



# LUPUS NEWS

## TASMANIA

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

# Sjögren's Syndrome



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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 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***

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**President's Message***Message from the President*

It has been an interesting three months as we have watched the unfolding story of the spread and impact of the coronavirus.

Across Australia the fitness level of dogs has risen dramatically and now the dog psychologists want to treat all the dogs for separation anxiety when their owners return to work. And here we were worrying about would we all be able fill our scripts for hydrochloroquine and are we at an increased risk and what that might mean.

Many members have mentioned they have enjoyed the quiet pace of life and the chance to catch up with no end of home projects-some put off for decades.

On the wider scene this pandemic has taught us a lot about infectious disease, and the massive death toll it can cause, especially among our older population and the more vulnerable.

The world's response and individual countries inaction and actions have been like a dramatic play with a mixture of comedy and tragedy. I have tried to focus on the positives and this is my list of what we have to be thankful for.

- We live in a country with a stable government who can work together when it is important and critical.( Hope this continues)
- We have a small population with an economy and social structure that can withstand an economic close down and not ignore people's needs
- We have enough medical beds and equipment to keep our health workers safe and provide the necessary care for those who were unfortunate to be exposed to the virus.
- We have a caring competent government and community who have worked well together in getting us this far despite the pain
- We can still laugh at the ridiculous, the conspiracy theories, and the never ending tweets from he who is a first rate idiot.
- We have had little things from family, friends, and strangers which has helped us stay connected and made us smile that someone cares.

Continue to stay safe and I look forward to sharing with you all in the further

## Regional Reports

### Southern Region

Due to COVID19 our luncheons remain 'cancelled till further notice' but fortunately the virus has not stopped the stork making a delivery. Most members will remember my son Heath and his wife Rachel, who came to lupus luncheons when their rosters allowed. On Wednesday 13<sup>th</sup> May the stork delivered to them a baby boy at 9.37pm. Both mother and babe well after a caesarian. My husband and I are grandparents for the first time. Unfortunately the COVID19 virus is preventing us visiting and having a cuddle but thankfully skype works. We are looking forward to interstate travel being restored.

Does anyone else have some good news stories to help make our newsletter have some interesting space fillers between the educational articles? If so contact the editor. Details at front of newsletter.

I'll let all southern members know when we can start meeting again. Keep well.

I am available if you want to chat on 62723096. It takes me some time to get to the phone, so please leave a message or name and phone number so I can get back to you if I miss the call. Usually I manage to answer calls just after the message starts. I live in a long house and the phone always seems to ring when I am either at the far end of the house or out in the garden. Hoping we will be able to meet again soon.

Heather Cowled

Southern Coordinator.

### North West

Nothing to report as Covid19 has had Fuschia Farm in lockdown. Hope all are well and have had a REST in isolation.

Leanne Collins

North West Co-Ordinator

### SUPPORT GROUPS

As we have been shut down for the past two and a half months, our groups have been in recess. We have endeavoured to keep in touch by phone and members have generally coped well. Some are keen to have a face to face with their doctors and manage their ongoing health issues. Many are relieved that there have been no medication shortages.

