brisbane.

LAQ Secretary Nerida Smith (above) gets hands on during the Living with Oedema workshop.





NODE NEWS IS GOOD NEWS

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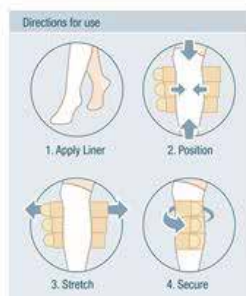
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