LUPUS NEWS

TASMANIA

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Committed to understanding and supporting people with Lupus, Sjögren’s, Scleroderma & Fibromyalgia or any autoimmune diseases.
Office Bearers
Lupus Association of Tasmania Inc.
Registered Charity  ABN 96 163 951 956
All Correspondence to:
PO Box 639
Launceston, 7250
Tasmania, Australia
Ph. 0459 397 942
Email: lupustas@lupustasmania.org.au
Website: www.lupustasmania.org.au

Patron: Hon. Michael Ferguson MHA
President: Dr. Lois Beckwith
Vice-President: Cheryl Dent
Secretary/Public Officer: Dianne Whitely
Treasurer: Murray Scales
Committee: Cheryl Dent, John Dent and Julie Scales
Librarian: Joan Keefe ph. 63449322
Northern Co-Ordinator: Lois Beckwith PO box 312 Deloraine 7304
E-mail loisbeckwith@bigpond.com Phone: 63695393

North-West Co-Ordinator: Leanne Stephens, 5/33 West Parade Deloraine, 7304
E-mail: Leanne.E. Stephens@alumni.uts.edu.au Phone: 0409713240
West Coast: Barbara Gruner.
Southern Co-Ordinator:
Heather Cowled
‘Phone 03 6272 3096
Email: lhcowled@bigpond.net.au
Editor: Edna Brock
Ph. 0419541989 Email: sbr87203@bigpond.net.au

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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.
From the editor’s desk

I sincerely hope that all our members have “weathered” the cold months reasonably well. It isn’t very nice to cope with the cold and I hope that you all have the rebate which is available in Tasmania. I also hope that the warmer spring weather is beginning to show in the gardens. The weather in Hervey Bay has been downright boring, everyday in the twenties although some of the nights have been cooler than normal. All up, very livable. The people of this area would give their eye teeth for some rain, it hasn’t rained for the last six months so they are looking at a rather catastrophic bush fire season. We can only pray for rain soon. Edna Brock Editor
**President’s Message**

Spring is coming and we are certainly looking forward to many of our return of many of our members who have spent time up north or had exotic holidays in all sorts of warm destinations. We are now busy planning Lupus awareness week. The theme is the Role of Nutrition in Autoimmune Disease. We are arranging a key note speaker for Tuesday 15th October, so please diary this day. It is a highly relevant subject for us all. We have our new library ready for loans to motivate you I have started reviewing some of these books. These will follow in the newsletter. Contact our Librarian Joan Keefe on 63449322 if you would like to borrow a book. We can post to the more distant members.

Regards
Lois Beckwith
President

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**Wise words**

Life is just a path  
If you follow your heart  
It will lead you  
In the right direction.

The love we give away  
Is the only love we keep.  
Elbert Hubbard

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**Regional reports**

During the winter we have continued to meet at the Kings Mead-ows Health Centre, and although small in number it has been nice to keep in contact with friends. We have had a good look at the new books and have share them around our groups. Now it’s your turn to take a look at the titles that are relevant to you. We look forward to having a big roll out in September so please mark on your calendar the fourth Thursday of the month at 10.30 am, and bring something to share. If you have not been for a while or are new to Lupus come along and catch up on the news

Best regards
Lois Beckwith
Northern Coordinator
Regional News

North-West Coast: We are still a small group, we are a friendly bunch and love to get together on the first Tuesday of every month at the Fuschia Farm, Lillico from 12-2.00 pm. The group will meet while we are away and we welcome anyone with autoimmune condition and all support family/friends. Robbie and I have gone for a 3 month holiday to Caloundra via Ballarat and back again.

Kind regards
Leanne Collins
North West Co-ordinator.

Have a nice break Leanne and Robbie. Ed

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West Coast: Unfortunately my group was cancelled due to the fact that the only member well enough to get out in the freezing weather was me! The West Coast has the coldest and wettest weather in Tasmania, and it can get really brutal; the weather is coming up from the Antarctic. Next month I am planning to change the venue to a café and get everyone revved up anew, so hopefully things will improve.