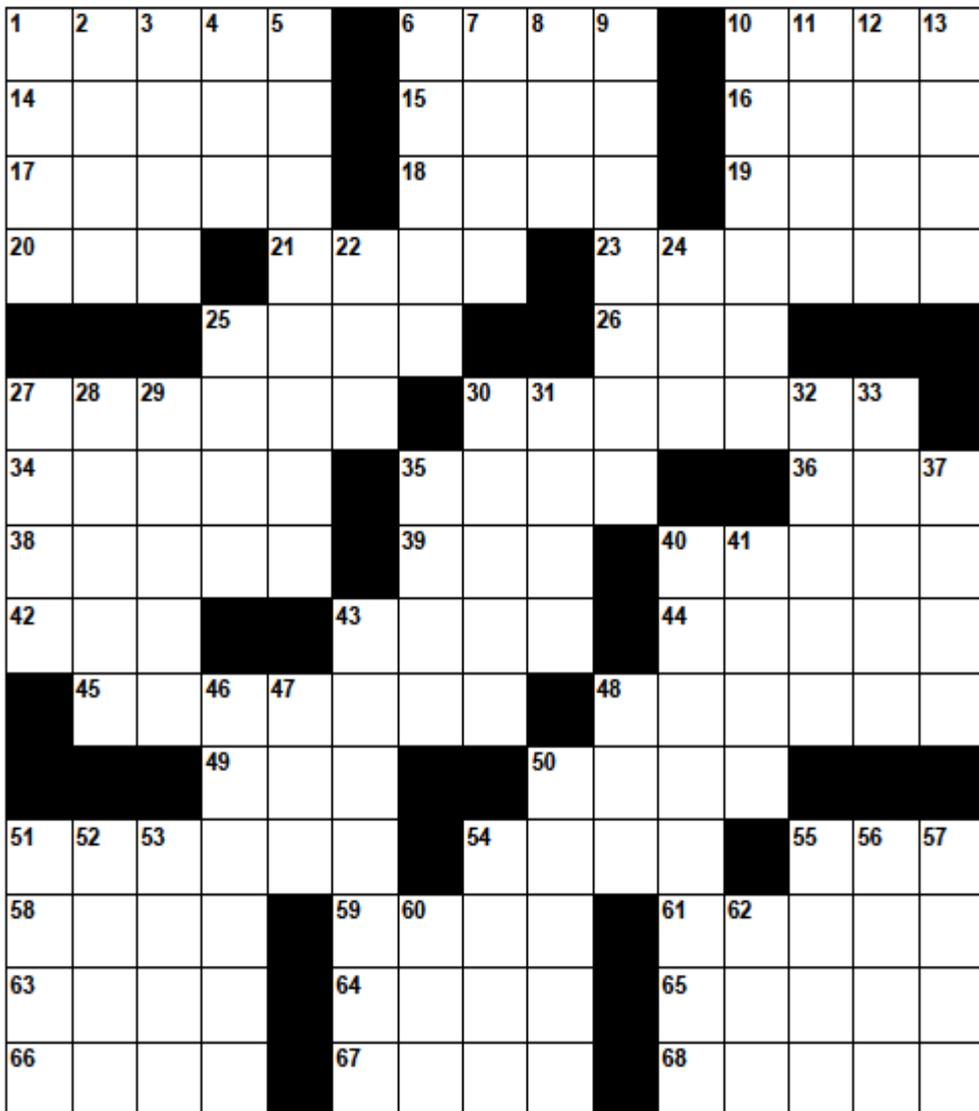
We are suggesting to groups to recommence in July if they feel their group is ready, had flu shots and the venue is suitable in this new climate. Each support group leader will contact members in July to let them know what is happening with their group.

### From the Editor's Desk.

There are few reports from our regions owing to isolation and COVID-19 . We hope that you are all keeping as well as possible and as winter approaches keeping warm. Don't forget there are rebates available on electricity accounts.

We do hope that meetings will be able to start again soon. In the meantime have a busy time in isolation.

Edna Brock



By Evelyn Johnson - www.qets.com

### ACROSS

- 1 Had a speed contest    6 **Baby** Sheep  
 10 Body of an organism    14 Before  
 15 Water (Spanish)    16 Oak  
 17 French monetary unit    18 Voiceless  
 19 Nurture    20 Toddler  
 21 Duelling sword    23 Frothy  
 25 Sign    26 Clock time  
 27 Sweet melon    30 Guacamole need  
 34 Flexible    35 Gush out  
 36 Ewe's mate    38 'love' (Italian)  
 39 United Parcel Service    40 Fire product  
 42 Morning moisture    43 Thaw  
 44 Shelter    45 Regardless of  
 48 Buddy    49 Scorching  
 50 Sliding toy    51 Word in U.S.S.R.  
 54 Move quickly    55 Metric weight unit  
 58 Tel \_\_ (Israel's capital)    60 Women's magazine  
 61 Fancy round mat    63 Wind  
 64 Element    65 Swiss mathematician  
 66 Like a wing    67 September (abbr.)  
 68 **San** .....

