



# LUPUS NEWS TASMANIA

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Committed to understanding and supporting people with Lupus, Sjögren's,  
Schleroderma & Fibromyalgia and all autoimmune diseases

## Autumn is Here



This Newsletter contains an explanation of what research is being done by one of our members and others from the Tasmanian University and Menzies' Research Institute.

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Registered Charity      ABN 96 163 951 956

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

<p>The Lupus Association of Tasmania, Inc. does not recommend or endorse any drugs, treatments or <b>procedures reported in this newsletter</b>. <b>The information is intended to keep you informed</b> and we recommend that you discuss any information mentioned with your Doctor.</p>
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## President Lois's Message

I hope everyone has enjoyed the long break and the nice warm weather. A small group of us got together for our annual Christmas celebration at Edna and Seton's house. We all enjoyed the lunch and chats and would like to thank our hosts, their family who drove from Mole Creek to help and members who managed to put on a very nice feast. The garden was very impressive and looked great even considering the warm weather. As a follow up to the Lupus Awareness Week Southern Cross has given us a further 2 weeks of free advertising and are showing our second advertisement during March. This advertisement talks about what is Lupus and explains that it has a wide variety of symptoms and related conditions. *It finishes with a message that the Lupus Association needs support as we can make a big difference.*

I am pleased to say we have another specialist in Launceston for people with auto-immune disease. Please contact me via email or through the lupus Tasmania email address if you would like more information and I look forward to meeting up with everyone as we advance through the new year.

Best Regards,

Lois Beckwith  
President



**Get well Julie**  
Get well Julie

## Editors Message

What a warm summer we have had. We send get well wishes to Julie Scales as her long stay in hospital has taken its toll on both Julie and Murray.

The weather lately has changed, and Autumn is here, so we need to get something warmer from our closets. I hope that everyone keeps well and that the Autumn is kind to those with aches and pains.

Some wise words which came up on my desktop

### **To WIN**

You must risk losing

### **To WALK**

You must first stumble

### **To ENJOY**

The sun you must be

Willing to accept

The rain.

## Regional Reports

### Southern

Christmas Luncheon 2017:

We had a most enjoyable Christmas lunch at the Esus Café, in the centre of Hobart.

One of the staff members has been there right from our first lunch at the Esus Café. We have encouraged her as she has progressed from waitress to chef, enjoyed her bridal photos and have watched her son grow. In February she shared the 'first day of school' photos with us. It is such a friendly restaurant and we keep going back because we are made to feel so welcome there.

The menu has an interesting variety of food and about \$20 gives us a large main course and drink, [alcohol, soft drinks, tea or coffee], so we don't need to cook when we get home. There are, of course, snack meals available. Everything is cooked fresh and most delicious. The members are very welcoming, and we talk about a wide variety of things, besides our aches and pains, like holidays, our friendships, family and special times.

The midday meeting time is usually quiet in the café, which is a big bonus as we can hear each other speak around the table or three tables, as they kindly put tables together for us. I ask people to let me know they are coming so I can let the café know how many tables we need putting together.

I always enjoy our time together and it would be great to have some new members and increase the tables to four or five or more ☺

We wish everyone a very healthy and happy 2018.

P.S. At the luncheon on the 14th February, it was decided that the southern members will meet four times a year. The day is the third Monday of May, August, November 2018 and February 2019. We will be still meeting at the same venue:

Esus Café  
Elizabeth Street  
Hobart at 12 noon

We hope the new day and frequency will suit more people.

Regards Heather Cowled  
Southern Co-ordinator

## **Northern**

Our group meet on the fourth (4th) Thursday in the month at 10.30am at the Joan Marshall Wing, Kings Meadows Health Centre. Occasionally we will consider having a meeting elsewhere this year and may be for morning tea or lunch. If anyone has any suggestions we will discuss them at our next meeting. We would like to ask our past members who have moved away to send us a message via our email - [lupustas1@lupustasmania.org.au](mailto:lupustas1@lupustasmania.org.au) or my email address before each meeting as we would love to keep connected.



