



# LUPUS NEWS

## TASMANIA

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

# Autoimmune Diseases and Pregnancy



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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.

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### President's Message

**This month the Northern Support Group joined the North West group at the Lillico Fuschia Farm. It was a good idea for us to have a combined meeting and meet members from each other's group. We broke a record at the Restaurant ordering the most gluten free meals at one table. It was great to have a wide choice and informed staff. A big thank you to the establishment.**

**Over the break I have had the opportunity to meet some more distant members and chat with them about how to develop support and understanding from friends, family, and the wider public. It does not seem to matter what age group we belong to, the issues associated with living with Lupus and other autoimmune diseases are the same. I came across a saying by Eckart Tolle, a German spiritual author, who reminds us to make the most of what we have got.**

**"In today's rush, we all think too much, want too much and forget the joy of living. "**

**Regards  
Lois Beckwith**



## Regional Reports

### **East Coast Support Group:**

We welcome our East Coast Support Group. They hold their meetings at Pasini's Café, Shop 2/70 Burgess Street Bicheno, on the first Monday of the month at 12.00 noon for lunch. This group includes members, family and friends from Bicheno, Scamander, St. Helens and all the east coast of Tasmania. We will be interested to hear from them next month and look forward to their input into our association.

Ms. Jasmine Rooney  
East Coast Co-ordinator

### **Northern Support Group:**

The group will be meeting at our usual spot at the Kings Meadows Health Centre, Joan Marshall Wing, at 10.30 am. I look forward to seeing everyone for morning tea at the end of March...maybe we will have an Easter egg hunt 😊. We also had a great time meeting up with the north west support group and we also welcomed back a few new members that have been away and have decided to come and join us for a cuppa again each month.

Lois Beckwith  
Northern Co-ordinator

### **North West Support Group:**

The Northern Support Group visited our North West Support Group for a social outing on the 4th February 2020 and had a very pleasant meal / few hours socialising. It was held at the Fuschia Farm, Lillico and we THANK them for their efficiency and great service.

Leanne Collins  
North West Co-ordinator

### **Southern Support Group:**

The Southern Region Members are meeting again on the 18th May, August 17th, and November 16th during 2020. Will Southern members please put these dates in your diary. Any one from across the state is always welcome to join us if you happen to be visiting Hobart, just let me know.

This year we will continue to meet at '**Mathers House**' at **108 Bathurst St. Hobart** and it is found between the Playbox Theatre and the Library i.e. between Elizabeth and Murray Streets opposite the Melville St car park. The first hour and a half of parking in the car park is free. We had a great time catching up in February and it

was nice to see some new members. Welcome to the New Year of luncheons with new and current members and can't wait until our next meeting.

Heather Cowled  
Southern Co-ordinator

### West Coast Support Group:

I had a small group of two again 😊 We had a lively discussion, nevertheless. It was fantastic!! but here's the good news! I took part in a local Summer market on Saturday, where I met a couple of ladies who told me they had been meaning to come to meetings but were a bit shy. Now that they have actually met me at the market, had a chat, it looks like I may have two newbies! The next meeting is on Tuesday 7<sup>th</sup> of April 2020 starting at 11.00am, at JJ's as usual and I'm looking forward to a great time! Maybe we will have some Easter buns to eat 😊

Barbara Gruner  
West Coast Co-ordinator

Some photos of members and friends that attended the luncheon on 4.2.2020



Leanne and Robbie



Cheryl, Narelle and Julie



Wendy and Christina

## From the Editor's Desk

This newsletter has been a learning curve for me as editor there are many articles on the internet re pregnancy and autoimmune diseases, however, they were all too long to be of use in this newsletter or too expensive to use copyright. Thanks to some very good friends the articles I have printed, permission to print was given. One from America and the other from the UK. I have had some correspondence with Eula in America who was the editor of the AARDA newsletter and have found a friend, in that when I needed help to find articles to print, she quickly pointed me in the right direction. Not only did she point me in the right direction but being the caring person, she is, she emailed me when the devastating bush fires were raging to inquire whether we were in the line of fire.

Also, Christine Watkins from the UK has also been very helpful with the March topic of the month article.

So, if you are pregnant or thinking of becoming pregnant please look on the internet for articles which individuals can access but not for republication.

