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

LUPUS NEWSLETTER

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All Correspondence to:  
PO Box 639  
Launceston, 7250  
Tasmania, Australia  
Phone: 0487 106 950 (sms or call)  
Email: lupustas1@lupustasmania.org.au

Website: www.lupustasmania.org.au

Patron: Hon. Michael Ferguson MP  
President: Lois Beckwith  
Vice-President: Leanne Stephens  
Secretary/Public Officer: Dianne Whiteley  
Treasurer: Murray Scales  
Committee: Cheryl Dent, John Dent, & Julie Scales  
Librarian: Joan Keefe Ph: 03 6344 9322

Northern Co-ordinator:  
Lois Beckwith  
Ph: 03 6369 5393  
E mail: loisbeckwith@bigpond.com

North-West Co-ordinator:  
Leanne Stephens  
Ph: 0409 713 240  
E-mail: Leanne.E.Stephens @alumni.uts.edu.au

Southern Co-ordinator:  
Heather Cowled  
Ph: 03 6272 3096

West Coast Co-ordinator:  
Barbara Gruner  
Ph: 6471 6506  
E-mail: TBC

Editor:  
Edna Brock  
Ph: 0419 541 989  
Email: sbr87203@bigpond.net.au

Merchandise For Sale: Lupus Badges $5, Embroidered or X-Stitch Butterfly Brooches $10 or 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 MP for the printing of our Newsletter and his continued support during 2017.

#
MESSAGE FROM PRESIDENT LOIS

Over the past three months we have planned the Lupus Awareness Week for 2017 and developed a media campaign which will be launched on October 6th at the Southern Cross Studio in Launceston. This year we will emphasise the hidden nature of Lupus and that treatment and support is available. A poster will be sent to all GPs, that will re-enforce this message and challenge people to learn more about Lupus and autoimmune diseases.

The Launch will be held at Southern Cross Television Station, 36 Watchorn Street, Launceston.

Starting at 10.30am for morning tea and at 11.00 I will welcome guests then the Minister of Health, The Hon Mr Michael Ferguson MP will launch the television advertisements. At 11.20 a professor representing the Menzies Institute for Medical Research will be speaking about recent research – “Searching New Biomarkers and Potential for SLE Therapy”. Members and supporters are encouraged to attend.

If you would like to attend please RSVP to our Secretary - Di Whiteley on 0487 106 950 (sms or call).

Western Support Group
After several phone calls / emails we are pleased to announce that we have a lovely lady that accepted the role of our West Coast Support Group Coordinator. Welcome Barbara.

More information can be found on the Regional Reports page.

In conclusion, it has been a challenging winter with many of our members affected by the usual winter colds, but also serious health issues. All those recovering from hospital stays, surgical procedures and treatment: our thoughts are with you.

I hope to see as many as you as possible at our launch and keep in touch with other members and supporters.

Lois Beckwith
Regional Reports

Northern Group
Our group continues to meet on the 4th Thursday of the month at Kings Meadows. It is great that we have a few new members who are attending. A shared morning tea and chat is always a relaxing affair. For a change, in May we had a lunch at our local Pub. We thought we might repeat this sometime later in the year.

Lois
Lois Beckwith
Northern Co-ordinator

North West Group
We are continuing to meet between Latrobe and the Fuschia Farm. The gatherings at the Fuschia Farm are bigger as we are having more people attending. Although our group is small, there is always much love and laughter within the group which is awesome :)

Our group down the coast would like to see the continuation of the get-together at the Forth Hotel at the end of Lupus Awareness Month.

Narelle Williams has offered to be our guest speaker and I have accepted her offer.

Hoping to have more new members attend, we all love a chin wag.

Kind regards
Leanne x

Leanne Stephens
North West Co-ordinator

Southern Support Group
We wish everyone who is ill a speedy recovery. Our June meeting was cancelled due to everyone either away or sick. Our next luncheon on 9th August will be at 12 noon at the Esus Café as usual. We hope to see you there. Everyone is welcome.

Regards
Heather

Heather Cowled
Southern Co-ordinator

West Coast Support Group
Congratulations to Barbara Gruner :)

Barbara is our new West Coast Support Co-ordinator. Through assistance from our President and Vice President, I think Barbara will build a caring, friendly support group. More information in the next newsletter regarding dates, time and venue for meetings. Anyone from Queenstown, Zeehan, Roseberry and other west coasters interested in joining / coming together to support each other for a catch up—just to get out of the house!! Stay tuned:)

* A small excerpt of Barbara’s ‘Lupus’ journey can be viewed on page 12.
Word from the Editor

No words from the editor for this edition of the Lupus Newsletter. Both Edna and her husband Seton have been very ill over the last few months. They have been in hospital in Queensland. Edna coped a double dose plus shingles and has had to stay in hospital for several months.

