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

LUPUS NEWSLETTER

Published Quarterly by

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

May 2017 Volume 37 No. 2

Happy Easter
Office Bearers

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Registered Charity        ABN 96 163 951 956

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Yearly Subscriptions: $15   Lupus Badges $5
Embroidered or X-Stitch Butterfly Brooches $10
Embroidered Butterfly Key Rings $5

Donations over $2 are tax deductible.

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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.
**President’s Message**

It is with great relief our Organisation has managed to secure all the positions needed to successfully operate and continue to offer support and education for people with Lupus. At the AGM, we were able to gather together a blend of old, recycled expertise of Murray, and the new I will give it a go, Leanne, and the very kind volunteer of Di Whiteley who has past experience as a club secretary and who is new to Lupus. A group of members, Julie, John, Cheryl, Edna, and Heather also rallied to help as co-ordinators, editor and committee members. Thanks to all we will stay viable and continue the work to improve the lives of people with Lupus.

President
Lois Beckwith
United By Our Disease
We Salute Them!!

We have been most fortunate to have had two outstanding couples devote an extraordinary amount of their lives to improving the outcomes for people with LUPUS. On behalf of all present and past members I wish to thank Bruce and Colleen McCormack and Vic and Denise Hartas for their outstanding work in building the Lupus Association of Tasmania.

During their commitment over the years, individually and collectively they have worked on all aspects of our organization. The skill they have brought to all their roles is far reaching and enormous; President, secretary, treasurer, committee member, regional co-ordinator, mentor, educator, publicists, conference and Lupus awareness week organisers, fundraisers research co-ordinator, political advocate, library and information gather and dispenser, caterers (dishwashers), and general organisers extraordinaire.

Having made this list I smile as I think that I am sure they could add a few more roles that I might have overlooked. They will certainly be missed and our supporters have rallied to fill the gap. We wish them all better health and time to enjoy retirement. Whenever you can we will still welcome your input and participation.

We wish them the very best. They will be our friends for ever.

President: Lois Beckwith

Colleen at our last morning Tea

Vic and Denise Hartas

Bruce and Colleen McCormack
Regional Reports

Northern Group
Our group decided to continue meeting on the fourth (4th) Thursday in the month at 10.30 am at the Joan Marshall Wing, Kings Meadows Health Centre to share Morning Tea (bring a small plate of food to share). We will also occasionally replace our morning tea catch up with a group lunch at a nearby venue. April 28th will be a morning tea, while the next month May 25th will be a lunch meeting starting at 12.00 at the Kings Meadows Pub. Pay for yourself. Hope to see you all there.

Lois Beckwith
Northern Co-ordinator

North West Group
Our first gathering was only small but was great all the same. We met at the Fuschia Farm on Lillico straight as one of our newest members lives close by to her beautiful family owned business. Always a great feed, along with fabulous company makes the Fuschia Farm a favourite place to visit.

Due to members present at the March get together, many were unable to attend in April so we voted to skip April and make a catch up day in May.

We have encouraged members past and present to bring along any new members who would like to have a chat and a chin wag. We have chosen to meet the 1st Tuesday of every month (you pay for your meal).

Dates from May to December are:
2nd May—Fuschia Farm, Lillico.
6th June—Shadows, Latrobe.
4th July—Gateway, Devonport.
1st August—Fuschia Farm, Lillico.
5th September—Lucas Hotel, Latrobe.
3rd October - The Scone Shop, Sheffield providing it does not clash with Lupus Awareness Week
North West Region Cont.
7th November—Argosy Motel, East Devonport
5th December—Fuschia Farm—Christmas Lunch for North West Group.

We are already starting to build capacity with 2 new members at the March Luncheon with the possibility of a few more at the May lunch. Looking forward to rebuilding the North West support group so we all have people that we can connect with and call when things get us down.

Leanne Stephens
North West Co-ordinator

** It is good to hear from our North West group again. Keep up the good work Leanne.
West Coast Support Group

Position Vacant: GROUP COORDINATOR

Our committee would like to have a support group ‘up and running’ down the west coast of Tasmania that will support people with Lupus, Sjögren’s, Schleroderma, Fibromyalgia and their family, carers and, friend’s etc.

For more information and a job description please phone or email Lois on 03 6369 5393 / loisbeckwith@bigpond.com

Southern Support Group

Two Southern Tasmanians attended the Lupus AGM and were very pleased that volunteers came forward to form a new committee so the Tasmanian Lupus Association can continue to exist. We greatly appreciate the generous gifts of time and energy that the new committee members have volunteered to the Association.

It was great to see Vic Hartas, who returned from Queensland for the meeting. We were extra pleased to hear of the marked improvement in Denise Hartas’ health. She escaped her wheel chair and has returned to light house work and gardening.

As a result of the continuation of the Lupus Association, the Southern lunches will continue on the second Wednesday of every second month, at the Esus Café in Elizabeth Street, Hobart at 12 midday. These are simple social support events at which we pay for ourselves. All I need is to know you are coming so I can book the table. My phone number is on page 2.