This will be my last year as editor so if you feel you could take over please let us know and I will help you through the "ins and outs". It is best to let us know earlier so as I can help ease my replacement in.

\*\*\*\*\*



### Some Wise Words

Follow the path that  
Affirms your values,  
Expresses your passion and empowers  
your soul.

Dreams are like Stars  
You may never touch them  
But if you follow them  
They will lead you to your destination

*Taken from the little cards which pop up on my desk.*

## **Women and Autoimmune Disease— again, the question:**

The million dollar question: Why do women suffer much higher rates of autoimmune disease than men do? In United States alone, women represent approximately 80 percent of all cases of autoimmune disease. Women are 16 times more likely than men to develop Sjögren’s syndrome, for example, and nine times more likely to have Hashimoto’s thyroiditis, the disease that caused tennis star Venus Williams to withdraw from the U.S. Open in 2011. Some scientists now think that the placenta itself might be the reason that women are so disproportionately affected. Some researchers at Arizona State University have put forward an explanation called the “pregnancy compensation hypothesis”. It suggests that women’s immune systems are engaged in a fierce tug of war with placentas, even when the organs aren’t actually present.

When the placenta grows during pregnancy, the organ sends signals to the mother’s immune system to change its activity so that the mother’s body doesn’t eject the placenta and the baby. This might mean turning down the immune system in some ways, or for a certain amount of time. Turning down the immune system too much, however, risks leaving women sensitive to pathogens, which would be bad also for the developing baby. So instead, the mother’s immune system ramps up in other ways throughout adulthood, suggests evolutionary biologist Melissa Wilson and her Arizona State colleagues, and remains vigilant against germs even when some of its parts are dormant during pregnancies.

Things get complicated when those pregnancies don’t actually occur. Women today tend to have fewer children than in previous decades—fewer than two on average in the US, according to the Centers for Disease Control and Prevention (CDC). Dr. Wilson reasons that without a more or less constant pushback from placentas during pregnancies—the pushback that women’s immune systems have evolved to anticipate—the immune system can get too aggressive. It starts looking for things to attack that aren’t dangerous, which is how autoimmune diseases set in.

Many theories have been put forth about why women suffer from more autoimmune disease than men do. The way Dr. Wilson sees it, the pregnancy compensation hypothesis synthesizes many of the previous theories into one and provides the evolutionary explanation behind them. She says that, so far, no one has come forward to attack her for being wrong, despite the seeming boldness of this theory.

Dr. Nikolaos Patsopoulos, assistant professor of neurology at Brigham and Women’s Hospital, in Boston, says that “this theory puts together a lot of things we know that are true and some that we are still trying to understand.” Dr. Wilson says that the hope is to learn eventually what it is in the immune system that’s trying to respond to the placenta and to target “that thing” with vaccines or treatments.

—Source: excerpted from “A Breakthrough in the Mystery of Why Women Get So Many Autoimmune Diseases,” Olga Khazan, *The Atlantic*, June 18, 2019.

*This may explain why after the birth of my first child I was diagnosed with Hypothyroidism, which at that time was practically untreatable, and little known.*

## Topic of February/ March

### **Lupus and Pregnancy**

In the past women with SLE were discouraged from becoming pregnant as there was concern about the health of both mother and baby. However, research in the last 10-20 years coupled with advancing technology a better understanding of autoimmune diseases along with the changes in Medical practice has come to mean that in more cases of pregnancy, with close supervision and advice have been successful.

### **Planning a Pregnancy**

For the best chance of a successful pregnancy it is important to plan for the pregnancy when SLE is “inactive” for approximately 6 months. Conceiving when in the active period can increase flares and complications for mother and baby.

It is strongly recommended that a visit to the doctor in advance to becoming pregnant, enabling them to screen for any factors such as kidney involvement, high blood pressure, and any heart or lung problems, and therefore make any recommendations for your treatment.

