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

Merry Christmas
Office Bearers

Lupus Association of Tasmania Inc.
Registered Charity ABN 96 163 951 956

All Correspondence to:
PO Box 639
Launceston, 7250
Tasmania, Australia
Ph. (03) 64316042
Email: lupustas@lupustasmania.org.au
Website: www.lupustasmania.org.au

Patron: Hon. Michael Ferguson MHA
President: Dr. Lois Beckwith
Vice-President: Leanne Stephens
Secretary/Public Officer: Dianne Whiteley
Treasurer: Murray Scales
Committee: Cheryl Dent, Claire Redfern, Queenie Ennis & Moira Keefe
Librarian: Joan Keefe ph. 63449322

Northern Co-ordinator: Lois Beckwith, PO Box 312, Deloraine, 7304
Email: loisbeckwith@bigpond.com Phone: 63695393

North-West Co-ordinator: Leanne Stephens, 5/53 West Parade, Deloraine, 7304
E-mail: Leanne.E. Stephens@alumni.uts.edu.au Phone: 0409713240

Southern Co-ordinator:
Heather Cowled ‘Phone 03 6272 3096
Email: lhcowled@bigpond.net.au

West Coast Co-ordinator: Barbara Gruner, Queenstown, Phone: 64716506/0419724384
E-mail: Barbara.rosalie@yahoo.com

Editor: Edna Brock
Ph. 03 6328 1166
Email: sbr87203@bigpond.net.au

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

Donations over $2 are tax deductible.

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
<table>
<thead>
<tr>
<th>This Issue</th>
<th>Pages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Message from President Lois</td>
<td>3/4</td>
</tr>
<tr>
<td>Regional reports</td>
<td>5</td>
</tr>
<tr>
<td>Word from the Editor</td>
<td>6</td>
</tr>
<tr>
<td>Hidden and unexplained: feeling in Fibromyalgia</td>
<td>7/8</td>
</tr>
<tr>
<td>Foot pain in Fibromyalgia. Is it a symptom or something else</td>
<td>9-11</td>
</tr>
<tr>
<td>The Christmas Truce</td>
<td>12/13</td>
</tr>
<tr>
<td>For Your Diary</td>
<td>14</td>
</tr>
</tbody>
</table>

The Lupus Awareness Launch on October 6th at Southern Cross Station was a great success with media coverage of the event on the evening Channel 6 news. A big thanks to Mark Trip the producer who worked with us in making two advertisements for regular airing during the Lupus Awareness Month and again in the new year. He helped organise the launch and secured a large amount of support from the company in free air time, to assist us in promoting a clear message about Lupus and autoimmune diseases. We are now negotiating with Medical Media to add advertisements to their In-Practice waiting room videos.

The Minister of health Mr Michael Ferguson launched the start of the month long campaign and talked about the multimedia approach and how the poster “This is Lupus; Help make this hidden autoimmune disease more visible”, are now in all GP waiting rooms across Tasmania. Some doctors requested more copies of our patient book as a result of receiving the new poster.

The confronting image as been noticed and appears to have increased the awareness of the potentially disabling and life threatening effects of Lupus.

To our Patron, the Minister thanks for your never ending support and also thanks to those members who were able to attend and put on such a lovely morning tea for the gathered group of politicians, health researchers, and supporters.
Regional Reports

Southern report
The number of people being able to attend luncheons is a real concern this year. It is due to people’s ill health not due to lack of interest. I completely understand this, as I myself have had difficulty attending this year due to three hospital admissions and the fourth coming up. So I fully understand how difficult it is to get to luncheons when we are unwell. A question to think about. Do we continue to meet every two months, or should we reduce to meeting a couple of times a year, or should we go into recess for a while? Perhaps members can let me know what they are thinking in this regard. I will let southern members know the decision after our December Christmas Luncheon on December 13th. Allyson hosted the luncheon for me in October and two people joined her. This time I was out of hospital but attending a wedding in NSW—a country wedding where the bride and flower girls arrived on the back of a decorated tractor! [for those concerned about safety it was a very short distance and all on the farm.]

