



# LUPUS NEWS

## TASMANIA

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Lupus Association of Tasmania Inc.  
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Committed to understanding and supporting people with Lupus, Sjögren's, Scleroderma & Fibromyalgia or any autoimmune disease

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Registered Charity ABN 96 163 951 956

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The Lupus Association of Tasmania, Inc. does not recommend or endorse any drugs, treatments or procedures reported in this newsletter. The information is intended to keep you informed and we recommend that you discuss any information mentioned with your Doctor.

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

## President's Message

Congratulations to Colleen McCormack for being honoured as a Member of the Order of Australia for her charitable and volunteer work she has performed in Launceston area over many years. Those of us that know Colleen can understand why she was bestowed such an honour, until last year she was our Northern Co-ordinator for many years, I have not known Colleen turn down a request for help even when she was in ill health. You are truly a deserved recipient of this award.

Recently my GP, and after a stern talking to from member nurse Pat, sought Palliative Care assistance for Denise and myself. I am including my experience in this newsletter because I am sure there are a lot of sufferers with family carers out there that can do with assistance. As my GP said "You are no good to Denise if you get burnt out", which was the way I was heading, she contacted Palliative Care and the rest is history. We were assessed by qualified people and were granted help. I now have a delightful housekeeper who has put a woman's touch back into the house and Hospice send wonderful volunteers to sit with Denise while I get some personal respite; Community nurses visit on a regular basis. They have a huge range of services which cover every situation possible. My advice, don't be a hero, get help.

I must pass on a huge thank you to our website manager, Stephen Smith, for looking after our website with updated information and articles, and also the setting up of face book social media networking site. Stephen makes sure the Association is getting the best service at the lowest price possible and has saved us a huge amount of money over the years. Stephen is a professional who has set up websites for various companies, thank you Stephen, sorry I haven't acknowledged your efforts earlier.

Our next meeting is an Annual General Meeting when all positions become vacant so if you would like to stand for any position come along or if unable to attend, put it in writing with a nominator and seconder and send it off to our address. I take this opportunity to thank all our office bearers and committee for their efforts during the past 12 months and thank you for your support especially during Denise's illness. Thank you to Bruce McCormack, our outgoing secretary, for filling in some of my duties during the year.

Vic Hartas  
President



## Reports

As I sit at my computer I once again wonder about the long term future of the Lupus Association of Tasmania Inc. As has been fore-shadowed, as of the AGM of March 2016 I will no longer be the secretary/public officer of the Association. Nobody had come forward to take on the position until probably our youngest member in Allyson Reedy-Mead put up her hand and said she would accept the position if appointed at the AGM. To me there is little doubt she will be voted in as no other member has evinced any interest in the position or for that matter any position save that one person has shown interest in becoming president. Allyson showed such willingness to do the job of secretary that she spent a full day with me learning all of the duties that the secretary performs; her attitude has been admirable and a metaphoric round of applause should be directed to this fine young lady. All members of the Association should search their inner selves and determine whether they wish the Association to remain vibrant and relevant and consider standing for a committee position. Finally thank you for member support in my time as secretary and in other roles and in closing I wish all members a happy and healthy year in 2016.

Bruce McCormack  
Secretary/public officer.

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### Southern Report.

Happy New Year greetings from the south of the State. 2015 was a year of significant illness for many southern members and as this year starts we are all hoping that 2016 will be a year of significant health improvement for all members.

We will continue to meet every second Wednesday of every second month, February 10th, April 13th, June 8th, August 10th, October 12th and December 14th. We meet at the Esus Café in Elizabeth Street because of its proximity to bus stops and council parking station. The Café is also usually quiet at lunch times so we can have confidential conversations without competing with other noises. We have about a dozen members who meet there regularly and catch up on all the news. It is a friendly time of general conversation and sharing of experiences. Everyone is welcome so if you are visiting Hobart or want to bring a family member or friend with you we will be pleased to meet them as well.

The menu is small but covers a good variety of dishes starting at about \$12. The seafood chowder is the most delicious full meal in a bowl and is highly recommended. Come along and try it.

We meet at 12 midday for about an hour to an hour and a half but please contact me the Monday before so I can book tables and seats needs.

My phone number is 6272 3096 or e-mail [hlcowled@bigpond.net.au](mailto:hlcowled@bigpond.net.au).