### DOWN

- 1 Log Boat    2 Big hairdo  
 3 Winter outerwear    4 Gray sea eagle  
 5 Twelfth month of the year    6 Encumbered  
 7 Accent mark    8 Calf (2 wds.)  
 10 Layer    11 Mined metals  
 12 Sandwich need    13 Visionary  
 22 Legume    24 Escudo (abbrev)  
 25 Hawaiian island    27 Dressed  
 28 Pointed at    29 Harriet Beacher \_\_  
 30 Orange's partner    31 Sleeveless shirt  
 32 Multitude    33 Similar to oak  
 35 Fat used making tallow    37 Heal  
 40 Grated  
 41 Hotel cleaner    43 Hand warmers  
 46 Move with cold    47 "Raven" author  
 48 Respiratory disease    50 Fragrance  
 51 Heroic tale    52 Ovale  
 53 Capital of Vanuatu    54 Swill  
 55 1.6 kilometers    56 Fly  
 57 Greek sandwich    60 Downwind  
 62 French "yes"

## **COVID 19 and advice for patients on Immune-suppressing medications**

### **IF YOU ARE WELL**

There is no evidence to suggest that WELL patients, without fever or signs of infection should change or stop any of their regular prescribed medications including:

- Usual DMARDs (methotrexate, hydroxychloroquine, leflunomide, mycophenolate, azathioprine, sulfasalazine)
- Biologics (bDMARDs) eg. etanercept, adalimumab etc or targeted DMARDs (tDMARDs) eg. tofacitinib, baricitinib
- Anti-inflammatories (ibuprofen, meloxicam, celecoxib etc)
- Steroids (prednisone or prednisolone)

*If you are on a biologic medication and someone close to you is proven to have COVID Infection, talk to your GP or rheumatologist about delaying your next dose.*

We would encourage our patients to get the annual Flu vaccination when available.

We would also recommend following general public health advice including:

- Frequent handwashing before eating and after being out in general community areas (schools, shops, after touching lifts, escalators, shopping trolleys etc) 20 seconds with soap and water (hand sanitiser if this is not available)
- Sneeze / cough into a disposable tissue or your elbow and then wash your hands
- Limit touching your face
- Sanitise your phone, computer and work surfaces regularly
- Avoid crowds and sick people (eg concerts, church services, sporting events, etc)

### **IF YOU GET SICK**

We recommend patients seek medical advice from either their usual general practitioner or hospital emergency department.

If you have fever or cough, we suggest you **CALL FIRST** and tell them you are on immunosuppressive medications.

*If you are an older adult with a chronic illness or you are taking medications that affect your immune system you may be at a higher risk of more serious COVID-19 disease. If you are at increased risk, it is especially important to take actions to reduce your risk of exposure. If you think you have been exposed or have developed symptoms, you should also contact your doctor early in the course of your illness, even if it is mild, and let them know if you are taking immune-suppressing drugs.*

### **MEDICATIONS**

Currently, there is no need to stockpile medications as Australian medications are sourced widely.

**This is GENERAL advice. If patients have specific questions about their situation, they should discuss this with their specialist.**

For the latest advice, information and resources, please refer to Department of Health.

(<https://www.health.gov.au/resources/collections/novel-coronavirus-2019-ncov-resources>)

National Coronavirus Health Information Line 1 800 020 080 – operates 24 hours, seven days a week. 17 March 2020 .

*Printed from Sjögren's Syndrome Newsletter May 2020*

### Shoes and Socks

A little boy about 10 years old was standing before a shoe store on the roadway, barefooted, peering through the window, and shivering with cold. A lady approached the boy and said, "My little fellow, why are you looking so earnestly in that window?" "I was asking [God](#) to give me a pair of shoes" was the boy's reply.