Lois Beckwith  
Northern Co-ordinator

## **West Coast**

The West Coast Support Group met at the Empire Hotel in Queenstown on the 6th of February with three members attending. If you did not receive your invitation, please let us know or just come and join us at our next meeting for morning tea. The hotel provides tea and coffee. Please bring a plate of goodies to share. At the next meeting we can discuss about having lunch there as it is also an option. I'm still optimistic about increasing our membership even though things are moving slowly on the West Coast! Bring it ON!!

Barbara Gruner  
West Coast Co-ordinator

## **North West**

We will continue to meet at the Fuschia Farm Café on Lillico Straight in between Devonport and Ulverstone for 2018. First Tuesday of the month, at 12 noon to approximately 2pm. We will continue to meet here because it is central to everyone who currently attends. We still look to attract new members and we find it easier to meet at the Fuschia Farm Cafe. If there is a new member who would like to have luncheons closer to where they live, please contact me to discuss.

Dates for the NW Lupus luncheons are 6th March, 3rd April, 1st May, 5th June, 3rd July, 7th August, 4th September, 2nd October, 6th November, 4th December (Christmas Lunch) please RSVP by the 30<sup>th</sup> of November for our Christmas luncheon.

These dates are locked in for the year, I have to start different treatment so somewhere closer to us is preferable, but if I am unable to attend, this venue will still be central to everyone else. If there is anyone who would love to come for a few hours of friendship,

understanding and a good chinwag, please contact me on 0409 713 240 or [Leanne.E.Stephens@alumni.uts.edu.au](mailto:Leanne.E.Stephens@alumni.uts.edu.au) , we would love to meet you.

Thank you  
Leanne Stephens  
North West Co-ordinator

### **Secretary's Message**

Membership registrations are due. Please complete and send form to address listed with payment. The forms can be found on page 13. Any queries please phone 0487 106 950 or email – [lupustas1@lupustasmania.org.au](mailto:lupustas1@lupustasmania.org.au). New members receive a hand book as well as the newsletter. If you know of someone that is not a member and would like them to join us, let me know and I can send information to them.

Sending 'Get well' wishes to Julie Scales (hip) and Charmaine Smigielski (leg)..... two members who have been in hospital and now on the mend.

Well done to Debbie Steer who has taken the liberty to try and help control / breakdown her issues with her illness. You can view a report on our facebook page - [www.facebook.com/lupustasmania](http://www.facebook.com/lupustasmania) or email / phone me and I will send you the information.

We will be holding raffles / sausage sizzles throughout Tasmania during the year to raise funds for Lupus Tasmania. If you wish to assist by donating to the raffles or selling tickets / firing up the BBQ at the sausage sizzles at different shopping complexes for our association, please email or phone me.

If there is any news, events, a member is sick or in hospital or you want to share ideas / recipes, medical information etc that may assist other members ...send an email or phone me. Details are above or on page 2 of this newsletter.

If you know of any medical centre / wellness centre / health centre that is not receiving our newsletter, please send me an email or sms so we can send them one. We are trying to send a newsletter to every medical centre in Tasmania and our small islands.

**REMEMBER** - always check our facebook page or website for up to date information and finally .....

Have a great day ☺

## Yik Chang Ho Research Project

The School of Health Sciences  
needs

### **Volunteers**

Aged between 18 and 80 years to take part  
(single blood sample) in a research project to  
investigate

How antibodies from Lupus or APS patients  
react with platelets?