Christmas Luncheon: December 13th at Esus Café as usual. The usual time of 12 md. We meet for about an hour which gives plenty of time for people to do their Christmas Shopping in Hobart. Everyone is welcome which means family, friends and carers included. We pay for ourselves. I am hopeful that 2018 will see us all spending more time at home and less in hospital.
Wishing you all a healthy and happy Christmas season.
Heather Cowled Southern Co-ordinator

West Coast News.
On Friday 13th October the West Coast Support Group met, for the first time in JJ’s coffee shop in Queenstown. We are a small group of four at the moment, but I have plans to improve that! We had a really enjoyable, and friendly, time chatting even though we had never met each other before, and when we left we each had a definite feeling of having achieved something. Plans were made for the next meeting to be held on November 7th in the beautiful and historic Empire Hotel in Queenstown. I have spoken to the publican and she will give us a private lounge area, which I will confirm beforehand. Rock on WCSG!
Barbara Gruner, West Coast Co-ordinator

The North West Group will be holding our Christmas Luncheon at the Fuschia Farm on Lillico Strait on Tuesday 5th December, starting at 12 noon. Please RSVP as soon as possible for catering purposes. Leanne 0409 713 240…..
We will be having a Secret Santa (please bring a wrapped gift to the value of $10. We welcome old and new members to come and celebrate Christmas with a beautiful meal and our regular attendees. We are only a small group, but personally I really look forward to these get togethers. It’s great to be able to meet with other people who know EXACTLY how you feel and are empathetic. We will be planning our next 12 months of when/where we will meet for 2018 after the festivities are over. Looking forward to catching up with you all on the 5th. Regards Leanne NW co-ordinator
Research Opportunities
A small group of members Denise O’Byre, Colleen McCormack, Leanne Stephens and Lois Beckwith represented our organization by attending the Menzies Institute for Medical Research Reception held in Launceston. It was a great opportunity to talk with Professor James Sharman the Deputy Director about future research in our area of interest. They now have 100 PhD students all working on health issues. This will provide us with more options into the future, especially in the field of nutrition and continuing research into biomarkers.
I am really pleased to announce that the new West Coast co-ordinator Barbara Gruner has successfully started a support group on that side of the island. I have asked her to now contribute regular reports and introduce herself to members. More will follow in this Newsletter.

Lois Beckwith
President/Northern Co-ordinator

*************************************************************************

Photos at LAW Launch

Michael Ferguson and President Lois
Michael Ferguson chatting to Treasurer Murray and Helen Edwards
Word from the Editor

Thank you Dianne, for getting the newsletter out last time. We had a rushed trip to Brisbane from Hervey Bay. I now know how valuable the Flying Doctor is, an hour trip to Brisbane instead of five in the car. The Flying Doctor is a very worthwhile service for the vast areas of Queensland. There are many smaller hospitals across the State but the specialists are all in Brisbane, so if needed one has to get to them.

Thank you to my fellow members for the number of get well messages that were given to us, I'm sure that it was them that helped us improve. I'm not sure that we want to repeat the problem. At least since coming back to Tasmania we have brought the lovely weather with us and sent them the rain, when we left they were in drought and had not seen any rain since April, since we came home they have had quite a lot of rain.

We hope to see everyone at our home for the Christmas Luncheon on December 10th. (Details on page14)

Welcome to the West Coast members, thanks to Barbara for setting things in motion on the West Coast. We welcome her and any other members to our Association and hope that they can join with us in telling our stories so that people become aware that there is an illness called Systemic Lupus Erythematosis. Barbara originally came from England but has been in Australia for a long time, and in Tassie for 12 years; with her husband, Helmut, who originally came from Austria. Before coming to Tasmania she worked as a nurse in a Melbourne hospital that specialised in the care of patients with MS and MND. She is a certified Adult Literacy Tutor, and Mental Health First Aider, and her hobbies are reading and listening to classical music and Opera. (I'm with you, Barbara. Ed)

I hope that the flu passed by our members, it was a rather nasty variety this year, and really raged in Queensland and the warmer states, hopefully if you succumbed, your are on the mend by now.

