



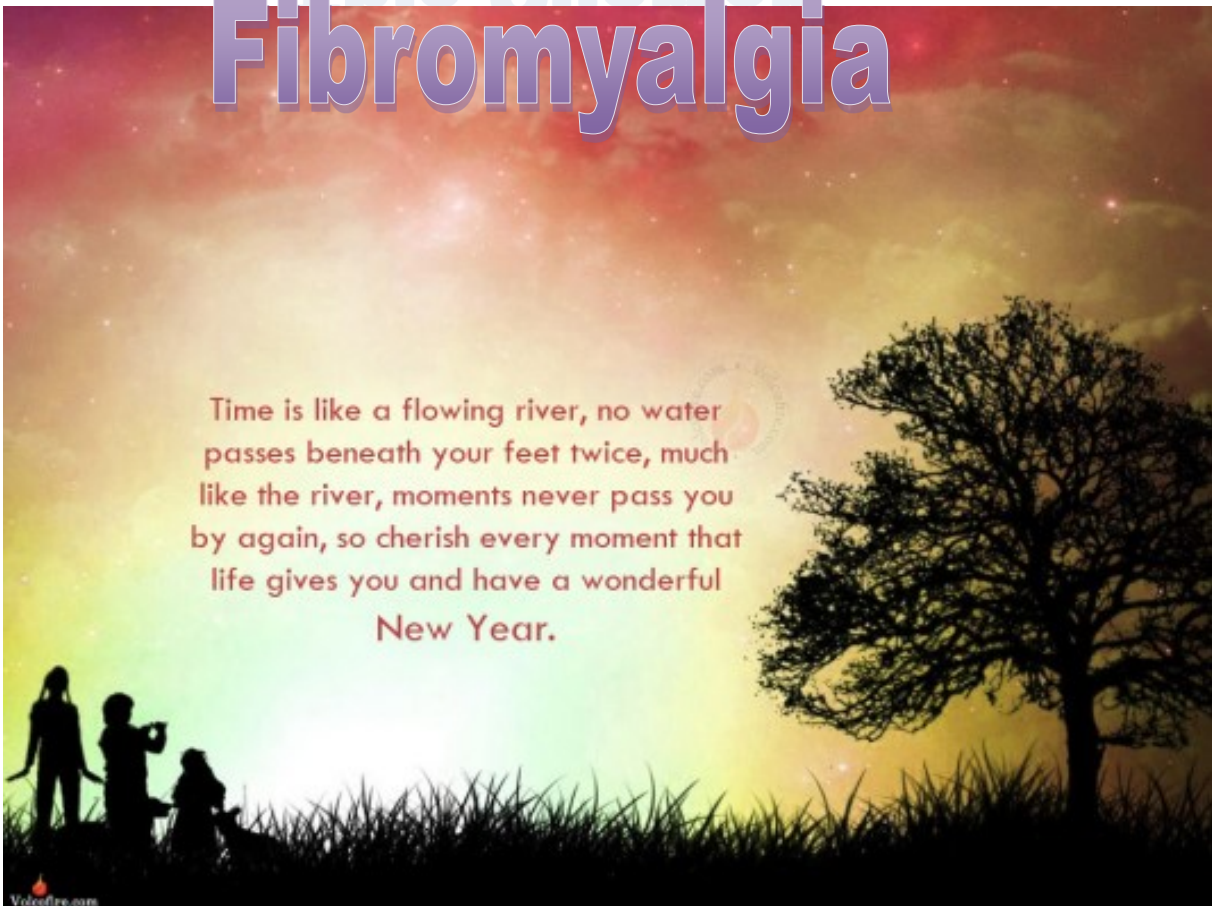
# Lupus Tasmania

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Lupus Association of Tasmania Inc.  
Registered Charity No. ABN 96 163 951 956

Committed to understanding and supporting people with Lupus, Sjögren's,  
Schleroderma & Fibromyalgia or any autoimmune disease

## This Quarter Fibromyalgia

Time is like a flowing river, no water  
passes beneath your feet twice, much  
like the river, moments never pass you  
by again, so cherish every moment that  
life gives you and have a wonderful  
New Year.