Heather Cowled  
Southern Co-ordinator

## Good Friends...

*I got this, thanks to a friend .....*

I grew up in the 50s/60s with practical parents. A mother, God love her, who washed aluminium foil after she cooked in it, then reused it. She was the original recycle queen, before they had a Name for it...

A father who was happier getting old shoes fixed than buying new ones. Their marriage was good, their dreams focused. Their best friends lived barely a wave away. I can see them now, Dad in trousers, tee shirt and a hat and Mom in a house dress, lawn mower in one hand, and dishtowel in the other. It was the time for fixing things. A curtain rod, the kitchen radio, screen door, the oven door, the hem in a dress. Things we keep. It was a way of life, and sometimes it made me crazy. All that re-fixing, eating, re-newing, I wanted just once to be wasteful. Waste meant affluence. Throwing things away meant you knew there'd always be more.

But then my mother died, and on that clear summer's night, in the warmth of the hospital room, I was struck with the pain of learning that sometimes there isn't any more.

Sometimes, what we care about most gets all used up and goes away...never to return. So...while we have it...it's best we love it.....and care for it... and fix it when it's broken.....and heal it when it's sick.

This is true. For marriage.....and old cars.....and children with bad report cards.....and dogs with bad hips.....and aging parents.....and grandparents.

We keep them because they are worth it, because we are worth it. Some things we keep. Like a best friend that moved away or a classmate we grew up with. There are just some things that make life important,! like people we know who are special.....and so, we keep them close!

I received this from someone who thinks I am a 'keeper,' so I've sent it to the people I think of in the same way. Now it's your turn to send this to those people that are "keepers" in your life.

Good friends are like stars....You don't always see them, but you know they are always there.

Keep them close!

### **TEN THINGS GOD WON'T ASK ON THAT DAY**

1...God won't ask what kind of car you drove. He'll ask how many people you drove who didn't have transportation.

2...God won't ask the square footage of your house. He'll ask how many people you welcomed into your home.

3...God won't ask about the clothes you had in your closet. He'll ask how many you helped to clothe.

4...God won't ask what your highest salary was. He'll ask if you compromised your character to obtain it.

5...God won't ask what your job title was. He'll ask if you performed your job to the best of our ability.

6...God won't ask how many friends you had. He'll ask how many people to whom you were a friend.

7...God won't ask in what neighbourhood you lived. He'll ask how you treated your neighbours.

## North and North West

Morning teas, in Launceston, on the fourth Thursday of each month have commenced for 2016. Bring along some finger food and if you have any problems or need answers to any questions please come along and someone will try to answer your query. These “meetings” are very informal and the time is quite enjoyable getting to know fellow sufferers. We had a few new members at our last morning tea and we would like to welcome them into our “Loopy family”.

**North Western** members are reminded that we have a different meeting day. All meals are pay for self, please see For Your Diary, page 12 for times and dates.

Our thoughts are with Vic and Denise and pray that Denise will continue to keep well.

\*\*\*\*\*

*Good friends continued:*

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8...God won't ask about the colour of your skin. He'll ask about the content of your character.

9...God won't ask why it took you so long to seek Salvation. He'll lovingly take you to your mansion in heaven and not to the gates of Hell.

10...God won't have to ask how many people you forwarded this to. He already knows.

\*\*\*\*\*

## Wise Words

Today, see if you can stretch your heart and expand your love so that it touches not only those to whom you can give it easily, but also to those who need it so much.

All that we are is the result of what we have thought. The mind is everything. What we think, we become. Peace comes from within.

At the centre of your being you have the answer; you know who you are and you know what you want.

Lao Tzu



## From Lupus Tasmania Web Site

### [LupusTasmania.org.au](http://LupusTasmania.org.au) WebSite.

The Lupus Tasmania web site has moved hosting. This means nothing to the user. I have organised a new home because:

1. it was \$1 month cheaper
2. the security is stronger with the new hoster
- 3) it is a little more convenient for me to have all the web sites I manage under one company.

#### *What is Hosting ?*

A web site has to be on a computer somewhere - it doesn't exist in thin air ! So, there are companies called Hosting Services that do this for you. There are special programs to control everything ! Their computers **have to be on and connected** to the internet 24/7 otherwise ... well no [Lupustasmania.org.au](http://Lupustasmania.org.au)

The second part is called the **Domain Name**. There is a second company that tells the world where [lupustasmania.org.au](http://lupustasmania.org.au) lives !