**************************************************************************

Wise words to live by

Switching focus from your own need to the needs of others brings out the best in you.

Life begins when you accept that you are responsible for your own destiny—take charge now.
Hidden and Unexplained: feeling the pain of Fibromyalgia

By Bernadette Fitzgibbon, Neuroscientist, Monash University

Fibromyalgia can be made more difficult when the pain doesn’t seem to have a visible cause. Silvia Sala

For some people, waking up every day means the start of persistent pain that effects their mood, thinking and relationships. This experience is more difficult when the pain doesn’t seem to have a cause; at least not a visible one.

That’s the reality for people with fibromyalgia, a chronic disorder characterised by pain and muscle tenderness throughout the body where even the slightest touch can be sensitive. Sufferers often have other health issues, including sleep difficulties and fatigue.

For a long time, fibromyalgia was thought of as a medical mystery. Technological advancement has allowed us to look closer. Today, it is a recognised disorder, part of a group of chronic pain syndromes described as central nervous system disorders.

The condition affects more that four times as many women as it does men. With as many as 2-5% of the developed world living with fibromyalgia, it is far from uncommon. Yet targeted and effective treatment options aren’t available for the condition. And compared to fibromyalgia’s impact, this area of research remains highly underfunded.

Chicken or the egg?

Fibromyalgia has a long history of stigma. Some explanations even pinned it down to being psychosomatic, “made up” and "all in your head", as well as people needed to "just get over ".

There may be some truth in saying fibromyalgia is “all in your head”, but more as a reflection of associated brain changes than a figment of the imagination. An explosion of recent research has shown brains of fibromyalgia sufferers are made up differently. There are variations, for instance, in regions key to how we think and feel.

Although our understanding has taken a dramatic leap in the last few decades, we can’t shut the book on fibromyalgia’s exact cause or causes. These reported brain changes pose a real chicken and egg scenario: are these brain changes causing fibromyalgia, or is fibromyalgia causing the brain changes?

The condition may have multiple causes. Some suggest biological factors, including a genetic basis for the disorder. Other research shows a history of sexual, emotional and physical abuse among sufferers. Psychological factors, including responses to chronic stress, have also been shown to contribute to its cause.

None of these are likely to be independent of each other.

Links to mood disorders

Further complicating explanations of fibromyalgia include its link to other illnesses, such as mood disorders like depression. This relationship likely reflects the fact they share some of the biological processes, such as inflammation.

Inflammation occurs when injury or infection triggers the production of messenger molecules that flood to the site of injury as a part of an immune response. It is now believed that, like injury to the body, psychological adversity and mental illness can trigger the same response affecting the
And recent research suggests the occurrence of fibromyalgia or depression may increase the likelihood of the other. Regardless of what came first, though, the presence of mood disorders in fibromyalgia is linked to more pain and reduced quality of life. It comes as no surprise, then, that if medical professionals and scientists can’t explain what causes fibromyalgia, it is even harder for the person living with the condition. In fact, those diagnosed have a significantly harder time understanding or explaining their pain to people with other disorders, like arthritis for instance.

**Treatment options**

It can take years to receive a fibromyalgia diagnosis, and some may have been misdiagnosed with one or more other conditions beforehand. This can be very frustrating for the patient as well as their doctor. Currently, the best method of diagnosis is classification based. Physicians assess the number of possible body areas where someone experienced pain in the last two weeks, and the severity of other symptoms, including fatigue and cognitive function. Following diagnosis, there is no universally effective treatment plan. It usually includes a multi-method pain management regime from a team of health care providers. But responses to treatments can be no better than chance, regardless of whether these are pharmacological or others such as acupuncture or hypnotherapy.