Next Luncheon Dates are June 4th, August 9th, October 11th and December 13th

I am also pleased to share that Allyson Reedy-Mead has agreed to be assistant Southern Co-ordinator. As you know, I have several elderly relatives on the mainland who may call me away from the state at any time, for an extended period.

Having Allyson as a backup is very reassuring for me. Allyson is a university student who will attend luncheons as her classes allow. Thank you Allyson for this generous gift of your time. Every one is welcome at our luncheons ..they can be their family, friends, visitors or carers.

Heather Cowled
Southern Co-ordinator
**Word from the Editor**

Hooray!!! We are still functioning as an Association. Thank you to Lois, Dianne, Murray and Leanne for putting up their hands, also to the committee, Julie, John and Cheryl, we should expect a good year.

I would like to thank Colleen, Bruce, Vic and Denise for supporting me as editor of the Newsletter, over the years. They will be missed greatly as “contact points” for info about the Association. We hope they are taking a well earned “rest”.

We also farewelled another stalwart of the Association, Queenie Ennis, who willingly became treasurer when it looked like Bruce would have to take that on as well. We wish Queenie all the best in South Australia and hope she too, has a healthy life in Adelaide where she will be near her family. We are about to sojourn to our warmer climes, so the next newsletter will come from Queensland.

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**Lupus Association Web Site**

**Things are about to improve!**

Lupus Tasmania has a website (http://lupustasmania.org.au/) and a Facebook Page (https://www.facebook.com/lupustasmania/)

We can make use of these resources by sharing information - such as

- information about our organisation,
- information available on the internet
- personal stories, reflections and successes and many others.

Kindly send ideas for contributions to our post office box or email address as listed on page 2. They will be forwarded for discussion and hopefully published as soon as possible.

Also, to help our association to gain new members and public understanding of who we are / what Lupus Tasmania stands for, please take time to fill in and return the forms on pages 13 and 14. In detail, we ask you to complete the form that matches your illness then cut on the dotted line. You can either send it via post or email.

Stephen Smith
Web Manager for Lupus Tasmania.
Sitting and Moods
Take a moment to think about your posture right now. Are you slouching in your chair with your shoulders rounded and your head leaning forward? This is one of the most common poor postures that people assume while sitting, and aside from giving you tight neck and shoulder muscles and tension headaches, this posture may bring down your mood.

Now, take a moment to straighten up. Elongate your spine and put your shoulders back. If your head is forward, move it back so your ears are in line with your shoulders. Feels good, doesn't it? It's not a coincidence, as this simple act of correcting your posture can trigger multiple physical and emotional benefits.

Boost Your Mood by Fixing Your Posture
If you tend to slouch when you sit, sitting up straight may be akin to an "instant mood lift," according to research published in Health Psychology. It's long been suggested that your body's muscular states are related to your emotions.

This has primarily been explored via facial expressions, and positive facial expressions, such as smiling, are associated with more positive mood. Body posture, however, is also thought to be important to both the initiation and modulation of emotions, which is what the featured study investigated.

It involved 74 participants who held either a slumped or upright seated posture while reading and engaging in other tasks and self-assessments. Those sitting in an upright posture enjoyed multiple benefits compared to those who were slouching, including:

* Higher self-esteem
* More arousal
* Better mood
* Lower fear
* Stronger pulse responses

A linguistic analysis further showed that when participants slouched, they used more negative emotion words, sadness words, and fewer positive emotion words during speech. The researchers concluded that sitting upright may be a simple way to boost your mood and resilience:

"Adopting an upright seated posture in the face of stress can maintain self-
Esteem, reduce negative mood, and increase positive mood compared to a slumped posture. Furthermore, sitting upright increases rate of speech and reduces self-focus. Sitting upright may be a simple behavioural strategy to help build resilience to stress."

Even with Proper Posture, Too Much Sitting Is Devastating to Your Health
Proper posture when you sit is important, but an even more pressing issue is the length of time you sit in a day. If you're like the average American, you sit for nearly eight hours a day, although some estimates suggest it's closer to 13-15 hours daily.

If you think about it, this is an extraordinary amount of time to be inactive. Even if you exercise for 30 minutes or so (and most don't), you're still sedentary for the vast majority of your day, and therein lies the problem.

Increasing research shows that a daily exercise session is not enough to counteract the effects of prolonged sitting, and sitting for extended periods is an independent risk factor for poor posture, poor health, and premature death.

One analysis of 18 studies found that those who sat for the longest periods of time were twice as likely to have diabetes or heart disease, compared to those who sat the least. According to lead researcher Thomas Yates, MD:

"Even for people who are otherwise active, sitting for long stretches seems to be an independent risk factor for conditions like diabetes, cardiovascular disease, and kidney disease."

An earlier study, published in 2009, also highlighted evidence linking sitting with biomarkers of poor metabolic health, showing how total sitting time correlates with an increased risk of type 2 diabetes, heart disease, and other prevalent chronic health problems—even if you exercise regularly.

