



We Welcome New Members

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Lymphoedema Association of Queensland Inc.  
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August 2016

Node News is Good News



Dear Readers

My how the time has passed quickly since Heather and I and several others from Qld attended the Public Information day in Darwin. The Theme of the Conference was New Networks-New Solutions. It was the first time that the Australasian Lymphology association and the International Lymphoedema framework had held a joint

conference.

There was information for those of us who have experienced lymphoedema long term and those newly diagnosed.

Heather Rutherford wrote:

As I have had Lymphoedema for the past 34 yrs, the first 8 of which I lived with a wrong diagnosis and a limb increasing in size and weight until I was diagnosed as lymphoedema and I received some of the first treatment available in Qld. It was exciting to learn of the increased knowledge and understanding that is now available and shared around the world. The Scientific Committee invited eminent speakers covering a wide range of related topics. 2 of the speakers I was really impressed with were **Professor Witte from University of Arizona** and **Anna Kennedy from the Canadian Lymphoedema Framework**. More in Nerida's Report on page 3.

A Q&A Session with expert panel was truly beneficial and we departed encouraged, hopes raised and aware that we to the consumer have a part to play and work to do.

It was a privilege to be there. I am looking forward to the next conference to be held in Brisbane in 2018.

Heather was recently honoured at a CCQ Luncheon in Bundaberg as the longest Breast Cancer Survivor (45yrs) and for her contribution toward Lymphoedema support in founding the Bundaberg Lymphoedema Support Group.

The LAQ Sponsored awards for the Best Qld Poster and the Best Overall Poster which I had the honour of presenting to the recipient. Jen Sanderson from Griffith University won the Qld poster prize. Her topic was "The pitting test: An investigation into an unstandardized assessment of oedema" The Best Poster by Patrick Wagner from Japan: Simplified compression therapy for lymphoedema: evaluation of compression levels and time required for application. I will include Jen's paragraph on Page 5.



**The 2016 Annual General Meeting will be held on the 12<sup>th</sup> November** at the Cancer Council Queensland Auditorium. Meeting will commence at 9.30am. Doors open at 9am.

11.00 am Guest Speakers Anna Finnane (Researcher) and Hildegard Reul-Hirche Physiotherapist. Using modern Technology to bring specific medical assistance ie Lymphoedema to those in rural and remote areas. "The feasibility of Telehealth for lymphoedema assessment and management"

### **AN IMPORTANT MESSAGE FROM THE PRESIDENT**

**New Committee members are urgently needed!!!** Most of the current Committee have served the Association for many years. Several have had to step aside over the past couple of years. We need fresh younger members to take up the baton and continue to advocate for better services and raise awareness. We need to have a voice and it rests with our members to keep the momentum going. If you are interested please complete the nomination form enclosed with this newsletter or call Nerida 07 3269 1498 for more information.



- *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*  
*Publicity/Public Relations*  
Mary Stewart

June Timms  
*Secretary*

Karin Swift  
*Treasurer*

General  
Leila Bourke  
*Pager Coordinator*

Hildegard Reul-Hirche  
Robyn Scheer  
*Education Officers*

Avon Mills

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.  
Margaret Rose Centre CCQ Bundaberg.312 Bourbong Street.  
  
MACKAY: Heather 0448 823 388  
Meeting Quarterly, 1st Friday at 11.30am at Porters Coffee Shop  
Phone for details if you plan to attend.
- **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

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### 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](http://www.lymphqld.org) for the current  
listing. The updated Treatment Facilities Directory has been finalised  
and distributed.

If you do not have access to the internet please phone  
our information line on 0403 782 795 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](http://www.lymphoedema.org.au)



2016 Asia Pacific  
**Lymphology** Conference  
Integrating the 11th Australasian Lymphology Association Conference  
and the 4th International Lymphoedema Framework Conference  
New Networks - New Solutions 26-28 May 2016 Darwin Australia



Darwin May 28, 2016 Public Day Report  
from Lymphology Conference.

