



Welcome New Members

Special Edition December 2014

Node News is Good News

Seasons Greetings to all our Readers.



This is a Special Edition of the newsletter to keep you informed of some of the latest information regarding the Association, National Advocacy Initiatives and Research opportunities in which you may wish to participate in the New Year.

Our AGM was held on the 25th October this year. Our Patron Teresa Gambaro MLA gave an opening address to the meeting and has pledged support to our cause.

The Executive Committee remains the same, however we would welcome any new faces to the Committee should you feel inclined to join us.

The list appears on page 2.

The meeting was followed by some interesting presentations and displays of 'What's New in Compression' which those in attendance found very informative.

I have included excerpts from the Annual Report in this issue for your information.

There have been some exciting developments and research opportunities you may be interested in. These are aimed at improving the profile of lymphoedema with Government and Health Professionals documenting information about costs of living with lymphoedema and plans for a lymphoedema register in order to gain statistics on the number of people with lymphoedema. This has involved a lot of guess work in the past.

It is our aim to reach as many of our members past and present with the information I have included so that we can encourage these positive initiatives. Numbers are very important in any lobbying of Government. They want 'Statistics' and that includes each and every one of us who are affected by lymphoedema.

If you know of someone who could benefit by joining, please share this newsletter with them.

Until next time I wish you Peace, Joy and Happiness with Family and Friends and the opportunity to keep cool in the summer heat.

Regards

Nerida Smith



- *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

Nerida Smith
President

Vice President

June Timms
Secretary

Karin Swift
Treasurer

Publicity/Public Relations

General

Leila Bourke
Pager Coordinator

Hildegard Reul-Hirche
Robyn Scheer
Education Officers

Noelene Kidd
Morag McGregor
Suzanne Godde

Dr. Di Smith
Medical Advisor

REGIONAL SUPPORT GROUPS

- **BRISBANE:** Nerida 3269 1498 or June 3865 1195
Meeting 4th Wednesday of the month at Noon - 2pm
Library Meeting Room, 1st Floor, Toowong Village Shopping Centre
- **BUNDABERG:** Olga 4152 8507
Meets Bi-Monthly, 3rd Monday at 10.00am.
Recreation Room, Mater Hospital, (from Hope St) Bundaberg.
- **MACKAY:** Heather 4959 1383
Meeting Bi-Monthly, 1st Friday at Noon at Porters Coffee shop
Phone for details if you plan to attend.
First meeting for 2015 Friday 6th February
- **SUNSHINE COAST:**
Margaret 5492 4437 Bev 5441 4420
Group will meet socially from April 2014.
- **TOOWOOMBA:**
Contact Amber or Joan on 4690 5900 at
The Cancer Council Queensland if you wish to be informed
of upcoming educational activities
- **TOWNSVILLE:** Libby 0439 745 716 or Neradah 4771 6377.
Formal meetings have ceased due to low numbers.
- **ROCKHAMPTON:** Meeting Last Thursday Month 2pm at Cancer
Council Rooms. Contact Jan 07 4928 6852

In This Issue

- 2..Association Details
& Support Group Details
- 3-5.. President's Report
- 5.. Treasurers Report
- 6-7 Opportunities and
Information
- 8..New Cookbook and
Encouragement pieces.

Please Note

Information Conveyed in any form (verbal or written) from the Lymphoedema Association of Queensland Inc, it's 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.

ARE YOU A MEMBER YET?

Call today for an application form 07 3269 1498

General Membership: Initial year \$30 then \$25 per year
July 1 to June 30 yearly

Concession: Health Card holder/Pensioner:

Initial year \$25 then \$20 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 updated Treatment Facilities Directory will be finalised for January 2015

If you do not have access to the internet please phone our information line on 38334376 for direction to services.

The booklet will be available from the website for Health Practitioners to download and print or a hard copy will be available upon request from the office on 3269 1498 or 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



President's Report AGM 25th October 2014

It is my pleasure once again to bring you the President's report for the Association in our 24th year of operation.