The lady took him by the hand and went into the store and asked the clerk to get half a dozen pairs of socks for the boy. She then asked if he could give her a basin of water and a towel. He quickly brought them to her. She took the little fellow to the back part of the store and, removing her gloves, knelt down, washed his little feet, and dried them with a towel.

By this time the clerk had returned with the socks. Placing a pair upon the boy's feet, she purchased him a pair of shoes. She tied up the remaining pairs of socks and gave them to him. She patted him on the head and said, "No doubt, my little fellow, you feel more comfortable now?"

As she turned to go, the astonished lad caught her by the hand, and looking up in her face, with tears his eyes, answered the question with these words: "Are you [God's Wife](#)?"

Author Unknown



## **Diet Tips for Sjogren's Syndrome Patients**

[sjogrensyndromenews.com/2020/03/22/diet-tips-when-you-have-sjogrens-syndrome/](https://sjogrensyndromenews.com/2020/03/22/diet-tips-when-you-have-sjogrens-syndrome/)

Sjogren's syndrome is an autoimmune disease characterized by dryness in the mouth and throat, eyes, skin, vagina, and other organs. This dryness may lead to irritation, soreness, and pain, and make you want to avoid food. This means you may have to make changes to your diet so that it is easier to eat and get proper nutrition. Avoid foods that dry your mouth. Caffeinated drinks and alcohol can dry your mouth, and you should avoid them. You should also avoid spices and acidic foods such as citrus, as these can irritate a dry, sore mouth. You should also avoid sugary foods that can contribute to rapid tooth decay, which is already increased by lower saliva production in Sjogren's syndrome.

Change the texture of your food to help with swallowing

You may have to modify the texture of your food to help you swallow it more easily. If possible, try to sip a drink while eating. You may use skimmed milk, broth, water, or melted margarine to soften your food.

Opt for an anti-inflammatory diet

Sjogren's syndrome and other autoimmune diseases are essentially triggered by inflammation reactions of the immune system. Opting for an anti-inflammatory diet may help combat inflammation and prevent symptom flares.

An anti-inflammatory diet includes the following:

- deep-colored fruits and vegetables that are rich in vitamins and minerals
- healthy fats such as omega-3 oils found in fatty fish, avocados, raw nuts, and extra virgin olive oil
- fiber-rich foods to promote healthy bowel movements moderate amounts of organic meat
- seasonings such as garlic and turmeric
- Avoid foods that can trigger inflammation

While following an anti-inflammatory diet, avoid the following kinds of inflammatory foods as much as possible:

- trans or hydrogenated fats that the body cannot use saturated fats
- refined oils rich in omega-6 oils
- refined carbohydrates red meat foods that cause allergies such as milk, eggs, wheat gluten, and peanuts artificial sweeteners and preservatives
- alcohol

Consult a dietitian for a proper diet plan

Diet requirements vary among individuals. For instance, recent research indicates that women with primary Sjogren's syndrome do not need to follow special dietary guidelines to maintain good nutrition and oral health.

Your doctor may prescribe you a corticosteroid such as prednisone to treat flare-ups.

One of the side effects of prednisone is increased appetite, which can lead to overeating.

### Diet continued:

Consult a dietitian, who will be able to chalk out a proper diet plan in accordance with your ongoing therapy.

### Avoid excess vitamin intake

Vitamin consumption that exceeds the recommended dietary intake can be counterproductive and lead to poor absorption or metabolism of other nutrients. Never take vitamins or supplements without first consulting your doctor.

Carry 'emergency food' while traveling

Eating away from home during travel can be problematic, so it is a good idea to carry some "emergency food." Foods such as oatmeal, soy milk, and instant soup have a long shelf life, and you can easily pack these for traveling. You can also carry fresh bananas, 2/4 cut vegetables, and tea bags.

Make a note of the list of foods that suit you best, and pack accordingly.