Found out 15.9.17 that Edna has gone home to her family from hospital but is in need of lots of rest. Hence the delay with this issue being released.

We wish Edna a speedy recovery and hopefully will get a chance to enjoy her time in Queensland before coming home in October.

From the Northern Support Group:
What some of our other Members have been up to!

The Greek Islands

Targa Rally Racing

# Moving House
Interesting....

...and reach the intestinal walls, inflammation is the result.

In a mouse study, the scientists found a mutation in the Gatm gene and used gene-editing technology to confirm this link. The scientists determined that the Gatm gene is required for the rapid replenishment of the intestinal mucosal barrier.

Nobel Laureate Dr. Bruce Beutler, senior author of the study, said that the Gatm gene is needed for the synthesis of creatine, a substance made in the liver that travels to the barrier cells and allows them to utilize energy in an efficient manner.

In the experiments, mice with two copies of the recessive Gatm mutation showed symptoms similar to people with IBD: diarrhea, weight loss, and the death of cells lining the intestine. The symptoms improved when the mice received creatine in their drinking water. The researchers explained that creatine is necessary for providing the energy needed for the rapid replenishment of the mucosal barrier.

Dr. Beutler said, “Mutations in this gene and others needed for mobilization of energy in cells may account for some cases of IBD in humans.” He said that current therapy tends to focus on reducing the inflammatory response. “However,” he added, “proper healing of the mucosal layer and cells that line the digestive tract is essential to long-term remission. This study indicates that healing requires effective energy metabolism.”

Dr. Beutler commented, “Knowing these genes may help us to understand how IBD occurs in humans, and how to treat it.”

—Source: UT Southwestern scientists discover gene that protects gut from IBD, UT Southwestern newsroom, February 2, 2017
Menzies Institute for Medical Research
Human Systemic lupus erythematosus (SLE): Searching new biomarkers and potential targets for therapy—Final Report

The Menzies Institute for Medical Research (Menzies) is an Institute of the University of Tasmania. Our 300 strong research team conducts internationally relevant research to improve human health and wellbeing. While our research focuses on the major diseases affecting the Tasmanian community and population health, our reach and impact is global.

Our ultimate goal is to cure or prevent disease, leading to better, healthier and longer lives. Research at Menzies is focused in five key theme areas:
- Public Health and Primary Care
- Neurodegenerative Diseases / Brain Injury
- Cardio-Metabolic Health and Diseases
- Musculoskeletal Health and Diseases - Cancer, Genetics and Immunology

Drawing on a number of unique data resources and more than 25 years of population health research, Menzies is and will continue to be exceptionally well placed to identify patterns and incidence of disease in the Tasmanian population. Our rigorous methodologies, world-class research and extensive international collaborations enable local discoveries to positively contribute to global health improvement. Our research is carried out in the state-of-the-art Medical Science Precinct in Hobart’s CBD.

Background
The generous funding of the Lupus Association has enabled research focussed on Systemic lupus erythematosus (SLE). SLE is a chronic inflammatory autoimmune disease in which the immune system mounts a spontaneous inflammatory response and damages healthy tissues.

Epidemiological analysis shows that the disease occurs more often in women than in men (9:1) and is more common among younger women (20-35 years). However, the clinical course of the disease and the organs targeted by the autoimmune response differ from one patient to the next, and current tests cannot predict accurately the complications that will occur in a particular patient. While the disease cannot be prevented or healed it can be treated using immunosuppressive medication.

In a large proportion of SLE sufferers we find an increased number of special microenvironments in the spleen called germinal centres. In these germinal centres B cells are selected for the quality of their antibodies and, naturally, many cells are rejected and die during this selection process.

One interesting hypothesis to explain the autoimmune response causing the symptoms in SLE is that there is a failure of the normal mechanisms responsible for removing dying cells in germinal centres. As a result, these cells disintegrate and cellular debris accumulates and begins to stimulate B cells with autoimmune specificity. However, the events during the early phases of the disease are still ill-defined and it is unclear how these autoimmune-specific B cells can escape regulation and are not suppressed in time to stop the autoimmune response.
Research progress

As previously reported, the work of two PhD students generated considerable data. This has enabled us to better understand the biological role of CCR6 in the immune system and its usability as a marker. At last contact, we were working hard to publish our findings.

