Committed to understanding and supporting people with Lupus, Sjögren’s, Scleroderma & Fibromyalgia or any autoimmune disease
Office Bearers

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Proudly Supported by Launceston Pathology

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

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.

Donations over $2 are tax deductible
**President’s message**

**Lupus Awareness Month**
Our Association has had a very busy and successful Lupus Awareness Month. Thanks to Auto-immune Resource and Research Centre we were able to secure their CEO Dr Marline Squance as our guest speaker with a presentation entitled “Knowing and Taming the Wolf.” This Centre is one of the few specialty facilities working on Lupus and auto-immune diseases. It is located at the John Hunter Hospital in the Hunter Valley and they have over 300 patients within the catchment area.

Dr Marline was great on the day addressing a group at the Launceston General Hospital. The members and allied health workers were impressed with the message and how she managed to fit in so much without losing anyone in the audience. The fact that we had two newly diagnosed young girls attend made it extremely valuable to them and it was great that they were able to spend some time before and after the presentation asking questions of Marline and other members. It was very interesting to have a clinical, diagnostic and therapeutic research overview given of the current status of Lupus research. Marlene’s passion to teaching self-management for people living with autoimmune disease was very apparent. We managed to get some media coverage with 2 large pictures in the Examiner and a promise of more to come from the young new reporter. If you missed the talk we have the slides on our web site.

As a part of the awareness campaign we held three days of stall, at Kings Meadows, Deloraine, and the Launceston General Hospital to promote Lupus and Autoimmune Awareness and sell raffle tickets.

We held a lunch meeting with Board members and members after the presentation where Marline talked about research we could be interested in which studies the role of Gut Micromes in people living with Lupus. She also described the significant changes that have occurred in Lupus groups across the country. They have all faced the problem of an aging membership and have moved to change the way they operate. Chat groups and less formal structures have emerged and some groups have merged or networked with other similar organizations. We have managed to survive where most groups on the mainland have not. We now have a lot to think about as we look forward to the best way to keep our organization relevant and viable.

Our monthly meeting was well attended and we enjoyed the late move in venue to Murry and Julie’s home. This was a very positive meeting and a number of motions were actioned.

**New Constitution**
It was decided that Peter Talbot and Lois Beckwith would write a new constitution as our existing one is very dated and needs a full review. We would like to update our structure and reduce some aspects of bureaucracy. A draft will be discussed with members, and sometime in the near future we will include it in a special meeting for finalization.

**Research**
We decided to formally request from Dr Squance a research proposal on gut flora and its possible impact on LUPUS. We asked for a study that would involve our members in Tasmania and one that would lead researchers into new areas that may help control flares. Marline has already replied and she has applied for a Microbiome Research Grant from Microba to undertake a preliminary pilot using subsidised testing from a Microba company.
October is #lupusawarenessmonth! Raising #lupusawareness at Launceston General Hospi-
tal #lupus #SLE #lupusadvocate #thisislupus #autoimmunedisease #chronicilln...

Shining a light on ‘hidden’ disease during Lupus Awareness Month
It took Lois Beckwith 35 years to receive her lupus diagnosis, after first presenting with
symptoms at age 11.
At the time she was told she wouldn’t live for more than five years.
Now …...

To find out more you will need to read our Facebook page
On the Website

Don’t forget Our Website: Lupus Association Tasmania Inc.
There are all the newsletters and information

Words of Wisdom
Peace is the beauty of life. It is sunshine. It is the smile of a child, the love of a mother, the joy of a father, the togetherness of a family. It is the advancement of man, the victory of a just cause, the triumph of truth.

Menachem Begin
**North West region**

Nothing really to report apart from we are having our Christmas luncheon at the Fuschia Farm, 1st Tuesday in December, Please bring a gift to the value of $10. Choosing from menu this time.
12.15pm - 2pm ish
Thank you

Leanne Stephens
North West Co-Ordinator

**Southern Region**

Three people travelled from Hobart for the meeting in October at Launceston General Hospital. I won’t go into details as I expect a report will be in the newsletter. I do want to say it was a very good day. An excellent speaker and wonderful to see people with Lupus from across the state, For those who missed it, you missed an excellent day.

We have our second Lupus Luncheon at Mather’s House at 108 Bathurst St. And is found between the Playbox Theatre and the Library i.e. Between Elizabeth and Murray St.

Our Christmas Luncheon here will be Monday 19th November 2018.

Note this is opposite the Hobart Central car park and near the pedestrian traffic lights, so crossing the road is easy.

Please let me know if you can come by the 16th November so I can reserve a table that day for the following Monday.