Cheers
Barbara Gruner
West Coast Co-ordinator

Hope all your members are back on deck and the weather is improving. When I worked at Rosebery in 1962 they told me it rained 367 days a year, I guess it feels like it. Apologies Barbara, I haven’t brought your phone number with me. Ed

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Southern Group: I hope you are avoiding all the winter viruses that seem to be going around and can find a warm sheltered spot to enjoy the early, nearly spring blossoms. My jonquils and daffodils are a beautiful splash of colour. Driving back from Kingston today the wattle, and other blossoms, seem to have suddenly appeared. I makes me hopeful that the warmer weather is on the way, but I have enjoyed getting some rain. The next Lupus Luncheon is November 18th 2019. I need to know if you are coming, please let me know by Thursday 14th November, during office hours, so a booking can be made on Friday. The Lupus Luncheon will be held at Mathers House, 108 Bathurst St. and is found between the Library and the Playbox Theatre i.e. between Elizabeth and Murray St. Opposite the Melville St. carpark. If you cross the road at the pedestrian lights in the middle of the block, from the carpark, you are facing Mathers House. The first hour and a half of parking in the car park is free. The provided information states: “The café is operated by volunteers and the menu changes daily (home style theme).” Reminder: No Eftpos so cash only.

Regards Heather Cowled  Southern Co-ordinator
Southern report continued
Despite the gale, snow down to 400 metres and heavy rain, everyone of our regulars came to our luncheon last Monday, August 19th.

Regards Heather Cowled
Southern Co-ordinator  Great job Heather. Pleased they all turned up, it must have been a feel good moment.

Puppies for Sale
A shop owner placed a sign above his door that said “Puppies For Sale”
Signs like this always have a way of attracting young children, and to no surprise, a boy saw the sign and approached the owner.
“How much are you going to sell the puppies for? “ He asked.
The store owner replied, “Any where between $30 and $50 .”
The little boy pulled some change from his pocket “I have $2.37,” he said. “Can I please look at them?”
The shop owner smiled and whistled. Out of the kennel came Lady, who ran down the aisle of his shop followed by five tiny balls of fur.
One puppy was lagging considerably behind. Immediately the little boy singled out the lagging, limping puppy and said, “What’s wrong with that little dog?”
The shop owner explained that the veterinarian had examined the little puppy and had discovered it didn’t have a hip socket. It would always limp. It would always be lame.
The little boy became excited. “That is the puppy I want to buy.”
The shop owner said “No, you don’t want to buy that little dog. If you want him, I’ll just give him to you.”
The little boy became quite upset. He looked straight into the store owners eyes pointing his finger, and said “I don’t want you to give him to me. That little dog is worth every bit as much as the other dogs and I’ll pay full price. In fact I’ll give you $2.37 now and 50cents each month until I have paid for him”.
The shop owner countered, “You don’t want to buy this little dog. He won’t be able to run and play with you like the other puppies.”
To the store owner’s surprise the little boy rolled up his trouser leg and reveals a badly twisted left leg. “Well I don’t run very fast myself therefore he’ll need someone who understands!”
Rheumatoid Arthritis
This article has been written for people affected by rheumatoid arthritis. It provides general information to help you understand how you may be affected and why early treatment is important. It also covers what you can do to manage rheumatoid arthritis and where you can go for further information.

What is rheumatoid arthritis?
Rheumatoid arthritis (RA) is an autoimmune disease that causes pain and swelling of the joints. The normal role of your body’s immune system is to fight off infections to keep you healthy. In an autoimmune disease, your system starts attacking your own healthy tissues. In RA, the autoimmune system targets the lining of the joints, causing inflammation and joint damage. RA usually affects the smaller joints, such as the joints in the hands and feet. However, larger joints such as hips and knees can also be affected.

What are the symptoms?
The symptoms of RA vary from person to person.
The most common symptoms are:
- Joint pain, swelling, and tenderness to touch
- Stiffness in the joints, especially in the morning
- Symmetrical (the same joints on both sides of the body are affected).

What causes it?
It is not known what causes RA. It is more common in people who smoke and/or have a family history of RA.

How is it diagnosed?
Your doctor will diagnose RA from your symptoms, a physical examination and various tests. These can include:
- Blood tests for inflammation
- Blood tests for antibodies (proteins, made by the body’s immune system). Testing for anti-cyclic citrullinated peptide (anti-CCP) and rheumatoid factor can help diagnose RA, although not all people with RA will test positive for these antibodies.
- X-rays to see if your joints are being damaged by the disease. X-ray changes are rare in the early stages of RA.

It can be difficult, and often takes time, to diagnose RA as the symptoms can be similar to other types of arthritis. If your doctor suspects you have RA you should be referred to a rheumatologist, a doctor who specialises in arthritis.