Our new hoster is <https://netvirtue.com.au/> .

Cheers,  
*Stephen Smith*  
Cheers

*Thanks Stephen for your article. This makes it easy to under stand*

\*\*\*\*\*

### February is Raynaud's Month

Raynaud's phenomenon is the name given to the temporary interruption of blood supply to the fingers or toes (occasionally the ears and nose) which occurs as a result of spasm causing the vessel to squeeze and get smaller. This reduces blood flow to many areas particularly those that have a lot of small blood vessels. It is characterised by a series of changes in the colour of the skin. Typically the finger or toes initially become white as blood supply is lost, then blue or dusky purple, and finally pink as blood flow improves.

Raynaud's is characterised by episodic changes that can be brought on by the effects of cold temperature and emotional upset. To protect yourself maintain a warm core body temperature, wear protective clothing and learn how to reduce stress and anxiety.

Reprinted from ARRC-hive, Summer edition, Vol. 1780.

## **Lupus and the feet**

*Dr Anita Williams PhD, BSc (hons) FCPodM, Senior Lecturer | Post Graduate Research student Co-ordinator, School of Health Science, University of Salford*

Lupus can affect the feet in relation to their structure, function, blood and nerve supply. People with lupus can also develop common foot problems just like anyone – skin problems such as corns and hard skin; nail problems such as thickened nails or ingrowing toe nails; infections such as verruca or athlete’s foot. When these problems occur they have the potential to cause pain, place the person at risk of bacterial infection and may cause problems with walking. Often these problems appear to be overlooked during medical consultations as the feet are hidden in shoes and there are usually other priorities to discuss.

The inflammation associated with lupus can affect the joints and tendons in the feet and ankles causing the arches to flatten and the heels to tilt (often the shoes wear out heavily at the back or the upper part of the shoe may become distorted). Because it is hard to rest the feet and the bodies weight is on them these problems tend to become worse over time if nothing is done to reduce the inflammation (through medication) or support the structures of the feet. Insoles (known as foot orthoses) with an arch often help and appropriate footwear with support can also supplement the effect of insoles in order to prevent these problems progressing.

Some people with lupus can experience decreased blood supply to feet and legs associated with atherosclerosis (hardening of the arteries) which can lead to cramp-like pains in your calf, thigh or buttock muscles when walking and other circulation related disorders such as Raynauds phenomena (Figure 1) where the small blood vessels in the skin of the hands and feet ‘shut down’ in response to changes in temperature leading to the following colour changes: toes/fingers go white, then blue and then red. These colour changes may also be accompanied by a tingling sensation in the affected areas and it is often made worse if the person smokes cigarettes.

Some people may experience problems with the nerve supply to their feet known as Peripheral Neuropathy (this can be caused by inflammation of the small blood vessels that feed the nerves and they can become damaged, thus leading to abnormal nerve function). This may mean that pain and other sensations such as temperature (hot or cold) and pressure are not felt, or ‘pins and needles’ may be experienced in certain parts of the feet as a result of a trapped nerve.

These are types of problems that are less common but you should be aware of the symptoms if they arise and inform your rheumatology Health Care Practitioner responsible for your care.

Some medications used to treat lupus can also have an effect on the skin and underlying tissues, making them more vulnerable to damage and infection. It is important that anyone that looks after your feet is aware of all the medications that you are taking so that they can manage any potential problems appropriately. If you develop any signs of infection in your feet such as localised redness, swelling, increased pain and pus coming from a wound, break in the skin or ingrowing toe-nail for example, you should notify your rheumatology Health Care Practitioner and /or Rheumatologist as a matter of urgency.



### **Common foot problems**

Shape changes in the front of the foot and the toes can create

pressure sites that develop corns and calluses (hard skin). These may develop into areas of ulceration if not treated appropriately, and so it is advisable to request guidance from a podiatrist if hard skin or corns (figure 1) are present on your feet. Sometimes nail can become thick due to pressure or it may be caused by a fungal infection in the nail (often yellow or brown and flaky. The nails can also become excessively curved causing discomfort (figure 2). Also when a spike of nail becomes embedded in the side of the toe (an ingrowing toes nail) this may become infected with redness and pus being the obvious signs as well as being very painful.