Despite the poor response rate, pharmaceutical methods are the main treatment option. Prescriptions are commonly made out for non-steroidal anti-inflammatory drugs (such as ibuprofen), opioid analgesics (such as codeine), anti-depressants, or anticonvulsants (drugs used to control seizures that also affect pain signals).

Because there is no clear treatment target for fibromyalgia, drug doses needed to manage symptoms have significant side effects. These include problems with thinking, drowsiness and the risk of drug dependency. We don’t know exactly what causes fibromyalgia, but treatments need to be developed based on what we do know. For instance, we know there are brain changes. One promising treatment may therefore be brain stimulation techniques like Transcranial Magnetic Stimulation (rTMS); a non-invasive technique that can change the activity of neurons in the brain.

There is clearly an urgent need to provide targeted and effective treatment options for fibromyalgia sufferers. Considering how far we have come in explaining the unexplained pain of the condition, there is real hope for the future.

Reprinted from the website of Fibromyalgia, First published by Conversation.com.
Foot Pain in Fibromyalgia: is it a symptom or Something Else?
By Adrienne Dellwo  Reviewed by a board-certified physician.  
Updated July 09, 2017.

Does fibromyalgia cause foot pain? Certainly, with this condition, pain can hit anywhere, at any intensity, at any time. Several studies show that we fibromites have more foot pain than other people. While all kinds of pain are unpleasant, some have a bigger impact on your life. Chief among these is foot pain, because walking is an essential function. Some readers have said:

- “The bottoms of my feet felt they were on fire. These pains come and go, sometimes [lasting] for months”.
- “[I] can’t wear a flip flop or any kind of shoe”.
- “I can’t stand to touch my bare feet to the floor. I have to wear memory foam slippers around the house.”

During a flare of foot pain, you may find that just resting your foot on the floor causes a burning pain. Shoes can hurt not only on the soles of your feet but the tops as well. Walking? Agony. Stepping on something like an electric cord can feel like you’re being cut by a razor blade. A common complaint is waking up with feet that feel like you’ve been walking for hours.

Foot pain is a major problem. When every step is agony, it makes it hard to do much of anything. When you’re already limited because of fibromyalgia, you hardly need one more thing to keep you from doing what you want or need to do.

What causes Foot Pain?
We’re just starting to see research specifically on foot pain in fibromyalgia. So far, we can’t say anything for sure about what causes it, but we’re starting to get support for some likely suspects.

A study published in Arthritis Research & Therapy found that 50 percent of people with fibromyalgia report pain in one or both feet. That seems like a lot of us, but the same study showed that 91 percent have neck pain 79 percent experience hip pain. In fact, the feet were among the least likely places to hurt.

Still, it’s important to look at foot pain because your ability to walk has a big impact on how functional you can be. Foot pain can make you walk differently, which may lead to back, hip and knee problems. Research lead by Ginevra Liptan, M.D., may shed light on one possible cause of our foot pain. It suggests that fibromyalgia involves inflammation of the fascia, which is a thin layer of connective tissue that runs throughout your entire body. If the word “fascia” reminds you of “plantar fasciitis, “ there’s a good reason.

Plantar fasciitis is a common cause of foot pain involving a band of fascia that runs along the bottom of your foot, helping support the arch. We do not know anything for sure yet, but some people speculate that plantar fasciitis is a symptom or common overlapping condition with fibromyalgia.
Foot pain in fibromyalgia, cont.

Another common condition in us, which also involves the fascia, is myofascial pain syndrome. It involves small, ropy nodules in the fascia called trigger points, which can be painful and may also cause what’s called referred pain, which is felt away from the trigger point.

In a 2016 study published in *Pain Medicine*, researchers say that pushing on trigger points reproduced foot pain in participants. They also found high sensitivity to pressure in the plantar region of the foot.

