



LUPUS NEWS TASMANIA

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

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Sjogren's Syndrome

Article written by Fred Fernandez , Member of the Board of Directors of Sjögrens Syndrome Foundation, USA

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 newsletter. The information is intended to
 keep you informed and we recommend that
 you discuss any information mentioned
 with your Doctor

Proudly Supported by Launceston Pathology

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

President's Report

Our recent AGM went off well with nothing notable to come from it. One area which was raised, which I totally agree with, is that we should get more aggressive with our Lupus awareness. Car stickers with our phone number and website shown is one thing that can be done, information sheets to be posted at chemists and GP reception areas, try to get more media coverage, which is usually in the lap of the gods, and any other area that may be useful. If you have an idea let us know.

Our current Office Bearers and committee Members are posted on page 2 of the newsletter. Our previous Vice-President has stood down and that position is now held by John Dent who along with his wife Cheryl have been long time supporters of the Association. Thanks to Murray Scales for his many years of service to the Association, he has held most positions over the years and was and still is a tireless worker for us.

Congratulations to our Patron Michael Ferguson on his election and being handed the Health portfolio and also to our past Patron Michelle O'Byrne for her election to deputy Leadership and opposition spokesperson on Health. Both have been great friends of the Association over many years.

Winter is sneaking up on us, so I do hope you have had your flu' shots and are braced for the upcoming cooler weather.

Vic Hartas
President

Editor's Blurp

The weather has certainly begun to change and I know now why I usually hibernate to Queensland at this time of year. We are a small group with a big heart and although our numbers are dwindling, we are still gaining some new members. Welcome to those who have recently joined. It is great catching up with you at our Morning Teas.

Remember that Vitamin D is a very necessary vitamin and that you need to get as much sunlight as possible over these winter's months. Find a warm spot to take your reading or knitting and soak up the wintry sun.

The leaves of the deciduous trees have really put on a show this year. The colours are vivid and stand out against the green of the native trees.

I hope that you all keep well over the winter and rug up well against the cold winds.

Edna Brock, Editor

Regional Reports

Northern Region

Another year has flown by and it has been very special to meet up with members we have not seen before and some of the new members we have gained; I hope they have enjoyed the gatherings as much as I have.

We have had some of the several members in hospital in the past months and hope they are doing well now. Good health to all our members and look after yourselves.

Joining with the Menzies Research Institute (MRI) has been very rewarding and soon we will hear of their findings from the research we funded. The seminar MRI held in Hobart was a very informative night with many discussions held and pamphlets handed out to attendees.

Our raffle was successful even though many books were returned unsold and some not returned at all. The raffle is our only fund raiser for the year and is what keeps our Association going. It was pleasing to have all prizes donated as this means total profit (after ticket printing). Donations for this year would be greatly appreciated whether big or small.

Once again Edna and Seton Brock's hospitality was appreciated by all for our Christmas dinner with much good food, drink and friendship.

Thank you to all who have helped me over the year your assistance is very valuable and much thought of.

Best wishes to the new office bearers (if any) and thankyou to any standing down for a job well done.

Colleen Mc Cormack

Northern Co-ordinator

Southern Report

A meeting of the Southern Tasmanian members was full of interesting discussions about symptoms and treatments, news of travels and future plans. We were delighted to have the chef and her baby join us for lunch. Michelle has been caring for our group at the café from her beginnings as a waitress through to her graduation as a chef. We have delighted in seeing wedding and baby photos over the years so we were delighted that she could join us and bring her baby Toby to meet us. It brings home how long we have been meeting in the one place.

We also had a new prospective member join us and were able to answer a lot of questions for her. About a dozen of us continue to meet on the second Wednesday of every even number month.

Where: Midcity Café Elizabeth Street Hobart.

Time: 12 noon

When: June 11th is our next meeting.

Please let me know if you are coming as I need to book seats on the Monday before the luncheon.