Podiatrists can provide foot care for all these common foot problems and also advice on how to self-manage these problems. They can assess your blood supply and nerve supply as well as evaluating foot structure and the way you walk. They also provide advice on suitable footwear and provide in-soles in order to relieve foot pain and improve the alignment of joints. Professional guidance should always be sought with regards self-treatment of hard skin and corns - you are advised not to use pedicure blades, corn plasters and paints on these areas.

Podiatrists are trained professionals who are registered with the Health and Care Professions Council (HCPC). Podiatrists who work in the NHS have to be registered with this organisation in order to practice as it ensures that they have undergone the correct training. Most independent (or private) podiatrists do register but some do not - it is important to check that the podiatrist you seek help from is registered with the HCPC. You can check online if you are unsure (<http://www.hpc-uk.org/landing/?id=4>)

A research team of podiatrists based at the University of Salford are carrying out a survey of foot problems and would be interested to find out from you what your experiences are in order to improve foot health services for people with lupus. If you are interested in this study please contact

**Dr Anita Williams** [a.e.williams1@salford.ac.uk](mailto:a.e.williams1@salford.ac.uk) or 0161 295 7027 or if you prefer to write to her the address is -

**Dr Anita Williams School of Health Science Office PO29 I Brian Blatchford Building University of Salford M6 6PU**

*Thank you to Dr Anita Williams and The Lupus UK News and Views, Summer 2014, Number 103, for granting permission to print this article.*

*Owing to have spent many years experiencing foot problems I felt this article was very appropriate for our members. Ed.*



## Meet a Tasmanian Researcher

Osteoarthritis and osteoporosis are ancient conditions and yet they continue to 'challenge' the understanding of researchers to this day. In Tasmania we are fortunate to have one of the world's truly iconic medical research institutes. The Menzies Institute has internationally regarded research teams—one dedicated team is working on musculoskeletal conditions including types of arthritis & also osteoporosis

Introducing Dr Benny Eathakkattu Antony

Dr Benny Eathakkattu Antony is a member of the highly regarded musculoskeletal research group at the Menzies Research Institute Tasmania, working with Professors Graeme Jones and Changhai Ding to explore the childhood determinants of adulthood knee joint health.

Dr Antony has received grants from competitive sources and has published twenty three articles primarily on the epidemiology of osteoarthritis. Half of his publications include the top rheumatology journal -"Annals of the Rheumatic Diseases". He has received awards from various rheumatology and bone research agencies and recently was selected as the Tasmanian state finalist for the Young Scientist Award. Dr Antony has delivered oral presentations at the annual scientific meetings of the American College of Rheumatology, European Rheumatology Conference (EULAR) and the Australian Rheumatology Conference.

### **Dr Antony can you explain your current research?**

My research interests are the factors that influence the development of peak bone mass and cartilage in children and young adults. Currently we are exploring if the physical activity, fitness and obesity measures in childhood influence the knee bone and cartilage health in adulthood.

### **What do you hope to achieve with this project?**

The peak bone mass and the amount of cartilage attained in early adulthood is a predictor of the fracture and osteoarthritis risk in later life. Therefore, identifying the early life modifiable risk factors associated with the peak bone mass and cartilage health can delay or prevent the development of osteoporosis and osteoarthritis in later life.

### **How could your work help people with arthritis?**

Osteoarthritis is the most common joint disorder in adults around the world and nearly one in three older adults will be affected by knee osteoarthritis. My research can identify the modifiable risk factors for the development of this incurable disease. I am also focussing on identifying the early markers of osteoarthritis that can be used as a target for the treatment for osteoarthritis.

### **To date what has been the highlight of your career; and what did you find?**

In 1985 there was a group of school students who underwent physical activity and fitness measurements as part of the Australian Schools Health and Fitness Survey. These students were contacted again 25 years later and asked to undergo knee MRI scans. When we studied these scans and compared them to the data that we had from their childhood, we found that children with higher fitness levels have a better chance of becoming adults with good knee cartilage regardless of adult fitness levels

*Dr Antony continued.*

We also found that childhood overweight measures were linked to higher knee pain in adulthood independent of their adulthood weight status. These findings have already gained media attention both nationally and internationally and have received national and international awards.