Final update from Professor Heinrich Korner 8/5/17:

On behalf of the Menzies Institute for Medical Research and the Cellular Immunology lab, I am pleased to provide you and the Lupus Association of Tasmania with the final report for the project "Human Systemic lupus erythematosus (SLE): Searching new biomarkers and potential targets for therapy".

German PhD student, Dorothea Reimer, spent 5 weeks at Menzies and worked with me and Adrian Lee, who you certainly remember. Your generosity enabled these two young scientists to generate enough data to finalize our publications. The timing was very important because Dorothea only had limited time for this collaboration and Adrian has meanwhile moved on to Sydney.

The first publication about the role of CCR6 has been published in January 2017 in the prestigious Australian Journal “Immunology and Cell Biology”. It describes a new aspect in the function of the chemokine receptor CCR6 on B cells.

Last week, I received confirmation that our second paper that summarizes the work we have done with the blood we collected from Tasmanian Lupus sufferers is now available online. It has been published in the journal Clinical Rheumatology under the title: “Expression of CCR6 on B cells in systemic lupus erythematosus patients”.

The last paper was finished in February and submitted to a very good journal which declined to publish it. We are now ready to submit it to another journal and are hopeful to have it published soon. Without your support this work would not have been possible and I am confident that these papers will raise the awareness that there is good SLE research being done in Tasmania.

We are pleased to present this report. We look forward to working with the Lupus Association over the coming years and keeping you informed of our progress in this area. If you plan an assembly of the Association this winter I would be very happy to come to Launceston and give you a personal report. Alternatively, I could come up during Lupus Awareness Week in Spring. If you or members of the executive are ever in Hobart, I extend an invitation for you to visit us for a private tour of the facilities.

Please give my regards to Colleen and the members of Lupus Association.

Best wishes

Heinrich Korner

Summarised outcomes to date

CCR6 is expressed on early B cells in mouse and human. It acts as an activation marker on B cells and we assume that it can be used as an early marker for Lupus.

Publications in Immunology and Cell Biology, Clinical Rheumatology and Frontiers of Immunology (submitted).

Engagement and acknowledgement with Lupus Association


Professor Heinrich Korner and the Menzies Institute for Medical Research delivered a public talk with the topic “Lupus in Australia” held at the Medical Science Precinct on the 13 November 2014.

Lupus Association of Tasmania acknowledged in publications and presentations.
The Environmental Determinants of Lupus Flares (EDOLF)

The environmental Determinant of Lupus Flares study (EDOLF) investigated the relationships between common environmental agents found indoors and self reported symptom flare days (SRF) in 101 Australian female lupus patients as compared to 41 age matched healthy controls. The study was retrospective and employed mixed methods examining differences in lifestyle behaviours and agent exposure with personal product use.

The study showed that the Australian population was similar to other Caucasian populations, with the average number of flares reported to be 29.9 SRF days, with 6.8 discrete flares for the study year. Flare symptoms were consistent with other population profiles published, however the EDOLF Australian population also reported gastrointestinal issues (13.9%) and shortness of breath (9.9%) as common symptoms. Commonly published flare triggers of UV radiation, infection and stress were confirmed, with the addition of new potential triggers: temperature & weather changes, work, and cleaning chemicals.

Use of personal care products, personal hygiene and lifestyle activities, resulted in significant increased risk associations for bath oil (IRR 1.008, CI 1.00– 1.02) and significant reduced SRF risk for cleansing beauty products (IRR0.999, CI 0.998-0.999) and a combined makeup group (foundation and sunscreen) (OR 0.998; CI 0.997-1.0). A flare a day reduction of 0.15% was calculated for each day of combined makeup group product use. In comparison to control participants, the SLE group showed significant difference in 25(OH)D deficiency (p=0.02) and 25 (OH)D levels (means-control 74nmol/L 29.5/ml); SLE 58nmol/L (23.1ng/ml), p=0.04. Reduced levels of 25 (OH)D were associated with expression of serological autoimmunity (ANA titres of 1:80) with odds ratios (OR) for ANA-positivity declining by 36% of the baseline OR for every two-fold rise in 25(OH)D and SRF. Significant associations were found for Finnish Job Exposure Matrix (FINJEM) occupational exposure classes; manual handling burden (p=0.02, IRR 1.01); iron (p=0.00, IRR 1.37); wood dust (p=0.00, IRR3.34); and asbestos (p=0.03, IRR 2.48), indicating that participating in occupations such as nursing, teaching and specialist labouring could pose an increased risk to SLE patients. Analysis of lifestyle factors indicates that the EDOLF SLE participants, as compared to the control participants, had reduced levels of QOL on VAS scales, lower levels of physical activity but similar dietary variables. SLE participants also used therapies such as acupuncture, hydrotherapy, massage and dietary supplements including vitamin D and anti-inflammatory homeopathic medications such as fish oils.