Our first meeting is on March 17th at Mather’s House at 12 noon.

I wish you all a Happy Christmas and a healthy and happy New Year

Heather Cowled
Southern Co-Ordinator

**West Coast:** Here’s the latest from The West Coast group. Thank you to Barbara for arranging the meetings.
A Letter to people that don’t have Lupus:

Having Lupus means many things change, And A lot of them are invisible. Unlike having cancer or being hurt in an accident, most people do not understand even a little about Lupus and its effects, and of those that think they know, many are actually misinformed.

In the spirit of informing those who wish to understand...

... These are the things that I would like you to understand about me before you judge me...

- Please understand that being sick doesn’t mean I’m not still a human being. I have to spend most of my day in considerable pain and exhaustion, and if you visit I probably don’t seem like much fun to be with, but I’m still me stuck inside this body. I still worry about school and work and my family and friends, and most of the time I’d still like to hear you talk about yours too.

- Please understand the difference between "happy" and "healthy". When you’ve got the flu you probably feel miserable with it, but I’ve been sick for years. I can’t be miserable all the time, in fact I work hard at not being miserable. So if you’re talking to me and I sound happy, it means I am happy. That’s all. It doesn’t mean that I’m not in a lot of pain, or extremely tired, or that I’m getting better, or any of those things. Please don’t say, “Oh you’re sounding better!”. I am not sounding better, I am sounding happy. If you want to comment on that, you’re welcome.

- Please understand that being able to stand up for ten minutes, doesn’t necessarily mean that I can stand up for twenty minutes, or an hour. And just because I managed to stand up for thirty yesterday doesn’t mean that I can do the same today. With a lot of diseases you’re either paralysed, or you can move. With this one it gets more complicated.

- Please repeat the above paragraph substituting, “sitting”, “walking”, “thinking”, “being sociable” and so on for “stand up”... it applies to everything. That’s what lupus does to you.

- Please understand that lupus is variable. It’s quite possible (for me it’s common) that one day I am able to walk to the park and back, while the next day I’ll have trouble getting to the kitchen. Please don’t attack me when I’m ill by saying “you did it before!”, if you want me to do something then ask if I can. In a similar vein, I may need to cancel an invitation at the last minute, if this happens please do not take it personally.

- Please understand that “getting out and doing things” does not make me feel better and can often make me seriously worse. Telling me that I need a treadmill, or that I just need to lose (or gain) weight, get this exercise machine, join this gym, try these classes... may frustrate me to tears, and is not correct... if I was capable of doing these things, don’t you know that I would? I am working with my doctor and physical therapist and am already doing the exercise and diet that I’m supposed to do. Another statement that hurts is, “You just need to push yourself more, exercise harder...” Obviously lupus/fibromyalgia deals directly with muscles, and because our muscles don’t repair themselves the way your muscles do, this does far more damage than good and could result in recovery time in days or weeks or months from a single activity. Also lupus may cause depression (wouldn’t you get depressed if you were hurting and exhausted for years on end?) but it is not created by depression.

This is not the end of the letter, however, room in this newsletter limits space so I will complete it in next Newsletter. Editor
President’s Message: continued
This will explore the gut-microbiome populations in a case control study to gain insight into any identifiable differences in the relative abundance of microbiome present. She will quantify and qualify the populations of people with lupus and that with a control group of age and sex matched participants without SLE. The Lupus Association of Tasmania will then hopefully help fund the next stage of research in this area. At this point in time we have not allocated any resources to the project, the grant may cover the initial first pilot and we should know this soon. It is really great that we have prompted this research avenue and it may open a huge amount of research around the world into exploring gut-microbiome profiles for potential gene function interactions in relation to anti-inflammatory, pro-inflammatory and innate immune responses. Assessment of gut populations will allow examination of prognostic factors of disease activity to be defined and contribute to our understanding of interactions between inflammation, lifestyle and environmental factors and their contribution to pathogenesis. This new knowledge will improve patient management, especially in SLE patient experiencing frequent and intense flares and intense adverse health events. (flares)

Educator Position
I have started research into the feasibility and effectiveness of having a designated health department worker who can provide support to people with autoimmune diseases within Tasmania. As our numbers are spread across the state it is difficult to determine how best to provide the necessary support resources and counselling that people need. There are a number of models operating in other states and other similar organizations who have part time outreach community workers. It may be time that we prepare a case for a more integrated service, so people living with complicated autoimmune diseases have access to the best local care and have support in developing self-management plans. Somehow we need to be better linked into the available resources and have a more effective referral system.