We also found that good cholesterol (HDL cholesterol) can increase the bone mass and can protect against development of bone marrow lesions which are predecessors of osteoarthritis.

**What is it like to work at the Menzies Research Institute?**

I am lucky to work within a team of well known researchers who support each other. The level of support from the Tasmanian community for our research projects both as participants and volunteers overwhelms me and keeps me in track of research.

This support encourages me to do further research and get involved with the community and public health initiatives focussing on prevention of these diseases.

**Why did you choose to pursue this type of work?**

Growing up I was very much interested in sports like all the other children of my age. However, injury limited my ability to perform and I always had problems with my knee. This created an interest in the human body and medicine with particular interest in research that related to the musculoskeletal system of the human body.

Moreover, the long 25 year data from childhood with MRI scans, that we can utilise for our research, is the only one of its kind in the world and gave me a chance to explore the novel concepts from childhood to adulthood.

**What would you say are the ‘take-home messages’ from your current research?**

Our research findings suggest that injury free physical activity in early childhood is beneficial not only for attaining higher bone mass, but also for the higher amount of cartilage which can prevent the development of osteoarthritis in later life. Conversely, obesity in childhood needs to be prevented as it can lead to higher knee pain and dysfunction in adulthood.

**Tell our members a little about what you like to do outside of your work?**

I like to travel and explore new places, do adventure trips. I love music and sports.

We thank Dr Benny Antony for giving us some insight into the wonderful research work that he is currently pursuing and congratulate him on his success both nationally and internationally.

*Thank you for permission to reprint this article from the “Arthritis Matters” issue 36, also thank you to Dr Antony for allowing us to print his answers to the questions put to him.*

*The Menzies Research Institute is nationally and internationally recognised for its excellence in and dedication to epidemiological research and has been instrumental in researching the diseases of autoimmunity. Dr Antony says that he knows little about autoimmune diseases but most of us with problems of autoimmune diseases has Osteoporosis and Osteoarthritis problems and I felt that this article deemed worthy of being included. Ed*

# For your Diary

**Annual General Meeting , Sunday, March 13th , 11.00 am Joan Marshall Wing, Kings Meadows Health Centre. McHugh Street Kings Meadows**

Please bring a plate of finger food to share.

**Northern Morning Teas** every fourth Thursday of the month at 10.30 am Joan Marshall wing, Kings Meadows Health centre. Please bring a small plate of finger food to share.

## **North West Lupus Support Group Luncheons**

All meals pay for self, friends and relatives of sufferers are encouraged to attend and are more than welcome.

For further information phone Denise or Vic on 6431 6042 or Charmaine on 0448 977 776. All venues are booked for **12 noon** sittings

**January, Tuesday 19th Gloria's Restaurant, Ulverstone**

**February, Tuesday 16th Fuschia Farm, Lillico**

**March, Tuesday 22nd, Lucas Hotel, Latrobe**

**April, Tuesday 19th Top of Town Hotel, Upper Burnie**

**May, Tuesday 17th , Gateway Hotel, Devonport.**

**June, Tuesday 21st, Gloria's Restaurant, Ulverstone**

**July, Tuesday 19th, Mackey's Hotel, Latrobe**

**August, Tuesday 23rd Club Hotel, Burnie**

**September, Tuesday 20th, Argosy Hotel, Devonport**

**October Lupus Awareness Week, SUNDAY 31ST FORTH HOTEL**

**November, Tuesday 22nd, Blue Wren, Ulverstone,**

**December, Tuesday 13th, Gateway Hotel, Devonport**

*The Lupus Association of Tasmania supports all sufferers of any autoimmune diseases and offers support and information to these sufferers, come along and enjoy great company.*

## **Southern Luncheons**

**Esus Café Elizabeth Street Hobart, Wednesday of every second month**

**February 10th, April 13th, June 8th, August 10th, October 12th and December 14th.**

**We meet at 12 noon, Esus Café because of proximity to bus stops and council parking stations.**

Everyone is welcome, the menu is small but covers a good variety of dishes.. Come along and try it. Please contact me, Heather, so I can book tables and seats. **Phone 6272 3096 or e-mail [hlcowled@bigpond.net.au](mailto:hlcowled@bigpond.net.au)**