The retrospective design of the EDOLF study may have resulted in a number of study limitations including misclassification and recall bias; however a number of data validation steps were incorporated to limit bias influences on reported results. One considerable limitation of the retrospective EDOLF study design was that establishment of firm casual relationships was not possible. Therefore, reported results can only infer potential significant relationships and health effects. In conclusion, the EDOLF study provides insight into SLE experience particularly perceived flare symptoms, triggers and management strategies.

Each year, the average SLE patient experiences 30 days of symptom flares which are commonly self-managed with no extra physician assistance. The study also identified that everyday environments and exposures in day-to-day life activities, including both home and work environments, could potentially trigger exacerbation of SLE symptoms. In addition, the use of UV protective products, whilst potentially reducing symptom exacerbation and flare days, may paradoxically influence serum 25(OH)D in a group of patients with a higher incidence of deficiency and insufficiency as compared to the general population. Importantly, the EDOLF study provides insight into the future research directions that will better inform appropriate protective measures that people living with SLE can adopt to reduce adverse health impacts and improve life potential and quality.

Thank you to ARRC newsletter for permission to publish this article from the Spring 2015 Vol. 177

Details
Written by WebMaster
Category: Medical Articles
Published: 04 December 2015
RAFFLE:

At the last Lupus Tasmania General Meeting, members agreed to hold a few raffles this year including a Christmas Stocking. We are seeking support from our members to donate items to fill the stocking, our food hamper (Please make sure that expiry date for food is after January 2018), basket of goodies, wine prize etc. One member has kindly already donated food (Thank you). It is amazing what you can find that you received as a present and stored it away :)

Other donations - several pampering packs from the body shop, some toys and other items. If you have a voucher or a prize that you would like to add to this raffle or a donation, please take items to your support group meetings or contact Dianne (the secretary) via email or phone to discuss collection.

Regarding our major raffle—yes where everyone receives a raffle book!!! If you know of a business that would be interested in donating a car, a luscious mat, wine, holiday etc please contact Lois to discuss.

REMINDER:

Check out our Website and/or Facebook page for current notices, events or discussions as well as news regarding the Launch and Lupus Month in October. On page 16 is our poster advertising ‘October is Lupus Awareness Month’. If you would like a poster to put up at your employment / business / school etc please contact Dianne to arrange.

** Hope to see many members as possible at the media launch at Southern Cross TV station on 6th October 2017.....I cannot wait to meet invited guests and maybe see Jo Palmer in person :)

PLEASE NOTE:

New phone number for Lupus Tasmania - 0487 106 950
Barbara's Story

How I was diagnosed…..

The millennium year, 2000, was one I am not likely to forget-for all the wrong reasons.

It was the year my son died from an overdose of prescription drugs, after years of depression, lack of employment, and dealing with the social stigma of being gay. I don’t think it needs to be said that I was shattered! I was working as a nurse at the time in a Melbourne hospital that specialised in the care of MS and MND patients, which was so intense I had little time to mourn, and with this, and the Compassionate Friends, I survived the worst days of my life! (The CF is run by bereaved parents for other bereaved parents)

The following year I was on “auto-pilot” until the day of his first anniversary drew near, and one month before the day, I started to feel unwell.

I went to see my family doctor twice who said I had the ‘flu both times, but I knew it wasn’t.

I had purple spots on my legs and the perspiration was literally running down my back. The next day I had a seizure and saw a different doctor who prescribed hydroxychloroquine.

After this I had symptoms of one illness after another, including malaria, which frustrated the doctor because he was at a loss to find the cause. I was pretty sure I had Lupus because my daughter had been diagnosed with it a few years earlier, and I had a grandson with Crohn’s disease, but the doctor didn’t agree. Finally, I had a bout of serious arthritis, and he sent me to a rheumatologist who made the accurate diagnosis.

Even though it wasn’t particularly thrilling to know I did have Lupus it was a relief to know what the problem was at last. Right now, my symptoms are just moderate with the odd flare or TIA, just to let me know the “wolf” is not far away!