**Gemma Arnold , ALA President** opened the day.

Gemma explained that the ALA consists of HP's and Sufferers working together. A major concern is the disintegrating services throughout Australia. The consumer representative on the committee is Monique Bareham from SA. A recent sub group is Friends of the ALA. The ALA is also a member of the Lymphoedema action alliance



**Anna Kennedy, Executive Director, Canadian Lymphedema Framework**

Anna spoke about the National Organisation of Lymphoedema groups in Canada. Lymphoedema is under the radar screen, poorly understood, 500,000 Canadians known to have L/O, 1/5 breast cancer patients, impact on life poorly understood. It is a myth that lymphoedema is just swelling. There is a national group which produces literature and a magazine. Inserts from Provincial groups are published with each edition of the Magazine. I was very impressed with the quality and information in the literature which was available. Her message was that Lymphoedema Community Organisations can drive change. An Australian example is the Breast Cancer Network of Australia.

**Professor Marlys Witte, University of Arizona - Oedema, lymphoedema, and medical ignorance: current and future perspectives.**

She said it was a radiologist that first researched the Lymphatics system "Opening a Window to discover more" Since then an Explosion of knowledge and emerging tools to explore the integrated system, has resulted in improved personalized care for patients and populations, she spoke of some of the future directions for their research  
There is an imbalance in the system and physicians need to investigate the cause.  
Two ways: speed up drainage or reduce the output into the tissues.  
eg. Genetic Research with all family members and the genes being found .  
Gene Therapy, Tissue Engineering  
Stem Cell , Cloning  
Comment: Heather thought this research may be worthy of a Nobel Prize.

**Prof Jane Turner – Psychiatrist, University of Queensland - Changes in roles and responsibilities.**

Jane's main interests of study centre around the physical and emotional wellbeing of cancer survivors. Depression is much more common than is recognised by clinicians. Her areas of research involve:

- Promotion of wellness following completion of active cancer treatment:
- The emotional dimensions of cancer for patients and dependent children:
  - Scholarship in research and collation of evidence into Clinical Practice Guidelines and implementation of these to guide health professionals in provision of optimal clinical care.



Jane spoke at the 2012 Conference in Cairns of which we have a recording. Her basic points are that after cancer things are not the same for the person or family , that there needs to be conversation about how things are and what needs to and has changed both for that person and the family. Acceptance and Commitment to therapy. Set Smart Goals aim to achieve one a day.



### **Dr Ramin Shayan, University of Melbourne and Team Leader O'Brien Institute of lymph – Surgery for lymphoedema, and how genes can help us treat lymphatic problems**

Illness and disability sets challenges as treatment often results in ongoing physical problems. Areas which are being explored by their team is microsurgery, lymphatic transplant and genetic engineering. He presented an overview of [Lymphatic and Regenerative Surgery](#)

The range of cancers for which radiotherapy is being used is ever expanding. There is an unavoidable dose exposure that occurs in surrounding normal cells. This radiation exposure does not have the effect of simply killing normal cells; but illicit a permanent damage or injury profile that not only persists, but continues to evolve throughout the life of the patient. These changes result in ongoing tissue contracture, pain, lymphoedema, and tissue breakdown; in turn leading to significant disability, impairment of quality of life, infection, and potentially life-threatening exposure of vital structures. To investigate these findings, we have developed in-vitro models that mimic the dosage regimes administered to cancer patients, specifically focussing on the cell types that occur in the skin: keratinocytes, fibroblasts, endothelial cells and adipose derived mesenchymal stem cells. We performed a raft of functional bioassays to specifically interrogate the key functions of each cell type and extracted the messenger RNA - the elements that translate DNA into the protein and downstream products that carry out the work of the cells. Using next-generation gene sequencing we obtained the patterns of alterations at the level of mRNA molecular and gene signalling that occurs in irradiated cells. Finally, we developed an in-vitro model to mimic the introduction of adipose-derived stem cells (ADSCs) into irradiated tissues in the clinic.