To the best of our knowledge we have complied with all the legal requirements of a not for profit organisation over the past 12 months and striven to achieve the aims and objectives outlined in our Constitution.

It has not been easy this past 12 months for me personally nor for several of us serving on the Committee with loss of close family and caring for sick spouses, however we have continued to serve our membership and the general community.

Personally I feel that my role with LAQ along with my faith in God have assisted me to cope and given me another focus away from life's circumstances. I believe that serving others can be a great healer.

We have continued our endeavours despite the fact we do not receive any additional funding from Government and rely on the voluntary support of the executive committee, the financial support of members and donors. The generosity of Councils in Brisbane, Moreton and Logan in the free use of venues for support and awareness meetings also that of the Cancer Council Qld. Brisbane and the CCQ Toowoomba and Rockhampton, the Brisbane Anglican Church and the Mater Hospital in Bundaberg has assisted us to spread our funds further.

A major accomplishment for this year was the Application for a change of status for the organisation from a Public benevolent Institution to a Health Promotion Charity with the ACNC which is the Federal Government Body which registers Australian Charities and Not for Profit Organisations. We felt this more fittingly described the aims and objectives of our organisation.

Simplicity is not the word when dealing with Government matters. This turned out to be a several month project to deal with all the legal requirements. Change of Constitution, a Special meeting to approve the changes and a need to submit to the ATO to ensure we retained our Deductible Gift Status and finally lodge it with Fair Trading. I am pleased to report that we have retained our DGR.

At the 2013 AGM we approved an increase in the Membership fees by \$5 for both General and Concession which we have implemented for the 2014 -2015.

We did not introduce a Health Professional Membership as we were advised by McCulloch Robertson that it would not be advisable to add another category to our membership so a health professional membership remains a General Membership.

We usually have an attrition rate of up to 1/3 of our members each year and the increase in membership fees does not appear to have changed our renewal numbers so far this year.

Awareness Sessions

Last April we held Awareness Sessions in 6 locations around Brisbane which consisted of a video presentation on the Management of lymphoedema and another on the psychological impact of managing lymphoedema. A trained Lymphoedema Therapist was in attendance to speak on compression garments.

CONSUMER REPRESENTATION

Queensland Health Clinical Practice Guideline.

I am pleased to announce that the (CPG) 2013 for use of compression in the management of adults with lymphoedema within a Queensland Australian Healthcare setting was finalized in late 2013.

Leila Bourke and I sat on the working party as consumer representatives.

This is a reference and a guide for Junior Clinicians and will be a great resource Opportunities such as this can be of great benefit to those we represent.

Metro North Hospital Health Service Lymphoedema Service Review

Several of our members participated in a working party regarding Lymphoedema Services in Metro North, providing information on the needs of those requiring lymphoedema treatments in this HSD. This was undertaken as a directive from the Health Minister. I have received a report this week re the progress so far.

A Pathway is now being planned with the aim to improve access to services closer to home for those at risk, those needing treatment and or/ monitoring.

It is envisaged that these services will be provided by a range of appropriately trained Health Professionals ranging from local GP's, Non Government Organisations such as Blue Care, private practices Physios and OT's and the Public hospitals system. The initial pathways are for cancer related lymphoedema.

The draft will now be sent out to stakeholder groups for feedback.



QLD HEALTH GUIDELINE FOR COMPRESSION GARMENTS FOR ADULTS WITH MALIGNANCY RELATED LYMPHOEDEMA AND PATIENT FACT SHEET

This is a recently launched initiative by Qld Health which has been developed following our deputation to Qld Health some several years ago seeking a fair and equitable distribution of garments in the Public Hospitals. We felt this was very important to ensure people on low incomes could adequately manage their lymphoedema. These garments are to be provided to those who qualify through the local Health Service Districts. Garments can be prescribed by Private Lymphoedema therapist or Qld Health Practitioners. A sheet has been printed to assist patients to understand eligibility and the procedure for ordering and receiving their garments. They are eligible to receive 2 garments every 6 months. We were disappointed that it was only for *Malignancy related lymphoedema* and have voiced out concerns that it was not for all lymphoedema, whatever the cause. I was invited to participate in the video conference on behalf of the Consumer and whilst I complimented the Minister and the Allied Health Professions Office Staff for the initiative in my conclusion I stated that "There is a need for a continuing dialogue on the needs of the people in Queensland with and or/at risk of lymphoedema ranging from babies to adult, not only those who have been affected by cancer in order for all to receive a fair and equitable supply of resources"

RESEARCH

There have been several requests for participation in research for lymphoedema. This we are happy to do once it has been passed by the Ethics Committee.