Also in 2016, the journal *Foot* published a study suggesting that the subtalar joint, which is just above the ankle, is frequently dysfunctional in fibromyalgia. Out of 20 women who participated, 12 had hypermobility (excessive range of motion) in that joint, while five had hypomobility (limited range of motion).

However, a 2017 study in *Foot* found no abnormalities in the joints of the feet, ankles, or legs of 50 people with fibromyalgia. We’ll need more research in this area to know for sure whether we’re more especially likely to have joint problems that could contribute to foot pain.

It’s also possible that, for some of us, foot pain is caused purely by fibromyalgia. Our nerves are highly sensitive, and few areas take a beating like our feet. It stands to reason that they could hurt “just” because the nerves get riled up.

Your foot may also come from an overlapping pain condition such as:
- Rheumatoid Arthritis
- Lupus
- Raynaud’s Syndrome.

Foot pain can also come from a lot of other sources that have nothing to do with fibromyalgia. If you have foot pain that is persistent or limits your ability to function, be sure to talk to your doctor about it and don’t just assume it’s part of your fibromyalgia.

No matter the cause of foot pain, fibromyalgia amplifies it, just as it does with all pain.

**Easing Your Foot Pain**

When foot pain is caused by an injury or an overlapping condition, your doctor can help find the right treatment. Otherwise, you’ll need to find ways to manage it. The following is a list of things that have helped some people with these conditions ease their foot pain (remember that these are only personal experiences and they might not work for you):
- Soft, well-cushioned socks
- Thick socks or diabetic socks
- Soft soled shoes
- Soaking in hot water and Epsom salts
- Gentle stretching
- Extremely gentle massage
- Cooling lotion
- Orthotics

A 2012 study on custom orthotics suggested that they may help people with fibromyalgia function better overall. (It did not look specifically at foot pain).

It’s likely to take some time and experimentation to find the best way(s) to relieve your foot pain.
Foot Pain cont.’
Sources:
Friend R, Bennett RM. Distinguishing fibromyalgia from rheumatoid arthritis and systemic lupus in clinical questionnaires: an analysis of the revised Fibromyalgia Impact Questionnaire (FIQR) and its variant, the Symptom Impact Questionnaire (SIQR), along with pain locations. Arthritis Research and Therapy. 2011 Apr 8;13 (2): R58.

Reprinted from the Fibromyalgia Web site and Verywell.com

Remember the Best
There are days when the world is against you.
There are moments when nothing goes right—when a heavy cloud seems to surround you and you cannot get through to the light.
When you feel that your courage is sagging it’s not easy to work up a smile—
There are rough bits of road on all journeys—for it couldn’t be smooth all the while.
But thinking of all your misfortunes—think too of how much you’ve been blessed...
Don’t brood on the worst that has happened and fail to remember the best.

Thanks to Patience Strong for these encouraging words.
The Christmas Truce  By David G. Stratman
From his book We Can Change the World

It was December 25, 1914, only 5 months into World War 1, German, British, and French soldiers, already sick and tired of the senseless killing, disobeyed their superiors and fraternized with “the enemy” along two-thirds of the Western Front (a crime punishable by death in times of war). German troops held Christmas trees up out of the trenches with sign, “Merry Christmas”.

“You no shoot, we no shoot.” Thousands of troops streamed across a no-man’s land strewn with rotting corpses. They sang Christmas carols, exchanged photographs of loved ones back home, shared rations, played football, even roasted some pigs. Soldiers embraced men they had been trying to kill a few short hours before. They agreed to warn each other if the top brass forced them to fire their weapons, and aim high.

A shudder ran through the high command on either side. Here was disaster in the making: soldiers declaring brotherhood with each other and refusing to fight. Generals on both sides declared this spontaneous peacemaking to be treasonous and subject to court martial. By March 1915 the fraternization movement had been eradicated and the killing machine put back in full operation. By the time of the armistice in 1918, fifteen million would be slaughtered.