What will happen to me?
With early diagnosis and the right treatment, most people with RA can lead full and active lives. However, the course of RA varies and no two cases are exactly the same. Many people with RA experience ‘flares’, periods when joints become more inflamed and painful. These can happen with no obvious cause. ‘Flares’ are commonly followed by months or even years when there is little inflammation. RA can cause permanent damage and deformity, especially in the first few years of the disease. The good news is that early diagnosis and treatment is shown to limit this type of damage.
Rheumatoid Arthritis cont.
Is there a cure for RA?
Currently there is no cure for RA. However, treatment has improved dramatically over the past 20 years, with new medicines now extremely helpful for people in the early stages of RA. Be wary of any products or therapies that claim to cure RA.
What treatments are there for RA?
Your rheumatologist will tailor your treatment to your symptoms and the severity of your condition. There is no way of predicting exactly which treatment will work best for you. Your doctor may need to trial several different treatments before finding the one that is right for you and may include:

- Medicines, such as
  - non-steroidal anti-inflammatory drugs (NSAIDS)
  - corticosteroid medicines or injections
  - disease-modifying anti-rheumatic drugs (DMARDs)
  - biological DMARDs.

For more information see the Australian Rheumatology Associations Patient Medicine Information or the Medicines and arthritis information sheet.

- Exercise to keep the joints flexible and muscles strong. See the Exercise and RA and Working with your health care team information sheets. (Last newsletter had these in it. Ed)

What can I do?
See a rheumatologist as early as possible. A rheumatologist can diagnose RA and make sure you get the right treatment. If you have RA and have not seen a rheumatologist, ask your doctor about a referral. See the Working with your healthcare team information sheet.

Learn about RA and play an active role in your treatment. Not all information you read or hear about is trustworthy so always talk to your doctor or healthcare team about treatments you are thinking about trying. Reliable sources of further information are also listed below. Self management courses aim to help you develop skills to be actively involved in your healthcare. Contact your local Arthritis Office for details of these courses.

Learn ways to manage pain. See the Dealing with pain information sheet.

Live a healthy life. Stay physically active, eat a healthy diet, stop smoking and reduce stress to help your overall health and wellbeing. See the Exercise and RA and Healthy eating information sheets.

Learn how to protect your joints and cope with tiredness. See the Saving energy information sheet.

Acknowledge your feelings and seek support. As there is currently no cure for RA and it can affect many parts of your life, it is natural to feel scared, frustrated, sad and sometimes angry. Be aware of these feelings and get help if they start affecting your daily life. See the Arthritis and emotions information sheet.

Learn about RA and your treatment options.
See a rheumatologist as early as possible.

Information sheet reprinted from article taken from the internet: Australian Rheumatology Association. Www.rheumatology.org.au
Rheumatoid Arthritis

Overview
Rheumatoid arthritis is a chronic inflammatory disorder that can affect more than just your joints. In some people, the condition can damage a wide variety of body systems, including the skin, eyes, lungs, heart and blood vessels.
An auto-immune disorder, rheumatoid arthritis occurs when your immune system mistakenly attacks your own body’s tissues. Unlike the wear-and-tear damage of osteoarthritis, rheumatoid arthritis affects the lining of your joints, causing a painful swelling that can eventually result in bone erosion and joint deformity.
The inflammation associated with rheumatoid arthritis is what can damage other parts of the body as well. While new types of medications have improved treatment options dramatically, severe rheumatoid arthritis can still cause physical disabilities.

Symptoms
Signs and symptoms of rheumatoid arthritis may include;
• Tender, warm, swollen joints
• Joint stiffness that is usually worse in the mornings and after inactivity
• Fatigue, fever and loss of appetite
Early rheumatoid Arthritis tends to affect the smaller joints first—particularly the joints that attach your fingers to your hands and your toes to your feet.
As the disease progresses, symptoms often spread to the wrists, knees, ankles, elbows, hips and shoulders. In some cases, symptoms occur in the same joints on both sides of your body.
About 40 percent of the people who have rheumatoid arthritis also experience signs and symptoms that don’t involve the joints. Rheumatoid arthritis can affect many nonjoint structures, including:
• Skin
• Eyes
• Lungs
• Heart
• Kidneys
• Salivary glands
• Nerve tissue
• Bone marrow
• Blood vessels
Rheumatoid arthritis signs and symptoms may vary in severity and may even come and go. Periods of increased disease activity, called flares, alternate with periods of relative remission — when the swelling and pain fade or disappear. Over time, rheumatoid arthritis can cause joints to deform and shift out of place.