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Registered Charity ABN 96 163 951 956

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We would like to acknowledge the Hon Mr. Michael Ferguson MHA for the printing of our Newsletter and his continued support.

***Donations over \$2 are tax deductible***

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Editors News.

I am loathe to tell you that the weather in Queensland is lovely. The nights are quite warm, although every one here says it is cold. I'm glad that our Association is still functioning and congratulations to Lois for keeping us afloat. As we are into 2018 I have put a reminder for membership at the end of this newsletter. Once again I have had computer problems and henceforth a new computer, and they couldn't put everything on to the new one, so hope that I have everything I need. Please bear with me if there are any omissions.

**President Lois' Message**

I am happy to inform members and supporters that the committee from last year were keen to continue in their roles and as the AGM unfolded it was apparent that everyone present were highly relieved to see continuity and voted the team back for another year. Thank you to those members who made the effort to make it to the AGM, this year it was a little later and unfortunately some of our members had already flown the coop to warmer sites. However, we managed a quorum and it was good to see the enthusiasm to continue providing a service to people with auto immune diseases. We are already busy planning the Lupus Awareness Week and our annual raffle. Thank you for your support.

\*\*\*\*\*

**Happy Belated 80th Birthday**

**Murray**

## **President's Annual Report**

Thanks to our new committee we transitioned into a new phase with our organization. We started the year with an executive workshop where we examined our current situation. We did find that we had lots of strengths, built on the previous work of many dedicated members. Our weaknesses were centred around the fact that we are an aging group with the ability to say that we are LUPUS survivors and despite our unpredictable and constantly changing health problems to cope with running a state wide organization.

With a changing world, membership is now quite different to that in the past. We still have not come to grips with how to connect with people who could benefit from information and support. It's not that we are not trying. We are looking for ideas and skills that might help us to stay relevant. Some of these opportunities for our organization has been put into practice and some will require more attention in this coming year. We would like to move to the option of paying for membership every 5 years. This will be given as a clear option this coming year. An on line option for payment proved to be too expensive but bank transfers could possible work for some.

Community awareness and promotion of our organization was enhanced with a media campaign supported by Southern Cross TV. This was launched in Lupus Awareness Month and we were able to run two advertisements over a two month period. A new poster for waiting rooms gave us high visibility and our Patient Education publication was enhanced by both the campaign and the availability of the patient book.

Our Lupus support groups continued to operate in the regions and it was great that we were able to add a group in the West; thanks to all coordinators and members who regularly attend and provide each other support.

Our annual raffle was postponed and this will be made a priority this coming year.

Looking back over our plan of action I can see that we have made some progress, but out of a list of nine activities we can say we met or made progress on over half. SO team it looks like we need another year to continue to address the issues and try and improve our operation.

Thanks to my committee, we have managed to not only survive the year but we left a little more to the legacy of our Organization. I hope to involve you all again this coming year.

Lois Beckwith.  
President.

## Regional Reports

### Southern Report

A small number of people attended the third Monday luncheon on 21st May. On 22nd May the TV News report came out that the Midcity Motel had been sold to the University. At this stage I don't know if the ESUS Café will continue to trade, i.e. not included in the sale, or close when the sale is completed. With the sale of the hotel just happened it will take a while for us to find out what is happening. I will let people know when I know.

If it does close I will try to find another venue, suggestions would be appreciated.

I am still waiting for replies to my email/letter that I sent out generally asking for people to confirm they want to continue to be members of the Lupus Association. Please let me know if you want to continue as members [cost \$15 a year} or if you want your name removed from the list. No reply will mean you stay on the list and will receive another membership form. The \$15 membership helps cover costs of the newsletter and the remainder goes into the research fund. Donations can be added to the membership fee and are always gratefully received, and are tax deductible if over \$2. Sincere thanks to all those who have replied. Your prompt response is very much appreciated. I would like to complete this job by the 9th June, so please don't put off responding.

Next luncheon is scheduled for 20th August. Please put the date in your diary.

Regards  
Heather Cowled  
Southern Co-ordinator  
Phone 6272 3096

**North West:** Luncheons as previously announced, at Fuschia Farm, Lillico.

Leanne Stephens  
North West Co-ordinator  
Ph 0409 713 240

**West Coast:** Contact Barbara for details on 0419 724 384.

### BOOKS TO GIVE AWAY.....

There are about 30 books, videos and tapes that are not required to stay on the reference shelves at the library any more.