### **Prof Terence Ryan, Oxford University - Why is the science and practice of skin care so important in lymphoedema?**

His early career focused on Blood supply and Lymphatic drainage of the skin and included Presidency of World congresses in the field of microcirculation. Later career mainly focuses on Public Health relevant to Dermatology, Wound Healing, Lymphoedema and Neglected Tropical Diseases. Founder of Community dermatology skincare for all [www.skincareforall.org](http://www.skincareforall.org) with a focus on Africa, India and China. For some 50 years he has played roles concerning a failing skin in many parts of the world, tending to skin disease, wounds, lymphoedema and tropical diseases such as leprosy.



#### **Lunch, posters and trade exhibition**

### **President Dr Karen Herbst, University of Arizona – Lipedema is not just fat legs!**

**Causes of Lipedema** -The cause is not known, but doctors suspect female hormones play a role. That's because the condition affects mostly women, and it often begins or worsens at [puberty](#), during [pregnancy](#), following gynecologic surgery, and around the time of [menopause](#).

Scientists also believe genes are involved, because many women with the condition have family members with the condition.

#### **Lipedema (Lipoedema) Treatments**

[Dieting](#) and [exercising](#) will not reduce the fat involved in lipedema. But it's still important to do those things because they can help you lose weight from nonlipedema fat and reduce inflammation.

A treatment called complete decongestive therapy can ease painful symptoms.

Complete decongestive therapy involves:



**Manual lymphatic drainage.** A form of [massage](#) that uses gentle, rhythmic pumping movements to stimulate the flow of lymph around blocked areas to healthy vessels, where it can drain into the venous system. This helps relieve pain and prevent fibrosis.

**Liposuction**, specifically water-assisted [liposuction](#) and tumescent liposuction, can remove the lipedema fat. The procedure uses a hollow tube that is placed under the [skin](#) to suction the fat tissue. Several sessions may be needed depending on the amount of abnormal fat. WebMD Medical Reference



**Prof Neil Piller, Flinders University – Self management: one size doesn't fit all**

Professor Piller was awarded the ALA Research Prize at the Conference. It is always a privilege to have him speak. Neil's presentations are always easy to understand and are practical. He discussed very techniques that those living with (or at risk of) lymphoedema could use.

1. How much change load could make a difference.
2. Factors which contribute to lymphload.

Skincare is one of the main factors which can contribute to reducing the lymph load especially the absence of infection. High blood pressure, excessive weight and vein trouble can add to the lymphload.

Key Areas for Management are

- Early /Accurate identification of structural and functional changes.
- Early intervention and monitoring- targeted and subsequent treatment
- Roles for you , your partner or carer- Independence for key management area
- Think , manage and treat holistically

It was fabulous to hear from **Andrea Mangion, Lymphoedema Training and Education, Sydney - Compression garments: overview of prescription** We often receive questions about compression garments - here is Qld Health provides garments through some of its health services and through the Compression Garment Scheme for those on a low income who have been affected by malignancy and can be prescribed by a private physiotherapist or a NGO Organisation such as Blue Care. Compression is such a vital aspect of lymphoedema management and the costs are great so consumer's want to know about compression garments so that they can make the best choice possible - mistakes cost! What products are available? What should I wear? What does compression do? How do I care for my garments? How should I don and doff my garments?..and on the list of questions go! In Andrea's overview she answered all.

**Sharon Tilley, Lymphoedema and Laser, Adelaide 'Low level Laser for Lymphoedema - Science or just Science Fiction'** commenced with a scene from Star Trek showing a wound being healed by a laser light. Sharon spoke about the healing benefits of low level laser for lymphoedema including stimulating lymph vessels to pump more quickly, reducing fibrosis and improving immune function. During the break Sharon was able to demonstrate some low level laser too.