This article appeared in the Devon and Cornwall Lupus Group Newsletter and was extracted from www.drmercola.com - Mercola, J. “Slouching Makes You Sad” October 03, 2014

Thank You to Lupus UK News and views , Summer, 2016, No. 109 , for permission to reprint this article. As I sit around a lot, I found the article very interesting. Ed
Pacing?

**Introduction**
Many patients who have had a stay in the Intensive Care Unit (ITU) found that they could no longer perform certain tasks without experiencing increased fatigue when discharged home. This could lead to them becoming increasingly inactive, or catching up on jobs when they had a good day, which then leads to a flare-up of pain or general weakness and the need to rest for a few days.

![Diagram of the overactivity/underactivity pattern]

This overactivity/underactivity pattern can be represented in a cycle as shown.

**What is Pacing?**
“a way of increasing your activity level without stirring up your fatigue too much”

**Aim:** to maintain an even level of activity throughout the day instead of doing as much as possible in the morning and then resting all afternoon.

**How to use Pacing**

1. **Work out what you can manage now:**
   - Decide on your baseline – how much of your activity can you do on a good day and a bad day
   - This may take a couple of attempts to get right
   - **DO NOT** compare yourself to others or what you think you ought to be able to do

2. **Decide on a realistic build-up rate:**
   - Too much too soon will make you overdo things
   - Build up the task slowly and at a steady rate regardless of your fatigue

3. **Write your plan down and record your progress:**
   - Write down your plan and your daily progress (maybe in a diary)
   - This will allow you to easily notice your progress or if you’re slipping back
   - On a daily basis it is also difficult to remember things or how you were
Applying Pacing to a Task – The Rule of the 3 P’s

Prioritise  Do you need to do the entire task today / in one go?
Can you get someone else to help? Does the task need to be done at all?

Plan  Can you break the job into different stages?
What do you need to carry out the job?
What basic activities does each stage involve? (e.g. walking, sitting, standing)

Pacing Techniques:

There are 3 main aspects to pacing:

1. **Breaking tasks down into smaller bits** – Part of prioritising

2. **Take frequent short breaks**
   a. Do something for a set time
   b. This breaks the overactivity / underactivity cycle
   c. Helps to even out your activity over the course of a day
   d. ‘Taking a break’ does not mean stopping completely
   e. Change your position or do something else for a short while

3. **Gradually increase the amount you do**
   a. You may seem like you are going backwards and activities can take longer
   b. Gradually build up the amount you do
   c. ‘Pace up’ by a set amount
   d. Do not be tempted to try to do more on a ‘good day’ stick to pacing levels

Additional hints for using pacing:

- Start on activities that are easier
- For activities that you cannot leave, it is most important that you still try to pace yourself as much as possible
- Try to change your position regularly
- It is ok to ask for help with specific tasks
- Keep to your targets and plans if possible

If you understand and put into practice the concept of pacing, you should have fewer flare ups of pain or episodes of fatigue and gradually do more and more.

Setback or flare-ups

- Fatigue and setbacks are normal and everyone has them
- It does **NOT** mean you are back to square one
- How much pain or fatigue you experience will depend on how you react
- It is important to remember that pacing has worked for you before and can still continue to work for you

Tips for changing habits:

- write a list of your plans and stick it on the fridge
- start off with a small change and build on this
- make a list of why you want to change
· explain to others why you are changing a habit, get support and help from others if needed
· reward yourself with a treat
· do not worry if you fall back into your old habits, everyone does when they try to change, look at your plan and start afresh
· find a new way of doing something with pacing rather than stopping it altogether

Remember - be positive about what you can do rather than what you cannot do

With thanks to the South Devon Healthcare NHS Foundation Trust for allowing permission to use this patient information.

Thank you to Lupus UK, News and Views Summer 2015, No. 106, for allowing permission to print this article for our members information.

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Wise Words

To enjoy good Health,
To bring true happiness
    To your family,
To bring peace to all,
    You must discipline
And control your own mind.

    If you can
Control your mind
    You can find
Enlightenment
And all wisdom and virtue
    Will naturally
Come to you.

Buddha

Creating a life of Prosperity

Taken from “Well Being”, Affirmations Publishing House, Designed and Edited by Suzanne and Barbara Maher
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### Member with Sjögren’s

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### Member with Fibromyalgia

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General Meetings for 2017

June 11th
September 10th
December 10th

NOTE: All meetings are held at the Kings Meadows Health Centre in Kings Meadows starting at 10.30am. Please bring a small plate of food to share after the meetings.

LAW (Lupus Awareness Week) - TBA

Northern Group
Meet the 4th Thursday of every month

North West Group
Meet the 1st Tuesday of every month:

Southern Group
Meet every 2nd Wednesday of the even months.

NOTE: Please turn to page 4/5 for more information on the groups.

Have you registered for 2017 and 14.