If any member is interested in having one or more books to keep please contact our librarian, Joan on 6344 9322

Some of the books that are being culled (more on the website):

1. We All Can Be Doctors Of Common Sense.  
A Guide To Good Health And Well Being. (Copyright :1988)

2.You Can Heal Your Life  
(Copyright : 1984)

3. Lupus (The Body Against Itself)  
(Copyright: 1977)

4. Lupus Erythmatusus. Handbook For Nurses  
(Copyright: 1985- 2nd Edition)

5. The Golden Window. A Compelling Human-Inter Story.  
(Copyright: 1981)

6. Victorian Lupus Association.  
(Copyright: 1983-84)

7 How It feels To Fight For Your Life.  
(Copyright: 1989)

8 Something In Common.  
(Copyright: 1981)

9 Lonely Husbands, Lonely Wives.  
(Copyright: 1989)

10. The Chronic Pain Control Workbook  
(Copyright: 1987)

Video: Lupus Awareness. 1987

Tape: Lectures on SLE. (March 6, 1982)

## NIH Review Finds Non-Drug Approaches Effective For the Treatment Of Common Pain Conditions

*U.S. study reviews results on complementary health approaches for the pain for relief; aims to assist with pain management.*

Data from a review of U.S. based clinical trials published in *Mayo Clinic Proceedings* suggest that some of the most popular complimentary health approaches, such as yoga, tai-chi, and acupuncture, appear to be effective tools for helping to manage common pain conditions. The review was conducted by a group of scientists from the National Center for Complementary and Integrative Health (NCCIH) at the National Institutes of Health (NIH).

Millions of Americans suffer from persistent pain that may not be fully relieved by medications. They often turn to complementary health approaches to help, yet primary care providers have lacked a robust evidence base to guide recommendations on complimentary approaches as practiced and available in the United States,

“For many Americans who suffer from the chronic pain, medications may not completely relieve pain and can produce unwanted side effects. As a result, many people may turn to non-drug approaches to help manage their pain,” said Richard L. Nahin, Ph.D., NCCIH’s lead epidemiologist and lead author of the analysis. “Our goal for this study was to provide relevant, high-quality information for primary care providers and for patients who suffer from chronic pain.”

The researchers reviewed 105 U.S.-based, randomized controlled trials, from the past 50 years, That were relevant to pain patients in the United States and met inclusion criteria. Although the reporting of safety information was low overall, none of the clinical trials reported significant side effects due to the interventions.

In their published article, the researchers explained their research methodology as follows:

*“The randomized, controlled, clinical trial (RCT) is considered the strongest study design for investigating the efficacy and safety of pharmacological, behavioural, and physical interventions. To identify examples of RCT’s for each complementary approach, we performed searches of the MEDLINE database for articles*

*Published from January 1, 1966 , through March 31, 2016, using the search strategy outlined in Supplemental Appendix 2 (<http://www.mayoclinicproceedings.org>). In order to make this review as relevant as possible to primary care physicians in the United States, we limited this review to RCT’s either performed in United States or that included participants from the United States. ”(page 1294\* )*

The review focused on the U.S.-based trial results on seven approaches used for one or more of five painful conditions– back pain, osteoarthritis, neck pain, fibromyalgia (FM) and severe headaches and migraine– and found promise in the following for safety and effectiveness in treating pain:

- Acupuncture and yoga for back pain

Review continued:

- Acupuncture and tai-chi for osteoarthritis of the knee
- Massage therapy for neck pain with adequate doses and for short-term benefit.
- Relaxation techniques for severe headaches and migraine.

Though the evidence was weaker, the researchers also found that massage therapy, spinal manipulation may provide some help for back pain, and relaxation approaches and tai-chi might help people with fibromyalgia.

The specific types of relaxation studies which were reviewed for fibromyalgia included biofeed-back, mindfulness-based stress reduction, affective self awareness (of emotions underlying FM symptoms), and guided imagery. The tai chi studies of interest for fibromyalgia used Yang-style tai-chi modified for FM Patients.