**The day ended with the Expert Panel Session of Dr Ramin Shayan, Sharon Tilley, Karen Herbst, Andrea Mangion** who answered a range of lymphoedema related questions such as compression, diet, surgical options ,radiotherapy and lymphoedema and exercise questions. As is usual there were too many questions to be dealt with in the time allotted.

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**Jen Sanderson Qld best Poster winner summary of the poster titled "The pitting test"**

An investigation into an unstandardized assessment of oedema" is a component of a larger research project that will investigate tissue characteristics and tissue behaviour throughout application of pressure. Our aim was to share our initial findings. The pitting test itself is not standardised and neither identification nor characterisation of lymphoedematous pitting tissue has been assessed in a research setting. A lack of standardisation of palpation assessment introduces ambiguity to the accuracy and comparability of the assessments performed, which impacts evaluation of treatment effectiveness. As an initial step towards standardisation of the pitting test, this study investigated the breadth of pitting test techniques that therapists use to assess lymphoedematous and non-lymphoedematous tissue. The study was conducted at the Queensland Lymphedema and Breast Oncology Physiotherapy (QLBOP) practice in Brisbane. Six therapists of varying lymphoedema experience assessed a range of locations on six patients with unilateral limb lymphoedema of varying severity. Examination of the technique variables included applied contact area of the therapist's thumb, and the amount and duration of applied pressure. The consequence of an unstandardised test is demonstrated with the large range of techniques observed. Duration 1.10 to 76.00 seconds (s), Average pressure applied ranged from 1.30 to 14.36 Newtons (N)/cm<sup>2</sup>, and average contact area applied by the therapists' thumb ranged from 0.16cm<sup>2</sup> to 6.84cm<sup>2</sup>. The large range of pitting test techniques in this small sample reinforces the need to further investigate the underlying tissue response during the pitting test. Our future research will work towards standardisation of palpation assessment for the benefit of researchers, therapists and lymphoedema patients. Thank you Dr. Neil Tuttle, Dr. Robyn Box, Hildegard Reul-Hirche, and A/Prof Liisa Laakso for your contribution to the project."

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### Some other interesting research Topics from Darwin

1. Screening: deep infrared imaging to identify venous impairment after breast cancer surgery. Lymphoscintigraphy, 3D Imaging to measure circumference and limb volume on Lymphoedema, MRI.
2. Effects of different level load resistance exercise in women with breast cancer related Lymphoedema - recommendation moderate to high load resistance training recommended for the physiological and functional benefits.
3. Exercise barriers self- efficacy in women with breast cancer - related Lymphoedema: randomised trial on the effect of exercise mode -participation in supervised resistance or aerobic based exercise is recommended as an introduction to maintaining regular exercise for Health and quality of life and Lymphoedema management.
4. Lymphoedema education: are patients listening? - one off education at time of surgery is not easily retained. Followup needed!
5. Efficacy of the various methods of management and detection, water displacement, bioimpedence, circumferential measurement with tape measure, tonometry.
6. Negative assisted lymphatic drainage: improving conservative treatment options: PhysioTouch (HLD)
7. The use of telerehabilitation for those who have difficulty in accessing appropriate assessment and treatment in Australia and USA.
8. Diagnosis and management of Lymphoedema following various cancer surgeries.
9. Surgical management- liposuction, shunts, microsurgery( lymph node transfer)
10. Guidance of Clinical Care - evidence based best practice, how a unique national magazine in Canada has empowered patients and health professionals, the lymphoedema register increasing awareness and prevalence of lymphoedema.
11. Impact of Lymphoedema on quality of life.
12. Genetics
13. Non Cancer related Lymphoedema - in obesity and diabetes, filariasis, paediatric, transplant patients,
14. Risk Factors for upper limb Lymphoedema - lymph one dissection and radiation.