When to see a doctor
Make an appointment with your doctor if you have persistent discomfort and swelling in your joints.
Rheumatoid arthritis cont.

Causes
Rheumatoid arthritis occurs when the immune system attacks the synovi-um—the lining of the membranes that surround your joints. The resulting inflammation thickens the synovium, which can eventually destroy the cartilage and bone within the joint. The tendons and ligaments that hold the joint together weaken and stretch. Gradually, the joint loses shape and alignment. Doctors don’t know what starts this process, although a genetic component appears likely. While genes don’t actually cause Rheumatoid arthritis, they can make you more susceptible to environmental factors—such as infection with certain viruses and bacteria—that may trigger the disease.

Risk factors
Factors that may increase your risk of rheumatoid arthritis include:

- **Your sex.** Women are more likely than men to develop rheumatoid arthritis.
- **Age.** Rheumatoid arthritis can occur at any age, but is most commonly begins in middle age.
- **Family history.** If a member of your family has rheumatoid arthritis, you may have an increased risk of the disease.
- **Smoking.** Cigarette smoking increases your risk of developing rheumatoid arthritis, particularly if you have a genetic predisposition for developing the disease. Smoking also appears to be associated with greater disease severity.
- **Environmental exposures.** Although poorly understood, some exposures such as asbestos or silica may increase the risk of developing rheumatoid arthritis. Emergency workers exposed to dust from the collapse of the World Trade Centre are at higher risk of autoimmune diseases such as rheumatoid arthritis.
- **Obesity.** People—especially women age 55 and younger—who are overweight or obese appear to be at a somewhat higher risk of developing rheumatoid arthritis.

Complications
Rheumatoid arthritis increases your risk of developing:

- **Osteoporosis.** Rheumatoid arthritis itself, along with some medications used for treating rheumatoid arthritis, can increase your risk of osteoporosis—a condition that weakens your bones and makes them prone to fracture.
- **Rheumatoid nodules.** These firm bumps of tissue most commonly form around pressure points, such as the elbows. However, these nodules can form anywhere in the body, including the lungs.
- **Dry eyes and mouth.** People who have rheumatoid arthritis are much more likely to experience Sjogren’s syndrome, a disorder that decreases the amount of moisture in your eyes and mouth.
- **Infections.** The disease itself and many of the medications used to combat rheumatoid arthritis can impair the immune system, leading to increased infections.
- **Abnormal body composition.** The proportion of fat to lean mass is often higher in people who have rheumatoid arthritis, even in


**Rheumatoid Arthritis Cont.**
- people who have a normal body mass index (BMI).
- **Carpal tunnel syndrome.** If rheumatoid arthritis affects your wrists, the inflammation can compress the nerve that serves most of your hand and fingers.
- **Heart problems.** Rheumatoid arthritis can increase your risk of hardened and blocked arteries, as well as inflammation of the sac that encloses the heart.
- **Lung disease.** People with rheumatoid arthritis have an increased risk of inflammation and scarring of the lung tissues, which can lead to progressive shortness of breath.
- **Lymphoma.** Rheumatoid arthritis increases the risk of lymphoma, a group of blood cancers that develop in the lymph system.

*This article was reprinted from the Rheumatoid Arthritis web site. It was issued by the Mayo Clinic staff. Arizona, USA Mayo Foundation for Medical Education and Research (MFMER). I have been unable to obtain permission to reprint as there is no address apart from the above.*

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**Book Review**

Latest book in our library for loan

**Living Well With Autoimmune Disease** by Mary J Shomon, Harper Collins

People struggling to get diagnosis with or understand their autoimmune disease will find Mary’s book an extremely useful, essential resource to help them find practitioners and treatment — conventional and alternative — that will help them truly live. It is a comprehensive read covering all the immune diseases from Hashimoto’s Thyroiditis, Rheumatoid Arthritis to Lupus.

What I found particularly useful was a description of the newer forms of treatment for Lupus which depends on the extent and degree of the symptoms. The latest clinical trials and expected breakthroughs were highlighted. For example LJP 394 manufactured by la Jolla Pharmaceuticals, target antibodies in double-stranded DNA that are linked to Kidney failure, the primary cause of death in Lupus. The drug appears to prevent or delay renal failure and reduce the need for treatment with high-dose corticosteroids and/or chemotherapy.