“These data can equip providers and patients with the information they need to have informed conversations regarding non -drug approaches for treatment of specific pain conditions,” said David Shurtleff, Ph.D., Deputy Director of NCCIH. “It’s important that continued research explore how these approaches actually work and whether these findings apply broadly in diverse clinical settings and patient populations.”

In their published article in *Mayo Clinic Proceedings*, the researchers pointed out a few methodological limitations of their review:

*“the trial samples tend to be white, female, and older, with very few, if any minority group ; as such the generalizability of the findings to the breadth of patients seen by primary care physicians in the United States is still unresolved. Often the trials reviewed were small, with fewer than 100 total participants. Small trials are prone to more variability and to false-negative results. In many of the trials in which the statistical superiority of a given complementary health approach was reported, it was not clear if the differences vs. The control group were clinically relevant.” (page 1294)\**

They also noted in their article that the review was intended to be an overview of randomized clinical trials limited to the United States. This restriction was included because: (1) with its distinct medical system, U.S research control groups comprised of study volunteers undergoing “standard care” or “ usual care” would likely differ from that used in other countries, and (2) training and licensing procedures for practitioners of complementary medicine providers in the U.S. could also be quite different from those in other countries. If either of the above were true, then the researchers’ final treatment recommendations might have looked quite different. (page 1302)\*

Source: News release, National Institutes of Health, 9/1/2016

Website: [www.nih.gov/news-events/news-releases](http://www.nih.gov/news-events/news-releases)

\* **Journal Reference:** Nahin RL, Boineau R, Khalsa PS, Stussman BJ, Weber WJ. “Evidence-based evaluation of complementary health approaches for pain management in the United States.” *Mayo Clinic Proceedings*. 2016;91(9):1292– 1306.

**Sourced from National Fibromyalgia Partnership Inc. (NFP) *Fibromyalgia Frontiers*, 2017 (Volume 25 No. 1)**



## Recommendations For Resistance Training In Patients with Fibromyalgia

*By Kim Dupree Jones, Ph.D., FNP, FAAN*

**Abstract:** It may seem counter-intuitive to purposely stress muscle patients who have muscle pain. However, a growing body of evidence challenges the assumption that resistance (strength) training worsens muscle pain in people with Fibromyalgia (FM). In fact, the latest evidence indicates that when resistance training is tailored to individual needs, people with FM can obtain worthwhile improvements in FM severity. Clinicians need a deeper understanding of how resistance training helps people with FM, so as to prescribe more specific, personalized resistance training to their patients.

Resistance training is a type of exercise in which progressive resistance is used to improve muscle strength, endurance, power, or a combination. Resistance can be manipulated with free or machine weights, bands, or elastic tubing, or even with one's own body weight. Resistance training not only builds muscle strength and mass, it also produces improvements in balance, co-ordination, and agility.

In an article published recently in *Arthritis Research & Therapy*, Larsson et al. (1) report the results of a multicentre, parallel randomized controlled trial (RCT) in which they compared group-based progressive resistance (strength) training versus relaxation training in 130 Swedish women with Fibromyalgia (FM). The study was based on a "person-centered" model of exercise. This model actively involves the patient in planning the treatment, and optimizes self-confidence for exercise. Small groups of five to seven women exercised together under the supervision of a physiotherapist at a local gymnasium, twice weekly for 15 weeks. Starting loads were low (40% one repetition maximum (1RM), the heaviest weight a person can lift or move in one contraction) and slowly progressed to 80% 1RM. However patients could decline increasing loads if they were unsure they could manage the new load. Immediately post intervention, the resistance training group – compared with the relaxation training group – demonstrated significant improvements in isometric knee and elbow extension, 6-minute walk, and health status (Fibromyalgia Impact Questionnaire). At 13-18 months post intervention, differences were no longer found between the groups on any measure, underscoring the difficulty in adopting exercise outside of a formal program.