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The struggle when receiving a Lymphoedema/Lymphedema diagnosis is that management of it requires the commitment, the dedication, the decision that time now has to be allocated to self care, this is life changing, invasive, time consuming and vitally necessary.

The Statements in this paragraph are so true!

Lymphoedema does have a major impact on our lives not only when going through the initial treatment but with the ongoing self management required.

We need to speak up and let family and friends, our health Professionals and Governments know our needs. As Jane Turner reminded us in her talk in Darwin.

"Things are not the same!"

One of the things we need in the Tropics is cooling.

Did you know that the Qld Government has a Concession for Medical Cooling and Heating as does the Federal Government under the essential Medical Equipment Scheme. Details are on their websites. If you are not eligible you may wish to reduce your electricity costs by switching providers. Information at [www.qld.gov.au/energysave](http://www.qld.gov.au/energysave)



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**LYMPHOEDEMA REGISTRY**

A project of the ALA with support of the LAA and state lymphoedema support groups  
Analysis of collected data is provided via SPSS by an IBM Community Grant

The Lymphoedema Registry has been launched. I would encourage all members to participate. If you do not have access to a computer encourage friends or family to assist you to register. It is simple and easy to register. You will remain anonymous. [www.lymphoedemaregistry.org.au](http://www.lymphoedemaregistry.org.au)  
The data base will help to identify the prevalence of lymphoedema in Aust and NZ.

**For Sale:**

Riancorp LTU 904 low level light laser. Ideal for lymphoedema therapy. Suitable for practitioner or patient to use. Serviced new batteries and recalibrated 3.8.2016. Well cared for \$1250 ph Kate on 0448021023



**Support Group News**

**Brisbane-** June 3865 1195

Wednesday **September 28<sup>th</sup>** Outing.

Join us for a Morning Tea Cruise on the Brisbane River.

Phone June for further details and booking.

Wednesday **October 26<sup>th</sup>**

Melody Brown Occupational Therapist.

Compression garments and their role in Lymphoedema Management.

**Bundaberg-** Olga 4152 8507

Please note that meeting are now held at the Cancer Council Qld 212 Bourbong Street.

**Mackay-**

Heather 0448 823 388

has advised the meeting time be 11.30 at Porters Coffee Shop. Mackay group photo.



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**Did you know that QUT Kelvin Grove has health clinics you can attend at a reasonable cost?**

**These are run by the Students and are Supervised by their lecturers.**

**Clinics:**

**Exercise and Movement**

**Nutrition and Dietetics**

**Optometry**

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**Psychology and Counselling**

**General Enquiries and Appointments  
Phone 07 3138 9777**

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### Are you willing to become part of this movement for Change?

We need to take ownership of our needs as people with Lymphoedema.

Recognition of Lymphoedema as a chronic condition by Health Professionals and Governments  
So that we can be provided with the Medical Services and funding for our Compression Garments  
which are important part of the management.

The Health Professional Body the ALA is promoting Research and Awareness.

The Lymphoedema action Alliance in NSW is having a voice and each State Committee is speaking out on  
your behalf, however more needs to be done.

We encourage you to speak to your State and Federal member about lymphoedema and the needs of those  
with the condition. Take them a brochure or other information such as Node News.

Thank them if the services in your area are adequate

### Be part of the change Lymphoedema needs

<p>Diabetes, Heart disease, Breast Cancer, Epilepsy, Autism, Cerebral Palsy, Cancer, Downs Syndrome</p>	<p>Were all conditions along with many more that were under recognised in society</p>	<p>It took people with these conditions to become motivated, frustrated, determined, focussed at giving these conditions a VOICE of there own</p>
<p>This required Strength, Commitment, Focus, Belief, and most importantly a vision of improved services in the community</p>	<p><b>Lymphoedema can become this in each of our countries!</b></p>	<p>If we have the desire, the guts to step out of our Comfort zones and make our voices heard together!</p>
		<p>believe.</p>