DHEA (Dehydroepiandrosterone) Astera, has had extensive trials conducted over long periods and has the support of USA lupus Foundation. It is an androgen which is much weaker than testosterone and is less likely to have unpleasant masculinizing side effects. Results show patients reported feeling more energetic and less symptomatic, and less likely to need an immune-suppressant drug such as prednisone.
Another section of the book I found useful was on food allergies and sensitivities linked to all autoimmune diseases. This included gluten/grain, shell fish, fruits, nuts, corn, milk products, soy products; along with the over consumption of processes foods, insufficient fish oil in the diet, low protein diets, over consumption of sugar and simple carbohydrates and over consumption of animal fats.

There is a helpful section on recommended dietary changes to help immune systems and a how to, assess which foods may trigger reactions and why experts believe it is important to address possible food allergies.

**Review on the use of Herbs in treatment**

With a healthy degree of scepticism I started to read two new books we have added to our library. Both have been regularly quoted in other medical books as excellent sources to learn more about herbal medicine and its role in complimenting modern medicine.

The first one, *Herbal Defense* by Robyn Landis and Karta Purkh Singh Khalsa, is a very comprehensive, read that as big. I didn’t realize that the number of herbs with healing properties was so large. In 1985 the World Health Organization estimated that 80% of the world’s population relied on herbs for it’s primary health care needs. This widespread use of herbal medicines is not restricted to developing countries; for example 70% of all medical doctors in Germany regularly prescribe herbal medicines. The authors believe that new models of understanding are emerging, along with increasing evidence that the healing process is enhanced with the aid of natural non-toxic herbal therapies. Herbs have been used medically around the globe for centuries across a broad range of situations. Today research is continually confirming what these cultures have known and practiced all along: Herbs and foods can help you enhance your health, strength, youthfulness, and immunity for as long as you live. But what about treatment of chronic, non-life threatening diseases and the prevention of disease? To have to find out, you are going to have to read the book.

The content covers herbs for health and healing throughout life and includes herbs for allergies, arthritis, yeast infections, diabetes, heart, headaches, and digestion. The autoimmune diseases are included and each recommended herb is fully described with dosages, and what evidence based research exists to support the effectiveness of the herb. The chapter on Prevention Immune-Boosting Basics gives a lot of advice on how to assist the immune system, including diet, exercise, and life style. Another chapter in the book deals with treating infections and boosting the immune system to cope better with challenges.

I found it interesting to read and have a small list of herbs I am prepared to use and assess. It is a little like some drugs; apparently you have to be on the herb for a few months before the full effects can be noticed. So maybe in 4 months I will let you know how my trial works.
Book Reviews Continued:
The second book is The One Earth Herbal Sourcebook; Everything you need to know about Chinese, Western, and Ayurvedic herbal treatment by Alan Tillotson, Nai-shing Hu Tillotson and Robert Abel. This book is divided into three sections, A Guide to herbal Medicine, Getting to Know Your Herbs and Herbs To Treat the Whole Body. I found this book covered similar topics but was not as interesting to read and included a lot of obscure herbs from out of the way places and did not have relevance to someone new to the field. The book felt more like a text book and if you are very serious about learning everything about herbs it would be a good resource.

The One Earth Herbal Sourcebook; Everything you know about Chinese, Western, and Ayurvedic herbal treatment written by Alan Tillotson, Nai-shing Hu Tillotson and Robert Abel.
These books are all available from our library. If you would like to borrow them please phone our Librarian Joan on 63449322 and she will be able to help you.

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More Wise Words
To enjoy good health,
To bring true happiness
To your family,
To bring peace to all
You must first discipline
And control your own mind.

If you can control your mind
You can find the way to enlightenment,
And all wisdom and virtue
Will naturally come to you.

Buddha
Northern Group.
Every 4th Thursday of the month at Kings Meadows Health Centre, Joan Marshal Wing at 10.30 am. Bring something to share. Usually finish around 12 noon.

North west
1st Tuesday of the Month at the Fuschia Farm, Lillico, Devonport side of Ulverstone. 12 noon, Pay for self.

West Coast
Contact Barbara Gruner for venue and time.

Southern
November 18th at Mathers House, Please phone Heather prior to date for her to arrange bookings.
February meeting: February 17th, 2020

Lupus Awareness Week October 2019.
Launch October 15th, 1.30 Joan Marshal Wing, Kings Meadows Health Centre. Theme: Role of Nutrition in Auto Immune Disease. Speaker to be announced. Please mark this date in your diary.