Additional support for benefits of resistance training in FM can be found in a recent Cochrane Database review. [2] The authors concluded that resistance training improves multidimensional function, pain, tenderness, and muscle strength in women with FM. However, the level of evidence remains "low" owing to the small number of resistance training RCT's [randomized controlled trials] to date [3,4,5,6,7] Moreover, men have yet to be studied, and minority representation is small. The optimal training frequency, intensity, timing, and progression are not yet fully understood in FM. This gap is due, in part, to the heterogeneity of fitness levels and symptom burden in People with FM. There is good evidence for individualizing the prescription of exercise with the philosophy of "starting low and going slow" during progression. Realistically, most patients will have difficulty transferring these results into a long-term habit outside the support of a formal study. Beyond the results reported here, there is evidence for the benefits of resistance training in healthy individuals in terms of body composition, muscle strength, age-related muscle loss, and all-cause mortality. [8,9]

## Resistance Training in Patients with fibromyalgia Continued

Having FM poses hurdles that need to be overcome before reaping the rewards of resistance training. People with FM are less physically active compared with age-matched controls. [10] Deconditioned muscle is a potent pain generator owing to delayed onset muscle soreness (DOMS). This is a result of an inflammatory response during the repair and adaptation process of building muscle (e.g. microtrauma, repair, and growth). [11, 12] Not surprisingly, sedentary persons may have difficulty in initiating or maintaining an exercise program because of both immediate pain and DOMS. Simply put, being active will eventually lead to more pain on exertion and for many will result in a symptom flare.

Patients rarely have access to an academic RCT like that of Larsson et al. Clinicians therefore need to be able to give patients safe, evidence-based exercise advice. Here is some pragmatic guidance: do not expect resistance training to be a replacement for medications; instead think of exercise as a key part of the overall interdisciplinary management plan.

The following presents some general advice for patients. Have a well-defined goal in mind and focus on training consistently rather than intensively. Minimize eccentric muscle loading, a major cause of DOMS [delayed-onset muscle soreness], by limiting overhead arm work and exercises done with limbs farther away from the body's midline. Do not attempt to do strength training during a symptom flare. Do not attempt high-intensity, power-based workouts (e.g. plyometrics, CrossFit, bootcamps). Limit pain-provoking postures by working within the natural lines; this reduces the risk of aggravating tendinopathies or over-extending hypermobile joints. Avoid the urge to overtrain on days you feel better. Be proactive by providing FM-specific advice to a fitness trainer. [13] Work out at home with DVDs especially formulated for FM patients. [14] Lastly, link an exercise with an activity you like or do regularly to increase the likelihood that exercise will become a life-long habit.

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Notes: see also related research by Larsson et al., <http://www.arthritis-research.com/content/17/1/161>

### Some light Entertainment

While I sat in the reception area of my doctor's office a woman rolled an elderly man in a wheelchair into the room. As she went to the receptionist's desk, the man sat there, alone and silent. Just as I was thinking I should make small talk with him, a little boy slipped off his mother's lap and walked over to the wheelchair.

Placing his hand on the man's, he said, "I know how you feel. My Mum makes me ride in the stroller too".

\*\*\*\*\*

Out bicycling one day with my eight-year-old granddaughter, Carolyn, I got a little wistful. "In ten years," I said, "you'll want to be with your friends and you won't go walking, biking, and swimming with me like you do now.

Carolyn shrugged. "In ten years you'll be too old to do all those things anyway".

\*\*\*\*\*

### Nap often

When my children were young, I had a rule: Unless the house is on fire, everyone takes a nap after lunch. They've long cut and run, but if there is one childhood they would love to reclaim, it is napping midday. There's good reason for their wistful longing: A nap is renewal. A nap is escape.

Forward-thinking employers may sanction a resting of the eyes mid-day, but never a nap, for the difference between a nap and a rest is when preparing for a nap, you take off your clothes and get into bed. Do try this at home.

*Taken from Apronisms  
Pocket Wisdom for every day  
Compiled by EllyAnne Geisel  
Copyright 2008*



# For Your Diary

## Northern

Every 4th Thursday in the month at Kings Meadows Health Centre, Joan Marshall Wing. 10.30 am bring some morning tea and enjoy a chat over a cup of tea or coffee.

## Southern

20th August, ESUS Café Elizabeth St Hobart, at 12 noon. Pay for self.

Please contact Heather to book 6272 3096

North West: Fuschia Farm, Lillico June 5th and July 3rd

West Coast: Please phone Barbara for information on 6471 6506 or 0419 724 384



# Lupus Association Of Tasmania Inc.



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Membership of \$15 includes newsletters

This registration covers you and family members