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

** “Lupus is Latin for wolf, Erythematosus means red, it was just starting to be recognized as a disease, it was caused by the bite of a wolf. This may have been because of lupus. (Once full-blown, the round, disk-shaped rash leaves a bite-like imprint.)” **
In the last Newsletter we asked members to fill in forms to help the public to understand a bit more about their disease. Thanks goes to the members who participated :)  

Here are a few:

<table>
<thead>
<tr>
<th>Region</th>
<th>Date of Diagnosis</th>
<th>Symptoms</th>
<th>Good Day</th>
<th>Bad Day</th>
<th>Wish List</th>
<th>Favourite Food</th>
<th>Favourite Music</th>
</tr>
</thead>
<tbody>
<tr>
<td>Launceston</td>
<td>2000</td>
<td>Rhayruris - Reflux, Pulmonary Hypertension</td>
<td>Most Days</td>
<td>When muscles get effected and have to lift 1 leg to get in/out of a car or arm (won't do what expected)</td>
<td>To be well, happy and enjoy life</td>
<td>Roast Dinner - Sponge Cake</td>
<td>A Good Tenor Singing</td>
</tr>
<tr>
<td>N.E.</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
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</table>
### Member with Lupus

<table>
<thead>
<tr>
<th>Region: NSW</th>
<th>Date of Diagnosis: 1994</th>
</tr>
</thead>
<tbody>
<tr>
<td>Symptoms:</td>
<td>Fatigue</td>
</tr>
<tr>
<td>Good Day:</td>
<td>Full of energy</td>
</tr>
<tr>
<td>Bad Day:</td>
<td>Tired and Sleepy</td>
</tr>
<tr>
<td>Wish List:</td>
<td>core</td>
</tr>
<tr>
<td>Favourite Food:</td>
<td>soup / casseroles</td>
</tr>
</tbody>
</table>

### Member with Scleroderma

<table>
<thead>
<tr>
<th>Region:</th>
<th>Date of Diagnosis: 2003</th>
</tr>
</thead>
<tbody>
<tr>
<td>Symptoms:</td>
<td>Arthritis, skin rashes, ulcers, reflux, bone problems</td>
</tr>
<tr>
<td>Good Day:</td>
<td>Good weather, medication working</td>
</tr>
<tr>
<td>Bad Day:</td>
<td>Meat day (can't get about)</td>
</tr>
<tr>
<td>Wish List:</td>
<td>Good day</td>
</tr>
<tr>
<td>Favourite Food:</td>
<td>vegan food, karengo</td>
</tr>
<tr>
<td>Favourite Music:</td>
<td>all except opera</td>
</tr>
<tr>
<td>Favourite TV Program and Star:</td>
<td>Who Shot Mr. Burns?</td>
</tr>
<tr>
<td></td>
<td>Neil Love Child</td>
</tr>
</tbody>
</table>

Tick this box if you approve your anonymous information to be published on the

### Member with Lupus

<table>
<thead>
<tr>
<th>Region: South</th>
<th>Date of Diagnosis: 1981</th>
</tr>
</thead>
<tbody>
<tr>
<td>Symptoms:</td>
<td>Sore bones, tiredness, face rash</td>
</tr>
<tr>
<td>Good Day:</td>
<td>Having enough energy to do something I enjoy on top of what I have to do</td>
</tr>
<tr>
<td>Bad Day:</td>
<td>Too sore and tired to do anything so a completely wasted day</td>
</tr>
<tr>
<td>Wish List:</td>
<td>To be able to regularly do my housework and gardening</td>
</tr>
<tr>
<td>Favourite Food:</td>
<td>Chocolate ice cream</td>
</tr>
<tr>
<td>Favourite Music:</td>
<td>Anything with French horns</td>
</tr>
<tr>
<td>Favourite TV Program and Star:</td>
<td>David Attenborough nature series</td>
</tr>
</tbody>
</table>
General Meetings for 2017

September 17th
December 10th

AGM and General Meeting

18 March 2018

NOTE: All meetings are held at the Kings Meadows Health Centre, McHugh Street, Kings Meadows starting at 10.30am. Please bring a small plate of food to share after the meetings. However, the December general meeting will be held at Brocks Residence in Windmere. Christmas break up lunch follows the meeting. More details in next issue :)

LAW (Lupus Awareness Week) Media Launch at Southern Cross—6th October 2017

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.

Western Group
TBC

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