We recently published the results of QUT Student Anna Finnane's Research

'Patient's experiences of lymphoedema treatments' the outcomes of research may be used to bring about change in future treatments.

Thanks you to the members who are willing to give of their time to participate in these research activities.

AUSTRALASIAN LYMPHOLOGY ASSOCIATION ACTIVITIES

The ALA held their biannual Conference in New Zealand this year; the theme was 'Koru, life, growth, movement'. 80 consumers attended the public day for which we provided our LAQ carry bags for literature.

We supported the event by donating 2 Prizes for the poster competition. The best poster from was by Denise Stewart and the Best Overall Poster was by Ronna Moore. We look forward to their contribution of an article for Node News in the upcoming edition.

Amanda Purcell is now the State ALA Representative for Qld. Robyn Scheer recently stepped down from this position.

We have also become a Friend of the ALA since our last meeting this will keep us abreast of their Activities.

Their major fundraiser is the iced tea party to raise funds. Any time in summer is a good time to support this cause by entertaining a few friends and serving iced tea.

Details can be found on the ALA website www.lymphoedema.org.au

COMMUNICATION

One of our main means of communication in the office these days is by email; it is convenient and can be handled at ones convenience. The office phone serves as a fax as well, which is still a convenient way of receiving and sending documents

We have had a change to our Enquiry Line recently as we have cancelled the Answering Service which we have used for over 20 years and now have a mobile phone 0403 782 795 which will allow queries to be sent by text also messages can be left and the call returned.

Our website is a valuable source of information for those seeking Treatment Providers and can be accessed 24 hours a day. Other information regarding lymphoedema is available as well.

Our quarterly Node News allows us to keep members informed about lymphoedema matters.

Regional Groups

The Sunshine Coast Lymphoedema Branch closed in May

We thanked Sandi and Margaret for the many years of Service to the Group and several other members with a letter and a certificate of recognition.

The group had worked tirelessly fundraising through regular raffles to assist members with subsidized treatment and garment assistance. Members plan to meet socially from time to time. Margaret has agreed to remain a contact for the group.

Bundaberg is our only group operating as a Branch/Support Group under the direction of Olga Beath and Helen Skippen who provides valuable information to members in a Health Professional capacity.

Monthly support groups also meet in Brisbane, Rockhampton and Mackay.



VOTE OF THANKS

Thank you Teresa for your attendance today and the interest and support you give to the Lymphoedema Association of Qld. and Veronica for your services as Minutes Secretary for our AGM each year. It is very much appreciated. Thank you to the Cancer Council Queensland for their assistance with the use of the facilities today, the information they pass on to callers on the Helpline and the
Last but not least I wish to thank the other members of the Executive especially June Timms as Secretary, Karin Swift Treasurer and Leila Bourke who takes the calls on the Enquiry Line. Not forgetting the members who have supported and encouraged me throughout the year and those of you who have taken the time to attend today to show your support for our efforts.

Nerida Smith
President

**LYMPHOEDEMA ASSOCIATION OF QUEENSLAND INC.
TREASURERS REPORT
FOR THE YEAR ENDING 30TH JUNE 2014**

P. Stokes & Co (AUST) Pty Ltd has prepared an audited report of the financial year 2013-2014.

Please see attached Auditor's Report

In reference with the Income and Expenditure Statement, presented on page 2 of the auditor's report, one can observe total income was \$11,093.35. (-\$4,873.61 or 36 % down on prior year). Membership income has increased to \$4,515.00. (+\$575.00 or 13 % up on 2013) This reflects the beginnings of early membership renewals with the new price membership increase which was accepted and passed at the last AGM. Fundraising income is down significantly as no major fundraising initiative such as the calendar was taken this year. Fundraising down to \$926.10 (-\$5,799.90 down from 2013). Donations are still running on par with previous years and boost our income significantly. Thank you, our kind benefactors for your generous support.