Resource Library
We have now completed our review of our library and all out dated books have been culled. I have a list of 6 new books that we will be soon sourcing and circulating amongst members.

Christmas Lunch
I urge you all to make our Christmas lunch if you possibly can. It is always great to finish the year on a high

Best Regards Lois

President

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Northern Region

Christmas Luncheon at Kings Meadows Health Centre Joan Marshall Wing, Please bring your favourite salad. Drinks, sweets and meat supplied. General meeting starts at 11.00 am lunch at 12-00 noon.

Usual meetings on 4th Thursday in the month at 10.30am . Bring some morning tea to share and have a chat.

Lois Beckwith
Northern Co-ordinator
My grandma taught me everything about Christmas. I was just a kid. I remember tearing across town on my bike to visit her on the day my big sister dropped the bomb: "There is no Santa Claus," jeered my sister. "Even dummies know that!"

My grandma was not the gushy kind, never had been. I fled to her that day because I knew she would be straight with me. I knew Grandma always told the truth, and I knew that the truth always went down a whole lot easier when swallowed with one of her world-famous cinnamon buns. Grandma was home, and the buns were still warm. Between bites, I told her everything. She was ready for me.

"No Santa Claus!" she snorted. "Ridiculous! Don't believe it. That rumour has been going around for years, and it makes me mad, let's go."

"Go where, Grandma?" I asked. I hadn't even finished my second cinnamon bun. "Where" turned out to be Kerby's General Store, the one store in town that had a little bit of just about everything. As we walked through its doors, Grandma handed me ten dollars. That was a bundle in those days. Take this money," she said, "and buy something for someone who needs it. I'll wait for you in the car." Then she turned and walked out of Kerby's.

I was only eight years old. I'd often gone shopping with my mother, but never had I shopped for anything all by myself. The store seemed big and crowded, full of people scrambling to finish their Christmas shopping. For a few moments I just stood there, confused, clutching that ten-dollar bill, wondering what to buy, and who on earth to buy it for. I thought of everybody I knew: my family, my friends, my neighbours, the kids at school, the people who went to my church.

I was just about thought out, when I suddenly thought of Bobbie Decker. He was a kid with bad breath and messy hair, and he sat right behind me in Mrs. Pollock's grade-two class. Bobbie Decker didn't have a coat. I knew that because he never went out for recess during the winter. His mother always wrote a note, telling the teacher that he had a cough; but all we kids knew that Bobbie Decker didn't have a cough, and he didn't have a coat.

I fingered the ten-dollar bill with growing excitement. I would buy Bobbie Decker a coat. I settled on a red corduroy one that had a hood to it. It looked real warm, and he would like that. I didn't see a price tag, but ten dollars ought to buy anything. I put the coat and my ten-dollar bill on the counter and pushed them toward the lady behind it. Suddenly, Grandma gave me a nudge. "All right, Santa Claus," she whispered, "get going." I took a deep breath, dashed for his front door, threw the present down on his step, pounded his doorbell twice and flew back to the safety of the bushes and Grandma. Together we waited breathlessly in the darkness for the front door to open. Finally it did, and there stood Bobbie. He looked down, looked around, picked up his present, took it inside and closed the door.

Forty years haven't dimmed the thrill of those moments spent shivering, beside my grandma, in Bobbie Decker's bushes. That night, I realized that those awful rumours about Santa Claus were just what Grandma said they were: Ridiculous!

Santa was alive and well ... AND WE WERE ON HIS TEAM!
**Parry Romberg Syndrome**  
*Questions and Answers about scleroderma*

Q. My daughter was diagnosed by one physician as having Parry Romberg Syndrome, and another called it “en coup de sabre”. Are these the same or different conditions?

A. Parry Romberg Syndrome and scleroderma “en coup de sabre” are subtypes of linear scleroderma affecting the head. The classic findings on examination in Parry Romberg Syndrome are progressive facial hemiatrophy (half the face becomes smaller or depressed over time) with sunken-in fatty tissue underneath the skin and smaller bone structures of the face (mandible and maxilla), most often with little or no facial skin abnormality. The typical “en coup de sabre” findings include a deep, linear band on the scalp and forehead, which is discoloured and sometimes associated with thickening of the skin. The term is derived from its appearance as “like the cut of a sword”. Though these conditions are sometimes considered to be separate, most clinicians now agree they are both part of the same spectrum of disease. The majority of patients with linear scleroderma affecting the head (face and/or scalp) have a mixture of the two conditions, meaning they may have a linear band or depression of the scalp or face but also have a smaller face in that area or sometimes on the other side. When investigated patients with both conditions have some amount of extracutaneous (or non-skin) clinical manifestations, such as dental, eye and neurological involvement, further supporting that these are one and the same disorder.