Some SLE treatments will need to be stopped or changed to an alternative prior to conception. These need to be stopped before conception:

- Methotrexate (stop for 3 months before conception)
- Cyclophosphamide (stop 3 months before conception)
- Mycophenolate mofetil (stop 3 months before conception)
- Rituximab (stop 1 year prior to conception)
- Belimumab (stop 1 year prior to conception)
- Leflunomide (stop 2 years prior to conception)
- Bisphosphonates (stop 2 years prior to conception)

Other medications that are contraindicated in pregnancy and therefore will be stopped or switched for alternatives include;

- ACE inhibitors (commonly used to treat heart failure and high blood pressure)
- Warfarin (a blood thinning treatment most commonly used to treat antiphospholipid syndrome, APS, in people with lupus).

### **Blood Tests**

It is important to know whether you have antiphospholipid syndrome (APS) or the antibodies associated with it, as this will increase the risk of blood clots (thrombosis). The presence of these antibodies can increase the risk of pregnancy-related complications such as pre-eclampsia, IGUR (intra Uterine Growth Restriction), premature delivery or stillbirth.

### **Lifestyle and supplements**

To improve the chances of having a healthy pregnancy following these guidelines will help achieve this:

- Take a 0.4mg supplement of folic acid for 3 months before conception and during the first 12 weeks of pregnancy, to reduce the risk of neural tube defects.
- Stop smoking
- Cut out alcohol
- Calcium and vitamin D3 are encouraged before and during pregnancy
- Keep a healthy weight

- Get any necessary vaccines –rubella (German Measles) can harm your baby

### **During pregnancy**

Common health problems during pregnancy. Your body has a great deal to do during pregnancy. Sometimes the changes taking place can cause irritation and discomfort and sometimes you may be concerned. You may experience a number of problems that are unrelated to your lupus but are rarely a need for alarm, however, it is wise to mention any concerns to your doctor.

Some common health problems include:

- Constipation
- Cramp
- Feeling faint
- Feeling hot
- Incontinence
- Frequent urination
- Skin and hair changes
- Varicose veins

Some common changes can be due to pregnancy and be mistaken for lupus flares. All pregnant women can develop knee swelling (effusions) or carpal tunnel syndrome during pregnancy, however, if there is a lupus flare your doctor should detect synovitis (inflammation in the joint lining). Pregnant women can develop redness (erythema) of palms and face, which is important to differentiate from a lupus rash.

### **Lupus flares during pregnancy**

The risk of flares during and after pregnancy due to hormonal changes is estimated to be approximately 50%, but most of these will be mild to moderate affecting skin and joints predominantly rather than kidneys. The risk does vary according to the patients' background; a higher risk of flares is seen in women who have had a flare within six months prior to conception, previously very active disease, and if SLE therapy has been stopped. It is important to promptly identify and treat flares during pregnancy as they can cause complications to both mother and baby, Complications include a possible increase in pre-eclampsia in mothers and a threefold increase in prematurity (birth before 37 weeks) and IUGR (poor growth of the baby) resulting in still birth.

It is important not to mistake active lupus nephritis (kidney disease) for preeclamosia. For doctors to diagnose lupus nephritis it is essential that the urine is examined for cells and/or casts. If cells are present, infection of the urine must be excluded. In patients with lupus nephritis proteinuria will normally rise before the blood pressure whereas in pre-eclampsia the opposite is true. To assist with diagnosing a renal flare, there will often be other features of active disease in the patient and a change in blood test results; rising anti double stranded DNA antibodies and/or low complement.

Preeclampsia will be more likely if associated with the features of HELLP syndrome (Haemolysis Elevated Liver enzymes Low Platelets).

If new symptoms are due to a lupus flare then it should be treated with steroids and immunosuppression, but if due to pre-eclampsia then steroids may make the blood pressure worse. The ultimate treatment for pre-eclampsia Lupus and pregnancy continued:

is the delivery of the foetus, but anti-hypertensives (treatment for high blood pressure) may be used in the first instance.

One interesting phenomenon that can occur during pregnancy is that some women will actually have decreased lupus activity. This may be related to the fact that the foetus and placenta actually produce steroids such as cortisone and progesterone during pregnancy. These steroids can enter the mother's bloodstream and help decrease lupus activity, especially during the second and third trimesters.