### **Eligibility:**

Males and females with systemic lupus  
erythematosus (Lupus) and  
antiphospholipidsyndrome (APS)  
or Healthy males and females

If you would like to participate or want more information, please contact:

**YikChang Ho (PhD candidate)**

email : yik.ho@utas.edu.au

**Dr KiranAhuja**

email: Kiran.ahuja@utas.edu.au phone  
: 6324 5478



School of Health Sciences University of Tasmania

**PARTICIPANTS WITH AUTOIMMUNE DISEASES  
INFORMATION AND CONSENT  
TO PARTICIPATE IN A RESEARCH STUDY  
General Title:**

How do antibodies from Lupus or APS patients react with platelets?

**Scientific Title:**

Pilot study to investigate the mechanism of interaction between anti-beta 2 glycoprotein 1 antibodies,  $\beta$ 2GP1 and platelets

**Research Team:**

Yik Chang Ho (PhD student), Dr Kiran Ahuja, Dr Murray Adams, Prof Heinrich Körner  
School of Health Science, University of Tasmania

**1. What is the purpose of this study?**

The purpose of this study is to understand how and why certain antibodies, especially anti-beta-2-glycoprotein 1 (anti- $\beta$ 2GP1) antibodies, produced in systemic lupus erythematosus (also known as Lupus or SLE) and/or antiphospholipid syndrome (APS) patients, increase the risk of excess blood clotting and/or pregnancy complications. Antibodies are blood proteins produced by the immune system to help stop intruders like bacteria from harming the body. However, some antibodies produced by Lupus and APS patients target patients' own cells and protein, rather than foreign bodies such as bacteria. To understand the relation between anti- $\beta$ 2GP1 antibodies and blood clotting, we are conducting this study where antibodies removed from the blood of Lupus and APS patients will be mixed with platelets (very small cell fragments in blood) collected from healthy individuals. How healthy platelets react to these antibodies will provide us some clues on the nature of these antibodies. This research may help in the development of treatments for Lupus and APS patients.

**2. Why have I been invited to participate in this study?**

You are eligible to participate in this study because you either have Lupus or APS. The inclusion and exclusion criteria are listed below:

**Inclusion criteria**

Male and female with either Lupus or APS, 18-80 years of age

**Exclusion criteria**

No exclusion criteria because anti- $\beta$ 2GP1 antibodies in patients are not known to be affected by any medications/supplements

**3. What if I don't want to take part in this study, or if I want to withdraw later?**

Participation is voluntary and you may choose to withdraw at any stage. However, anti- $\beta$ 2GP1 antibodies purified from your blood sample collected prior to withdrawal will be not be destroyed.

**4. What does this study involve?**

To participate, you will be required to attend the clinical room of School of Health Sciences on one (may be two) occasions.

**School of Health Sciences:** Continued

The study involves donation of 30 mL (~1 ½ tablespoons) of blood sample. This sample will be tested for the presence of anti- $\beta$ 2GP1 antibodies. If present, these anti- $\beta$ 2GP1 antibodies will be used to test their effect(s) on platelets from healthy participants. Only 15% of the SLE patients have anti- $\beta$ 2GP1 antibodies. If anti- $\beta$ 2GP1 antibodies are identified in your blood, we may contact you for another blood donation for the same study.

**5. What if my blood has anti- $\beta$ 2GP1 antibodies?**

If your blood contains anti- $\beta$ 2GP1 antibodies, we will inform you and your clinician. We may also invite you to provide us more blood sample on a later date, if we are unable to recruit enough people in the study whose blood contains anti- $\beta$ 2GP1 antibodies.

### **6. Are there risks to me in taking part in this study?**

Blood sampling is a low risk activity but you should be aware that there are a number of minor complications that can result from the procedure. In order for you to give informed consent to blood sampling you will be given the following information:

#### Complications of blood sampling

1. Syncope (fainting): This is uncommon but will happen if you are unwell or suffering from a viral infection such as a cold or flu. If you are extremely apprehensive about the procedure or the sight of blood, you are also prone to fainting. If this does occur you will be laid down, and adequate ventilation with fresh air will be provided. A glass of cold water often helps to alleviate the symptoms.
2. Nausea and Vomiting: Whilst a feeling of nausea is a relatively common response (especially in first time subjects), vomiting is quite uncommon in adults as a response to blood sampling.
3. Bruising and Haematoma formation: Bruising is the most common post-procedure complication. The likelihood of bruising can be greatly diminished by applying pressure to the puncture site for 5 minutes after the completion of the procedure. Haematoma formation (bleeding under the skin to form a raised swelling) can also occasionally occur and is minimised with prolonged application of pressure to the site.
4. Convulsions: Usually only seen in those who faint. These are usually minor in nature and last less than a minute. The procedures for this are the same as for fainting although, of course, care is taken to ensure that you do not hurt yourself

### **7. Will I benefit from the study?**

There will be no benefit in the short term. However, the understanding of the effect(s) of anti- $\beta$ 2GP1 antibodies on platelets can potentially assist in the future development of treatments for patients with Lupus and APS.

### **8. Will taking part in this study cost me anything?**

Participation in this trial will not result in any costs for you and there is no payment for participation in this study.

### **9. How will my confidentiality be protected?**

Information and Consent for Patients with Autoimmune Diseases, Version 3,  
17/08/2016 2

#### **School of Health Sciences : continued**

**General Title:** How do antibodies from Lupus or APS patients react with platelets?

**Scientific Title:** Pilot study to investigate the mechanism of interaction between anti-beta 2 glycoprotein 1 antibodies,  $\beta$ 2GP1 and platelets

## Informed Consent Form for Participants with Autoimmune Diseases

1. I, \_\_\_\_\_ have read the above information and I agree to take part in the pilot study investigating the mechanism of interaction between anti-beta 2 glycoprotein 1 antibodies,  $\beta_2$ GP1 and platelets.
2. I was given time and opportunity to inquire about the study and all my questions were answered to my satisfaction.
3. I have received an explanation of the possible risks and discomforts in providing a blood sample for this study.
4. I am aware that I may be contacted to attend a second session for blood collection.
5. I am aware that a Tasmania Health and Medical Human Research Ethics Committee have subjected this study for review and approval.
6. I understand that I am free to withdraw from the study at any time, without the need to justify my decision.
7. I understand that any anti- $\beta_2$ GP1 antibodies isolated will not be destroyed if I choose to withdraw from this study.
8. I agree that the results of the study may be published or presented however my name and contact details will be kept secret.
9. I understand that the research will be conducted in accordance with the Declaration of Helsinki, NH&MRC Guidelines and applicable privacy laws.

I voluntarily consent to participate in this study.

-----  
Subject's Signature Date

Investigator Statement

I \_\_\_\_\_ have explained this study and the implications of participating in it to this volunteer and I believe that the consent is informed and that he/she understands the implications of participating in the study. The subject consented to participate by his/her personally dated signature.

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Investigator's Signature Date

Information and Consent for Patients with Autoimmune Diseases, Version 3, 17/08/2016  
School of Health Sciences

School of Health Sciences

General Information Questionnaire for Patients with Autoimmune Diseases Version 1,  
6/05/2016 **General Information Questionnaire for Patients with Lupus and APS**

Prior to providing a blood sample, please answer the following questions:

1. Have you been diagnosed with systemic lupus erythematosus (also known as SLE or lupus) or antiphospholipid syndrome (APS)?

A) Lupus Yes  No

If yes, at what age? \_\_\_\_\_

B) APS Yes  No

If yes, at what age? \_\_\_\_\_

2. Gender (tick box): Male  Female

3. Date of Birth (dd/mm/yyyy) \_\_\_\_/\_\_\_\_/\_\_\_\_\_

4. Are you currently taking any prescribed or other medications/supplements?

Yes  No  If yes, please list.

5. Have you previously been diagnosed with a blood clot (thrombosis) e.g. deep vein thrombosis (DVT)?

Yes  No  If yes, please provide more details.