Reprinted from University of Pittsburgh and University of Pittsburgh Medical Center Scleroderma Center’s Collagen Connection Newsletter.  

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Please note change of Phone details

**0459 397 942**

**Raffle and results**

Raffle winners are as follows:

1st prize, Traditional Rug (Mat)  Heather Cowled, Rosetta
2nd Prize, TEAC High Definition Digital Recorder, Faith Layton, Glenara- Lakes
3rd Prize Pampering Gift Set, Marie Yeats, Mt Nelson
4th Prize, Wine and Chocolates, Lance Cowled, Rosetta
5th Prize, Pantry Hamper, Edna Brock, Windermere
6th Prize, Linen Set, Marie Yeats, Mt Nelson
7th Prize Children’s Gift Set, Leanne Stephens, Deloraine

*Congratulations to all prize winners and thank you to all those members who sold tickets.. Our association raised $1150 towards our programme.*
What is scleroderma?

Scleroderma

This sheet has been written for people affected by scleroderma. It provides general information to help you understand how scleroderma affects you and what you can do to manage it. It also tells you where to find further information and advice.

The word ‘scleroderma’ means ‘hard skin’. Scleroderma affects the connective tissues of the body (tissues that hold together joints, muscles, blood vessels and internal organs). The connective tissues of people with scleroderma have too much of a protein called collagen. Collagen is important to give connective tissue its strength, but excess collagen causes hardening and tightening of the affected area. Many different areas of the body can be affected.

There are two major types of scleroderma:

- Localised scleroderma (sometimes called ‘morphea’). This form of scleroderma affects only the skin and sometimes the tissues beneath it (for example, muscle). This can lead to stiffness and difficulties moving the joints in the affected areas.

- Systemic sclerosis. This form affects the connective tissue throughout the body, including blood vessels, joints, the digestive system (oesophagus, stomach and bowel), and occasionally the lungs, heart, kidneys and muscles.

Scleroderma is an autoimmune condition. The normal role of your body’s immune system is to fight off infections and diseases to keep you healthy. In an autoimmune disease like scleroderma, your immune system starts attacking your own healthy tissues. This stimulates the production of excess collagen.

What are the symptoms?

Symptoms vary greatly from person to person and also depend on what part of the body is involved. Symptoms may include any of the following:

- Thickening and hardening of the skin, particularly on the fingers, arms and face.
- Raynaud’s phenomenon: The fingers or toes turn white, then blue in the cold, and then red as blood flow returns. This is caused by narrowing of the blood vessels, in response to cold weather. It is possible to have Raynaud’s without having scleroderma, but most people with scleroderma will have symptoms of Raynaud’s at some time and it is often one of the first symptoms to appear.
- Small white chalky lumps (calcium deposits) under the skin.
- Stiffness and pain in the muscles and/or joints.
- Indigestion or heartburn.
- Diarrhoea or constipation.
- Shortness of breath or reduced ability to exercise.

What causes it?

The exact cause of scleroderma is unknown. Genetics, the immune system and environmental factors may play roles in causing this condition. This has yet to be proven in research.

How is it diagnosed?

There is no specific test for scleroderma. Your doctor will diagnose scleroderma from your symptoms, a physical examination and various tests, such as blood tests or a skin biopsy (a small piece of skin is removed and examined under a microscope).

doctor can tell if you have scleroderma as the symptoms can overlap with other diseases and types of arthritis.

What will happen to me?

Many people with scleroderma have few or minimal symptoms and are able to lead a
normal, or nearly normal, life with simple treatment or lifestyle changes. However the course of scleroderma is variable and no two cases are the same. People with more severe forms of scleroderma can have serious problems with organs such as the kidneys, lungs and heart. If these organs are affected, you may need to see a specialist (for example, a kidney specialist if your kidneys are affected).

It may take several visits before your doctor can tell if you have scleroderma as the symptoms can overlap with other diseases and types of arthritis.

What will happen to me?

Many people with scleroderma have few or minimal symptoms and are able to lead a normal, or nearly normal, life with simple treatment or lifestyle changes. However the course of scleroderma is variable and no two cases are the same. People with more severe forms of scleroderma can have serious problems with organs such as the kidneys, lungs and heart. If these organs are affected, you may need to see a specialist (for example, a kidney specialist if your kidneys are affected).

**Scleroderma**

This sheet has been written for people affected by scleroderma. It provides general information to help you understand how scleroderma affects you and what you can do to manage it. It also tells you where to find further information and advice.