### **Thrombosis (blood clots)**

All pregnant women are at risk of thrombosis, but especially those with lupus and/or antiphospholipid (APS) antibodies. Patients with confirmed APS are likely to require treatment with both aspirin and subcutaneous heparin throughout pregnancy. Patients with recurrent miscarriages in the first trimester may be treated with aspirin. Aspirin may also be commonly used in women with SLE who do not have antiphospholipid antibodies to prevent thrombosis and pre-eclampsia

### **Effects of lupus on the baby**

**Intrauterine growth restriction (IUGR):** This refers to poor growth of a baby while in the mother's womb during pregnancy. The risk of IUGR is increased in women with lupus when compared to the general population, especially in those who have antiphospholipid antibodies, active lupus at conception and high blood pressure during pregnancy. IUGR increases the risk of premature delivery.

### **Premature Delivery**

This is more common in women with lupus and is defined as delivery before 37 weeks. It occurs in 40-50% of SLE pregnancies.

The risk of premature

Delivery increases if the mother has active lupus, kidney involvement, hypertension, pre-eclampsia and high dose steroids (20mg or more of prednisolone). The delivery may be spontaneous or more often induced due to concerns regarding foetal growth (IUGR), reduced liquor (amniotic fluid around the foetus), foetal distress or rupture of membranes. Once the baby is mature enough to be delivered and survive in a neonatal ward, it is often advised to have an induced birth or caesarean to deliver the baby before it dies in utero, if there are concerns. There are numerous consequences of premature delivery for the foetus. The most serious are breathing problems:

mothers will normally be given a course of special corticosteroids (e.g. dexamethasone, which can cross the placenta), to promote foetal lung development. Other possible complications include infection, liver problems (jaundice), feeding difficulties, developmental delays or neonatal death (within 4 weeks of birth).

**Foetal loss:** Foetal loss includes spontaneous abortion before 10 weeks, miscarriages between 10 and 19 weeks and still births from 20 weeks onwards. There is an increased rate of foetal loss and miscarriages in lupus patients. The risk is higher in those with a previous history of foetal loss (especially before 10 weeks), APS, active lupus before and during pregnancy, kidney disease and pre-eclampsia.

**Congenital heart block:** In approximately 1% of cases anti-Ro and anti-La antibodies can cross the placenta and cause congenital heart block. If these antibodies are present they can only cross the placenta after about 16 weeks and pregnancy continued: weeks and therefore weekly heart monitoring will be

undertaken by a midwife/doctor from this point. A few babies will die in utero due to congenital heart block and the related cardiac complications. The majority who are born do well. However, approximately 30% will require a pacemaker during the first month of life, 30% in the first year, and the remainder will require a pacemaker by the age of 10 to 12 years.

### **Delivery**

In people with SLE a vaginal delivery should be possible, with pregnancy planning and joint care. A caesarean is normally reserved for emergencies, women who have previously had a caesarean and do not want the trial of vaginal delivery, and women with severe hip disease. However, to reduce the risk of still birth in women with active lupus and/or antiphospholipid syndrome, induction is usually planned at 38-39 weeks.

### **Breast feeding**

Breast feeding has multiple benefits and can reduce the risk of certain health complication for baby such as:

- Atopic dermatitis
- Asthma □
- Obesity
- Type1 and 2 diabetes
- Childhood leukaemia
- Sudden infant death syndrome

It can also reduce the risk of health complications for the mother:

- Type 2 diabetes
- Breast cancer
- Ovarian cancer
- Postnatal depression

It is safe to breastfeed whilst on prednisolone, hydroxychloroquine and heparin or warfarin. It is increasingly accepted that it is safe to breastfeed whilst taking azathioprine as there are only low levels of the active form of the drug in breast milk.

### **Lupus flares**

There is a risk of flares in the postpartum period, even if the disease has been stable during pregnancy. It is important to seek medical attention if you experience any symptoms of a lupus flare, so your drugs can be appropriately managed.

### **Blood Clots**

All women will have an increased risk of blood clots after pregnancy; this risk is increased in women with lupus (with or without ASP). It is essential to keep as active as possible and remain on any blood thinning medication (heparin or warfarin). If you experience any symptoms of a blood clot such as a swollen calf or breathlessness with chest pain, you must seek urgent medical attention.