Heather Cowled

Southern Co-ordinator.

North West Report

Our last couple of lunches were reasonable attended but would like more sufferers to come along and share a meal with good friends. Our next lunches are at:

Seabrook Hotel, Somerset, on Sunday May 25th at 12 noon

Gloria's Restaurant, Ulverstone, June 29th at 12 noon

All meals are pay for self

Having a quiet period regarding phone enquiries, just a few which were dealt with, and relevant information passed on. We did, however, have a few inquiries from our friends at ARRC, Autoimmune resource and Research Centre, asking for support group information in the north and south for sufferers who have moved to Tasmania. They are very supportive and have a great website.

Time to start rugging up as the cool weather is closing in. Hope you all have had your flu' shots and take all precautions against the dreaded flu', we do not need any extra suffering.

See you at our lunches.

Denise Hartas

Co-ordinator

From The Treasurer

Hello Members! I don't have a lot to report for this newsletter. I will have accounts paid and bank balances etc. for our meeting. However, I would like to share something with my friends, who are members. It is a private matter but... here goes... When our world as you know it is turned upside down.....what do you do? As a counsellor I should know... but when it is your private world.... It hurts... feels awful... makes you sick ...BUT.. You pick yourself up and do the very best you can....never lose your faith...never give up... just do the best you can and remember... God loves us all.. From Bev. PS A special thankyou to Colleen for being there for me...even when she was in pain...worried about her health...THATS WHAT FRIENDS ARE FOR.. Thank you

Bev Wallace Treasurer

Thanks Bev for sharing this with us, there are times we all need someone to be there for us. Ed.

Media Release

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

For more information contact:

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 Thank you to ARRC for permission to print this article



Some Inspirational Words

Be positive.
 Not just a blood group.
 A whole way of life.
 No matter what, your path is yours.
 Devote every moment of your life to improving your dreams.
 Love your world.
 Cherish the good you do.
 Let go of the hatred.
 Dream of love

She has Sjögren's- Positive Actions and Attitudes that can be Supportive to You Both

by Fred Fernandez, Member SSF Board of Directors

For everyone who is the spouse of a Sjögren's syndrome patient, you completely understand that you both have an important role in managing the disease. Few things impact the life and activities of a marriage partnership like the unplanned complications of one of you being diagnosed with an incurable autoimmune disease. Just as with so many things in life, actions and attitudes are critical to outcomes and being in control. With Sjögren's, 90% of the time it is she who has been diagnosed, but make no mistake about it, you both are now faced with learning to deal with the manifestations and what you can do together to keep your life and activities within the acceptable range of your goals as a couple. Each Sjögren's patient is unique in how he or she may be impacted; however, there are many proven actions which have been shown to be immensely helpful in managing life towards normalcy, what ever that is! When you find out, please be sure to let us all know!

The single most important step a spouse of a Sjögren's patient can take is addressing it together, focusing on the positive proactive steps that will make a difference in quality of life for her and you both! But just what does that mean, you ask? It is important that couples decide the answer to this question together and for them selves individually, as the best answers will be as diverse as the individuals involved and the varied ways relationships are constructed.

Since my wife received the diagnosis over 25 years ago, we have engaged in numerous opportunities to learn about Sjögren's and what we can do to manage it. We sought out the best information we could find from many sources and quickly discovered the Sjögren's Syndrome Foundation to be the most helpful resource out there. As a result, we attended many of the national conferences, made use of the Foundation resources, and have become financial contributors in support of the mission to create awareness and fund research to find a cure. This is a selfish activity we call "trying to help ourselves." We also work on behalf of the Foundation by volunteering our energy and resources to raise research funds and co-chair the annual Atlanta *Sip for Sjögren's* fine water tasting event. As I enter my second term as an active member of the SS Foundation board of directors, I have sought to be an integral part of the organization's efforts to serve the patient community, to educate others, and to create greater awareness about this little-known autoimmune disease.