*These articles have been sourced from the Scleroderma website, however, you should discuss any concerns with your doctor.*

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**Editor’s Report**

Please excuse any mistakes in this newsletter as I am writing it in Respite while my husband has his knee replaced. Also I do not have access to my proof reader. So there may be mistakes I have missed. I would like to wish everyone, members and families a very Happy, Healthy Christmas and New Year

Edna Brock
Editor
Is there a cure for scleroderma?
Currently there is no cure for scleroderma. While there are ways you can control your symptoms, you should be wary of any products or treatments that claim to cure scleroderma.

What treatments are there for scleroderma?
Many of the symptoms of scleroderma can be improved with medicines and/or lifestyle changes. Your doctor will tailor your treatment to your symptoms and how severe your condition is. There is no way of predicting exactly which treatment will work best for you. Your doctor may need to trial several different treatments and medicines before finding the one that is right for you.

What can I do?
1. Learn about scleroderma and play an active role in your treatment. Not all information you read or hear about is trustworthy so always talk to your doctor or healthcare team about treatments you are thinking about trying. Reliable sources of further information are also listed in the section below. Self management courses aim to help you develop skills to be actively involved in your healthcare. Contact your local Arthritis Office for details of these courses.
2. Talk to your doctor about medicines. Some medicines may help with problems with joints and muscles, blood vessels, kidneys, lungs or the digestive system. Always talk to your doctor or pharmacist before you start taking any medicines as even natural or over the counter medicines can have side effects. See the Medicines and Arthritis information sheet.
3. Manage Raynaud’s Phenomenon Minimise exposure to cold and sudden temperature changes. Make sure your whole body is kept warm and protect your hands and feet with gloves and warm socks. Avoid cigarette smoke.
4. Look after your skin. Keep skin clean, well lubricated and warm to help prevent dryness and infections.
5. Live a healthy life. Regular physical activity will help keep your skin and joints flexible and boost circulation. See the Physical activity information sheet. A healthy diet, including frequent small meals rather than the usual large meals, may help reduce problems with the digestive system. Stop smoking and reduce stress to help your overall health and well being.
6. Acknowledge your feelings and seek support. As there is no cure for scleroderma and it can affect many parts of your life, it is natural to feel scared, frustrated, sad and sometimes angry. Be aware of these feelings and get help if they start affecting your daily life. See the arthritis and emotions information sheet.

Scleroderma differs from person to person but can be treated effectively. Learn about your scleroderma and your treatment options.

For more information
Websites: Australian Rheumatology Association - information
about medicines and seeing a rheumatologist
www.rheumatology.org.au
Scleroderma Australia has a number of brochures available to
download at www.sclerodermaaustralia.com.au
American College of Rheumatology www.rheumatology.org
Arthritis Foundation (US) www.arthritis.org
© Copyright Arthritis Australia 2010. Reviewed May 2015. Source: A full list
of the references used to compile this sheet is available from your local Ar-
thritis Office The
Australian General Practice Network, Australian Physiotherapy Association,
Australian Practice Nurses Association, Pharmaceutical Society of Australia
and Royal Australian
College of General Practitioners contributed to the development of this fact
sheet. The Australian Government has provided funding to support this pro-
ject.

This article was sourced from the scleroderma website. And should not be
used in place of medical advice.
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Editor’s Report

Please excuse any mistakes in this newsletter as I am
writing it in Respite while my husband has his knee re-
placed. Also I do not have access to my proof reader.
So there may be mistakes I have missed. I would like
to wish everyone, members and families a very Happy,
Healthy Christmas and New Year.
Edna Brock
Editor

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In Memory

We were very sad at the Passing of Denise Hartas, wife of our
Past President, Vic. Our thoughts and prayers are with Vic and family.

We also remember Shirley Smith, a past member, and wish to
thank her family for the kind donation, which was in lieu of flow-
ers at her funeral.
Christmas Luncheon December 9th 2018 11.00 am.
Bring your favourite salad. Meat and sweets provided.
At the Joan Marshall Wing, Kings Meadows Health Centre.

Morning Teas every 4th Thursday of the month. Bring some morning tea to share.

North West Region.

Monthly lunches at Fuschia Farm, at Lillico near Ulverstone. At 12.00 noon, pay for self.

Southern region
March 19th 2019, Mather’s House, 108 Bathurst St., 12.00 noon pay for self

North West
Christmas Luncheon, Tuesday 4th December at Fuschia Farm.
Please bring a gift to the value of $10. 12.15 until approx. 2.00 pm. Choose from the menu