*This article was taken form Lupus UK "Lupus and Pregnancy" as part of their March topic of the month . I have abridged parts of it because of space. The article can be viewed in full on Lupus Uk Website . [www.lupusuk.org.uk](http://www.lupusuk.org.uk) I have omitted the comments made by different patients which although interesting I felt were irrelevant to our situation. Thank you to UK Lupus association for permission to print this article.*

## The Mayonnaise Jar

When things in your life seem almost too much to handle, when 24 hours a day are not enough, remember the mayonnaise jar.....

A professor stood before his philosophy class began, wordlessly, he picked up a very large and empty mayonnaise jar and proceeded to fill it with golf balls.

He then asked the students if the jar was full. They agreed that it was. The professor then picked up a box of pebbles and poured them into the jar. He shook the jar lightly. The pebbles rolled into the open areas between the golf balls. He then asked the students again if the jar was full.

They agreed it was.

The professor next picked up a box of sand and poured it into the jar. Of course the sand filled up everything else. He asked once more if the jar was full. The students responded with a unanimous "yes".

The professor then produced two cups of coffee from under the table and poured the entire contents into the jar, effectively filling the empty space between the sand. The students laughed.

"Now," said the professor, as the laughter subsided, "I want you to recognize that this jar represents your life: the golf balls are the important things, your spirituality, family, your children, your health, your friends and your favourite passion things, that if everything was lost and only they remained, your life would still be full."

"The pebbles are the other things which matter like your job, your house, your car."

"The sand is everything else: the small stuff."

"If you put the sand into the jar first," he continued, "there is no room for the pebbles or the golf balls. The same goes for life. If you spend all your time and energy on the small stuff, you will never have room for the things that are important to you. Pay attention to the things that are critical to your happiness. Play with your children. Take time to get medical check ups. Take your partner out to dinner. Play another 18 holes of golf. There will always be time to clean the house and fix the disposal."

"Take care of the golf balls first, the things that really matter. Set your priorities. The rest is just sand."

One of the students raised her hand and inquired what the coffee represented. The professor smiled, "I'm glad you asked. It just goes to show you that no matter how full your life may seem, there's always room for a couple of cups of coffee with a friend."

*This article was sent to me by a very good friend and the philosophy behind it has been with me for a long time. Do we fill our lives with sand and then try to cope with the BIG things which really matter? Ed*

Some pictures from our Christmas Luncheon



Helen

Bruce, Robyn,



Cheryl, John, Colleen, Bruce Robyn



Helen, Dorothy, Edna and Julie

# For Your Diary



**AGM March 15th: The annual general meeting will be held at Joan Marshall Wing Kings Meadows Health Centre on March 15th at 11.00 am. Please bring a plate of finger food to share. All positions are vacant**

East Coast Support Group:

First Monday of the month at 12.00 noon for lunch at Pasini's Café, Shop 2/70 Burgess St., Bicheno.

Northern Support Group:

The 4th Thursday of every month at Kings Meadows Health Centre. Joan Marshall Wing, 10.30 am please bring a plate.

North West Support Group:

First Tuesday of the month at Fuschia Farm Café 12.00 noon, pay for self. Please come along and have a natter with other members

Southern Support Group:

Dates are - Monday May 18th, August 17<sup>th</sup> and November 16th 2020. "The café is operated by volunteers and the menu changes daily (home style theme). No EFTOS so cash only.

We do need to book to get a table. If you are coming please let me know by replying to email [hlcowled@bigpond.net.au](mailto:hlcowled@bigpond.net.au) or phoning 6272 3096 by the Thursday before the meeting so I can make the booking on Friday. Ours is a friendly welcoming group who enjoy our time together.

West Coast Support Group:

1st Tuesday in the month at JJ's Café, Queenstown starting at 11.30am. Please join us for a cuppa and something to eat.



LUPUS ASSOCIATION OF TASMANIA INC. INVITES **YOU** TO JOIN  
OUR  
**EAST COAST SUPPORT GROUP**

**Venue: Pasini's Café**

**Day: Every first Monday of the month**

**Dates: 6<sup>th</sup> April 2020 /4<sup>th</sup> May 2020.....**

**Time: Noon (12.00) for lunch**

**Area: Bicheno, Scamander, St. Helens etc.**

**Coordinator: Ms. Jasmine Rooney**

**Lupus Association of Tasmania Inc.**

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