The knowledge we gained includes the importance of proper diet and avoiding foods which contribute to dehydration. We are very specific when ordering food in restaurants and only frequent those which are welcoming to our concern for customizing her food order. We prepare food more often at home where we are in complete control of the content and preparation. We have learned to recognize there are times when our best-made plans might be interrupted by fatigue which can weigh down many Sjögren's patients. Since failing to heed the signs of fatigue only leads to greater exhaustion and weakening of her immune system, we are quick to respond with a change of plans and some needed down time rest. I look to do small things

She Has Sjögren's... Continued

To help her with this and to insure we do not add even more emotional stress than she might already feel about not being up to doing more. Another area of importance is to actively participate in addressing your knowledge of Sjögren's by joining her at the doctor's office for visits or attending educational programs like the Sjögren's national or regional conferences or local support group events. Learning about the pathology and what is going on in her body as well as about the various treatments and medications will greatly increase your ability to be constructively helpful and will insure you understand what is going on with her overall health and how you can be supportive. Her best tool, and we recommend everyone do this, is to update her written account of how she is doing between doctor visits and provide this information to each of her doctors along with any questions she has. She always takes notes of each visit and has noticed this helps her to get more thorough responses from the doctors and helps them understand she is taking responsibility and control of her treatment. So what does addressing it together mean to you? Perhaps like us, it really is no different than what you would do for any other important issue in your life as a couple. Being a central part of the learning, participating actively, finding ways in which you each can help create the best possible outcome, making adjustments where needed and planning a life routine which allows you to maximize your success and enjoyment while maintaining the best possible control over her health. Or it might mean taking on a more active role of finding new solutions through supporting research by doing critical fundraising and volunteering your most important resource...Time. Your positive actions and attitudes are two areas where as a couple, you have complete control. How well you use this power will help lead you to the best possible outcome. We wish you a successful path in your individual journeys as couples learning to take as much constructive control of Sjögren's as possible.

This article was first printed in the Sjögren's Syndrome Foundation's newsletter, The Moisture Seekers, Vol. 29 Issue 1 January 2011. Please visit www.sjogrens.org to learn more

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Some Inspirational Words

When you do nothing you feel overwhelmed and powerless.
But when you get involved you feel the sense of hope and accomplishment that comes from knowing you are working to make things better.

Taken from a small book "Inspiration". Published by Affirmations Australia Pty. Ltd Designed and edited by Suzanne and Barbara Maher.

Bring Back Any Memories?

Someone asked the other day, 'What was your favourite 'fast food' when you were growing up?'

We didn't have fast food when I was growing up,' I informed him.

'All food was slow.'

C'mon, seriously.. Where did you eat?'

It was a place called home,' I explained.!

'Mum cooked every day and when Dad got home from work, we sat down together at the dining room table, and if I didn't like what she put on my plate, I was allowed to sit there until I did like it.'

By this time, the lad was laughing so hard I was afraid he was going to suffer serious internal damage, so I didn't tell him the part about how I had to have permission to leave the table.

But here are some other things I would have told him about my childhood if I'd figured his system could have handled it:

Some parents NEVER owned their own house, wore jeans, set foot on a golf course, travelled out of the country or had a credit card.

My parents never drove me to school...I had a bicycle that weighed probably 50 pounds, and had only one speed (slow).

We didn't have a television in our house until I was 10. It was, of course, black and white, and the station went off the air at 10PM, after playing the national anthem and epilogue; it came back on the air at about 6AM. And there was usually a locally produced news and farm show on, featuring local people...

Pizzas were not delivered to our home...But milk was

All newspapers were delivered by boys and all boys delivered newspapers — My brother delivered a newspaper, seven days a week. He had to get up at 6am every morning.

Film stars kissed with their mouths shut. At least, they did in the films. There were no movie ratings because all movies were produced for everyone to enjoy viewing, without profanity or violence or almost anything offensive.