6. Do you have any other medical problem which you are currently receiving medical attention and/or treatment?

Yes  No  If yes, please provide more details. School of Health Sciences

General Information Questionnaire for Patients with Autoimmune Do you have any problems during blood collection i.e.: severe bruising, fainting.

Yes  No

If yes, please provide more details

8. Are you interested in taking part in this study? If so, kindly provide your contact details. Please  to indicate best method of contact.

Phone (BH):\_\_\_\_\_

Phone (AH):\_\_\_\_\_

Mobile: \_\_\_\_\_  Email:

If phone, best time to call: \_\_\_\_\_ 11.

Any questions or feedback?

Please kindly return this form to the distributor of this questionnaire.

Otherwise, you can also email this form to [yik.ho@utas.edu.au](mailto:yik.ho@utas.edu.au) or contact +61 3 6324 5478 to return it.

You can also post it to:

Yik Chang Ho, School of Health Sciences University of Tasmania, (UTAS), Locked Bag 1322, Launceston, TAS, Australia

*This study is being conducted by Yik Chang Ho (PhD candidate, Dr Kiran Ahuja, Dr Murray Adams, Prof Heinrich Körner, University of Tasmania*

*Yik Chang Ho has become a member of our Association while he is studying in Tasmania and has an interest in Blood and autoimmune diseases. If you would like to talk to him please come along to our monthly morning teas, or use the phone number above. We thank you Yik Chang Ho et al. for your interest in our diseases.*

## The Mother Camel 's Message

A mother and a baby camel were lying around, and suddenly the baby camel asked, “mother, may I ask you some questions? The mother said, “Sure! Why son, is there something bothering you? Baby said, “Why do camels have humps?” The mother said, “Well son, we are desert animals, we need the humps to store water and we are known to survive without water”.

Baby said, “Okay, then why are our legs long and our feet rounded?” The mother said, “Son, obviously they are meant for walking in the desert. You know with these legs I can move around the desert better than anyone does!” Baby said, “Okay, then why are our eyelashes long? Sometimes it bothers my sight”. Mother with pride said, “My son, those long thick eyelashes are your protective cover. They help to protect your eyes from the desert sand and wind”.

Baby after thinking said, “I see. So the hump is to store water when we are in the desert, the legs are for walking through the desert and these eyelashes protect my eyes from the desert then what in God’s name are we doing here in the Zoo!?”



**Moral:** Skills, knowledge, abilities and experiences are only useful if you are at the right place.

**Memberships are due:** Please fill out form below

# Lupus Association Of Tasmania Inc.



Lupus Association of Tasmania Inc.  
PO Box 639 Launceston Tasmania 7250

Name.....

Address.....

.....

Email:.....

Phone:.....

Membership of \$15 includes newsletters

This registration covers family

As you can read from this newsletter that research is being carried out by Tasmanian University and there is no other way but to pay for it.



# For Your Diary



**Northern:** Last Thursday of each month at the Kings Meadows Health Centre - Joan Marshall Wing. 10.30 am for morning tea. Please bring some food to share. Open to everyone interested in Auto-immune diseases.

**North West:** 1st Tuesday of each month at Fuschia Farm Cafe, Lillico Road, Lillico (near Turners Beach). 12 noon for lunch. Pay for your own meal. Open to everyone interested in Autoimmune diseases welcome.

**West Coast:** Meetings are on the 1st Tuesday of each month at the Empire Hotel in Queenstown starting at 11am for morning tea. Please bring some food to share. Open to everyone interested in Auto-immune diseases.

## **Southern Support Group:**

3rd Monday of May, August, November 2018 and February 2019 at Esus Café Elizabeth St. Hobart at 12 noon for lunch.

**AGM** - 11.00am Sunday March 25th at the Joan Marshall Wing, Kings Meadows Health Centre, Launceston. Please bring finger food to share. This will be an important meeting so please endeavour to attend.

**Appreciate that  
Everyone has a reason  
For doing what  
They do**