Not many people have heard the story of the Christmas Truce. On Christmas Day, 1988, a story in the Boston Globe mentioned that the local FM radio host played “Christmas in the trenches,” a ballad about the Christmas Truce, several times and was startled by the effect. The song became the most requested recording during the holidays in Boston on several FM stations. “Even more startling than the number of requests I get is the reaction to the ballad afterward by callers who hadn’t heard it before,” said the radio host. “They telephone me deeply moved, sometimes in tears asking, “What the hell did I just hear?””

You can probably guess why the callers were in tears. The Christmas Truce goes against most of what we have been taught about people. It gives us a glimpse of the world as we wish it could be and says, “This really happened once.” It reminds us of those thoughts we keep hidden away, out of range of the TV and newspaper stories that tell us how trivial and mean human life is. It is like hearing that our deepest wishes really are true: the world really could be different.

Christmas in the Trenches  Words and music by John McCutcheon
This song is based on a true story from the front lines of World War 1 that I’ve heard many times. Ian Calhoun, a Scot, was the commanding officer of the British forces involved in the story. He was subsequently court-martialed for ‘consorting with the enemy’ and sentenced to death. Only George V spared him from that fate. John McCutcheon

Words of the Ballad
My name is Francis Toliver, I come from Liverpool
Two years ago the war was waiting for me after school.
To Belgium and to Flanders, to Germany to here,
I fought for King and country I love dear.
Christmas Truce Ballad.
‘Twas Christmas in the trenches, where the frost so bitter hung.
The frozen fields of France were still, no Christmas song was sung.
Our families back in England were toasting us that day.
Their brave and glorious lads so far away.

I was lying with my messmate on the cold and rocky ground,
when across the lines of battle came a most peculiar sound
Says I, “Now listen up, me boys!” each soldier strained to hear,
As one young German voice sang out so clear.

“He’s singing bloody well, you know!” my partner says to me.
Soon, one by one, each German voice joined in harmony.
The cannons rested silent, the gas clouds rolled no more
As Christmas brought us respite from the war.

As soon as they were finished and a reverent pause was spent
“God Rest Ye Merry Gentlemen” struck up some lads from Kent.
The next they sang was “Stille Nacht.” Tis “Silent Night” says I,
And in two tongues one song filled up that sky.

“There’s someone coming towards us!” the front line sentry cried
All sights were fixed on one lone figure trudging from their side.
His truce flag, like a Christmas star, shone on that plain so bright
As he bravely strode unarmed into the night.

Then one by one on either side walked into No-Man’s land,
With neither gun nor bayonet we met there hand to hand.
We shared some secret brandy and wished each other well,
And in a flare lit soccer game we gave ‘em hell.

We traded chocolates, cigarettes and photographs from home.
These sons and fathers far away from families their own.
Young Sanders played his squeezebox and they had a violin
This curious and unlikely band of men.

Soon daylight stole upon us and France was France once more
With sad farewells we each began to settle back to war.
But the question haunted every heart that lived that wondrous night:
“Whose family have I fixed within my sights?”

‘Twas Christmas in the trenches where the frost so bitter hung.
The frozen fields of France were warmed as songs of peace were sung.
For the walls they’d kept between us to exact the work of war,
Had been crumbled and were gone for evermore.

My name is Francis Toliver, in Liverpool I dwell,
Each Christmas come since World War 1, I’ve learned its lesson well
That the ones who call the shots won’t be among the dead and lame,
And on each end of the rifle we’re the same.
North Group
Morning Teas 4th Thursday of the Month at Kings Meadows Community Health Centre 10.30 am. Bring a plate to share.

Christmas Luncheon: at 154 Windermere Road, Windermere. Bring your favourite salad. 11.00 am Meat, sweets and drinks provided. Everyone is invited. Please help us celebrate the year.

North West Group Christmas Luncheon. Fuschia Farm, December 5th, 12 noon, RSVP Leanne 0409 713 240, for catering purposes. Bring family, carers and yourself.