If you grew up in a generation before there was fast food, you may want to share some of these memories with your children or grandchildren. Just don't blame me if they do themselves an injury laughing.

Growing up isn't what it used to be, is it?

An article which arrived in my e-mail and I thought I'd share it. How many times do we say ..."When I was boy/girl....."



As Mother's Day has just passed I thought this article was very appropriate.

Why God Made Mums

The answers were given by 2nd grade school children to the following questions !!!!

Why did God make mothers?

1. She's the only one who knows where the sticky tape is.
2. Mostly to clean the house.
3. To help us out of there when we were getting born.

How did God make mothers?

1. He used dirt, just like for the rest of us.
2. Magic plus super powers and a lot of stirring.
3. God made my Mum just the same like he made me. He just used bigger parts.

What ingredients are mothers made of ?

1. God makes mothers out of the clouds and angel hair and everything nice in the world and one dab of mean.
2. They had to get their start from men's bones. Then they mostly use string, I think.

Why did God give you your mother and not some other mum?

1. We're related
2. God knew she likes me a lot more than other people's mums like me.

What kind of little girl was your mum?

1. My mum has always been my mum and none of that other stuff.
2. I don't know because I wasn't there, but my guess would be pretty bossy.
3. They say she used to be nice.

What did mum need to know about dad before she met him?

1. His last name.
2. She had to know his background. Like is he a crook? Does he get drunk on beer?
3. Does he make at least \$800 a year? Did he say NO to drugs and YES to chores?

Why did your mum marry your dad?

1. My dad makes the best spaghetti in the world. And mum eats a lot.
2. She got too old to do anything else with him
3. My grandma says that Mum didn't have her thinking cap on.

Who's the boss at your house?

1. Mum doesn't want to be boss, but she has to because dad's such a goof ball.
2. Mum. You can tell by room inspection. She sees stuff under the bed.
3. I guess mum is, but only because she has a lot more to do than dad.

What's the difference between mums and dads?

1. Mums work at work and work at home and dads just go to work at work.
2. Mums know how to talk to teachers with out scaring them.
3. Dads are taller and stronger, but mums have all the power 'cause that's who you got to ask if you want to sleep over at your friend's.
4. Mums have magic, they make you feel better without medicine.

Mothers: Continued

What does your mum do in her spare time?

1. Mothers don't do spare time
2. To hear her tell it, she pays bills all day long.

What would it take to make your mum perfect?

1. On the inside she's already perfect. Outside I think some kind of plastic surgery.
2. Diet. You know, her hair. I'd diet, maybe blue.

If you could change one thing about your Mum, what would it be?

1. She has this weird thing about me keeping my room clean. I'd get rid of that.
2. I'd make my mum smarter. Then she would know it was my sister who did it and not me.
3. I would like for her to get rid of those eyes on the back of her head.

This article made me laugh until I nearly split my sides. As a mother and having been a teacher of this age group some of their ideas are hilarious. Sometimes I'd shake my head and think, "Where did he/she get that idea"? So be careful what is discussed in their hearing.



Adopting an attitude

The teacher had the children draw pictures of their families. One child drew one boy with a different hair colour than the rest. A little girl suggested he was adopted. "I know all about adoption," she said. "I was adopted."

"What does it mean to be adopted?" Asked another child.

"It means," said the little girl, "that you grew in you mummy's heart instead of her tummy."

A lovely way to view adoption



For your Diary

Morning teas in the North
Every 4th Thursday of the month, 10.30 am.



Luncheons in the North West as in the Co-ordinator's Report on page 5

Southern Luncheons at Midcity Café Elizabeth St. Hobart
As in Co-ordinator's Report on page 4. Please ring 6272 3096 to make a booking.

Next General Meeting:

Sunday, June 15th At 11.00 am Joan Marshall Wing Kings meadows Health Centre. Please bring a plate to share for lunch.