Total expenses, \$10,644.51 are down on the previous year by -\$3,451.19 (27% decrease) a reflection on fewer expenses incurred due to fundraising. Printing dropped significantly as we did not print a calendar this year. Also notice that we have now bought a mobile phone which replaces the pager which was 20 years old. We no longer have a monthly pager bill of \$60 and costs to return calls. The monthly mobile cost is \$20 and this includes all calls and will provide us with a dedicated mobile phone to take to awareness days and conferences, thus saving us approximately \$480.00 a year.

Please Note: In the auditor's income and expenditure statement the pager figure for 2014 should read \$732.87. It was accidentally added into the postage figure \$1841.99 which should be 41109.12

Audit fees are increasing by 6% per year. This year, 2014 the audit cost \$1440.00. We are seeking an auditor who has a more reasonable fee as the fee for service at present is not representative of the work involved.

Insurance fees have increased at steady rate of 4%

All fixed expenses are remaining relatively steady.

Bank Balances as at 30th June 2014.

Westpac Account \$7,338.27

Westpac Maxi Direct Account \$12,990.48

Petty Cash \$300.00

Full Audited report available on our website www.lymphqld.org



Information and Opportunities



PUTTING VITAMIN D ON TRIAL – CALLING FOR VOLUNTEERS. Can vitamin D really reduce risk of cancer and heart disease? Can it make us feel better? The D-Health Trial is calling for volunteers to take part in Australia's largest trial of vitamin D to answer these questions. If you are over 60 years old you may be able to join the trial. You will be asked to take a tablet once each month for up to 5 years and to answer some questions about your health. For more information go to www.dhealth.qimrberghofer.edu.au or call 1300 735 920.

(Note – this research has no drug company funding).



CANCER INSTITUTE

AUSTRALIAN SCHOOL OF ADVANCED MEDICINE
2 TECHNOLOGY PLACE, MACQUARIE UNIVERSITY,
NSW 2109, AUSTRALIA

Help us raise awareness about the social and economic impact of breast-cancer related lymphoedema!

The Macquarie University Cancer Institute and the Department of Marketing and Management at Macquarie University are conducting the first Australian study exploring:

- how much it costs to live with lymphoedema of your hand or arm after treatment for breast cancer and;
- how living with lymphoedema affects your work, home and social life.

Please help us gather enough information so we can lobby government and health funds about subsidising costs of treatment; raise awareness about lymphoedema and educate employers about how to support employees living with lymphoedema.

If you have had a diagnosis of breast cancer and:

- ❖ are over 18 years old;
- ❖ have breast-cancer related lymphoedema, i.e. have been diagnosed with persistent and visible swelling of your arm, hand or both
- ❖ have sought advice from your therapist or doctor;
- ❖ have been advised to wear a compression garment;
- ❖ have completed your surgery and/or radiotherapy or chemotherapy at least one year ago (tablets such as Tamoxifen or Arimidex are OK).

To participate in our anonymous on-line survey which will take you between 25 and 35 minutes to complete please go to:

https://mqedu.qualtrics.com/SE/?SID=SV_7TWYoEBrWBscrgV

Or you can email Dr Cathy Xu (Research Fellow at Macquarie University) on cathy.xu@mq.edu.au who will return email the above link.

If you have any questions please contact Cathy Xu on (02) 9850 9281



LAUNCH OF THE LYMPHOEDEMA ACTION ALLIANCE

The Alliance is working to reduce the unnecessary suffering of people who have lymphoedema, by ensuring timely access to affordable lymphoedema services and compression garments regardless of where people live, their financial status and their health situation.