*Last updated: March 17, 2020*

*Sjogren's Syndrome News is strictly a news and information website about the disease. It does not provide medical advice, diagnosis, or treatment. This content is not intended to be a substitute for professional medical advice, diagnosis, or treatment. Always seek the advice of your physician or other qualified health provider with any questions you may have regarding a medical condition. Never disregard professional medical advice or delay in seeking it because of something you have read on this website.*

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**Date: 31st March 2014**

**Topic: “Dry Eyes, Dry Mouth”**

April is Sjögrens Syndrome Awareness Month. Sjögrens (show-grins) syndrome is an autoimmune disease which affects the moisture producing glands of the body it is typically characterized by dry eyes and mouth, however can also affect other parts of the body. Sjögrens is an autoimmune disease in which the body’s immune system mistakenly attacks its own moisture producing glands causing increased inflammation. The average age of onset is late 40s although Sjögrens occurs in all age groups in both women and men. Autoimmune illness is the 3rd major health issue behind cardiac illness and cancer. As 1 in 20 people living with autoimmunity, it seems no-one is “immune” (EMUne) to the condition.

Sjögrens causes inflammation and dryness which can affect the kidneys, Gastrointestinal tract, blood vessels, lung, liver, pancreas, and the central nervous system. Along with dryness, many patients experience debilitating fatigue and joint pain. Symptoms can plateau, worsen, or go into remission with patients experiencing an unpredictable pattern of illness. While some people experience mild symptoms, others suffer debilitating symptoms that greatly impair their quality of life.

Marline Squance, Executive Officer of the Autoimmune Resource & Research Centre, said that, “getting diagnosed with Sjögrens is often a battle, with a definitive diagnosis taking many years to be confirmed. Symptoms are often dismissed as being “just an annoyance” with people reporting dryness issues for many years before any changes are seen in blood and other tests. Symptoms may include a dry, gritty, or burning sensation in the eyes; difficulty talking, chewing, or swallowing; a sore or cracked tongue; dry or burning throat; a change in the sense of taste or smell; increased dental decay; joint pain; digestive problems; dry nose; dry skin; and fatigue. No two people have the exact same set of symptoms.

“There are many things that can help reduce the impact of Sjögrens including the use of artificial moisture substitutes for eyes and mouth as well as learning about how self-management techniques can become part of a new and improved lifestyle. Learning how to live well despite having an autoimmune illness such as Sjögrens is goal that can be achieved” Ms Squance said The Autoimmune Resource & Research Centre has produced a Sjögrens Awareness brochure as part of International Sjögrens Awareness Month. <http://www.autoimmune.org.au/SiteFiles/autoimmunecomau/sjogrens-brochure.pdf>

The Autoimmune Resource and Research Centre is a Not for Profit charity that is dedicated to providing education and support for individuals living with a variety of systemic autoimmune illnesses. For more information and to donate to help the centre continue it works please go to [www.autoimmune.org.au](http://www.autoimmune.org.au)

**For more information contact:**

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[www.autoimmune.org.au](http://www.autoimmune.org.au)

*With thanks to ARRC for permission to print*

## Two more Aisles

A man observed a woman in the grocery store with a three year old girl in her basket. As they passed the cookie section, the little girl asked for cookies and her mother told her no. The little girl immediately began to whine and fuss, and the mother said quietly, "Now Monica, we just have half of the aisles left to go through; don't be upset. It won't be long." Soon they came to the candy aisle, and the little girl began to shout for candy. And when told she couldn't have any, began to cry. The mother said, "There, there, Monica, don't cry-only two more aisles to go, and then we'll be checking out."

When they got to the check-out stand, the little girls immediately began to clamor for gum and burst into a terrible tantrum upon discovering there'd be no gum purchased. The mother patiently said, "Monica, we'll be through this check out stand in 5 minutes and then you can go home and have a nice nap."

The man followed them out to the parking lot and stopped the woman to compliment her. "I couldn't help noticing how patient you were with little Monica," he began. Whereupon the mother said, "I'm Monica . . . my little girl's name is Tammy." Author Unknown

*Have you ever been in the Supermarket when these littlies don't get what they want?*