Late last year a publication 'Lymphoedema Stories' The Untold Truth' was Published by the NSW Cancer Action Network Northern Suburbs Members of the LSGNSW were surveyed about their experiences with lymphoedema. The key issues highlighted by the respondents suggest that services are severely understaffed and underfunded, and there is limited understanding of lymphoedema among health professionals. This would be true in most Australian states and many overseas countries. Subsequent to the Media coverage the NSW Government and various other organisations who have banded together to form the Lymphoedema Action Alliance which was launched this month.

We plan to join the Alliance and add a voice to their Action to achieve 'Equitable sustainable access to affordable lymphoedema compression garments nationally'

Follow the Alliance on Facebook.

ALA BREAKING NEWS

Following the offer by IBM for a community IT grant the ALA Council has approved the development of a Lymphoedema Patient Registry.

The following is a brief introduction outlining the proposal and an explanation regarding the registry and the benefits of developing such a register. Full details regarding the register are on the website listed.

PROPOSAL FOR A NATIONAL LYMPHOEDEMA PATIENT REGISTRY

A PROJECT OF THE AUSTRALASIAN LYMPHOLOGY ASSOCIATION

SUPPORTED BY THE LYMPHOEDEMA ACTION ALLIANCE

DIRECTED BY THE REGISTRY COMMITTEE

Website: www.lymphoedemaregistry.org.au

www.lymphoedemaregistry.co.nz

Developing a National Lymphoedema Patient Registry

What is a registry?

A registry is a database or a collection of records of people identified as having lymphoedema. It includes information on personal details, such as age, sex, type of lymphoedema, severity, type and amount of treatment received. The data is kept in a computer database. A national registry centralizes this data.

The benefits of a National Lymphoedema Registry

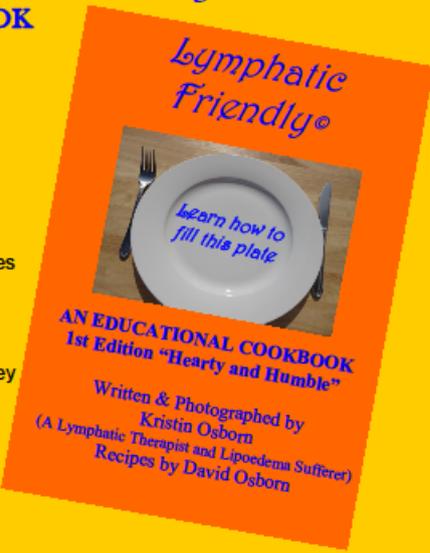
The primary goal of developing a national lymphoedema registry is to help those living with lymphoedema by increasing awareness of the prevalence of the disease, delineating needs of patients in the community, identifying shortcomings in the healthcare delivery system and empowering the ALA and other organisations to lobby effectively on behalf of people with lymphoedema.



Lymphatic Friendly[®]
AN EDUCATIONAL COOKBOOK

1st Edition "Hearty and Humble"
OUT NOW!
Go to
www.newlymphclinic.com.au
Click on the
"Cookbook" Button

This is the first known Lymphatic Cookbook that teaches what foods to cook and eat to assist in reducing your weight, limb size and creating a Healthy Lymphatic System. Written by a Lymphatic sufferer and a Therapist in the field, this book will take you on Kristin's personal journey through her weight issues over the years to how she presents today, keeping the weight permanently off, reducing her limb size and "Pausing The Progression" of her condition. Enjoy recipes for delicious Pizza, Burgers, Cake and many more. Combining helpful information and digitally photographed recipes you will be learning a new set of skills for a new way of living.



Lymphatic Friendly[®]
AN EDUCATIONAL COOKBOOK
1st Edition "Hearty and Humble"
Written & Photographed by
Kristin Osborn
(A Lymphatic Therapist and Lipoedema Sufferer)
Recipes by David Osborn

Get motivated.
Here are some nice words for you.

All is well.	Believe you can.	Everything is possible.
Stay strong.	Never give up.	Seize the day.
Do it now.	Make things happen.	Do your best.

aqua photo | i turn

