

# LUPUS NEWS TASMANIA

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

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**Spring is here**



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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

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

## President's Report

Boy, some sort of weather we have had up here in the north west. I do hope members from this area came through the strong winds unscathed, which has now been replaced with icy conditions.

Thank you to all those members for their kind thoughts and cards I received after my recent operation, yes another one. I was looked after very well in RHH but after 3 days they had had enough of me and tossed me out, Denise was a bit upset as she was short changed an extra 4 days of peace and quiet as I was booked in for 7 days. I was booked in for hernia repairs 2 weeks later my bowel busted out again, but was put off due to lack of beds. No doubt you have all experienced this or know someone that it has happened to, but I look at it this way, the person who took my bed is in need of it much more than me, I can wait. I was hoping to recoup from both operations together, but that will not be the case now.

We are now coming up to our busy period with Lupus Awareness Week in October. We have some special guest speakers at the launch in Launceston and Luciana Torrents, a pharmacist, will be our guest speaker at the close of Lupus Awareness Week at Forth. Time and dates will be listed in our upcoming events page of this newsletter. You will also receive raffle books for our annual raffle which is our only fund raising revenue to keep the Association going and raising funds for research. I thank all those members who donated prizes for this year's raffle and it is a great bunch of prizes to be won. Don't forget to return all raffle books please, sold or unsold.

Wishing you all the very best.  
Vic Hartas  
President

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## Words of Wisdom

Encourage others to reach their full potential—sometime all it takes is a few inspired words.

Never leave for tomorrow a loving comment that could be made today

When making major choices, be guided by what is most precious to you, not by others' expectations of you



## Regional Reports

Southern News.

Southern members have been watching the weather and hoping all our fellow sufferers are coping well with the stormy, wintry weather. Definitely winter but the daffodils are starting to flower in the south so we take that as a sign that Spring is on the way. In the meantime we are enjoying our coats, gloves and beanies as we watch Mount Wellington sparkle with the sun on the snow.

Our luncheon group wish Vic a speedy recovery after his recent surgery. Our August 13th luncheon will be hosted by my husband Lance because I will be in South Australia providing parent care.

I should be home for the October 8th luncheon and look forward to catching up on all the news then. I hope to see you at the Esus Café in Elizabeth Street, Hobart at midday. Please remember to give me a call [6272 3096] or email [hlcowled@bigpond.net.au] to let me know you are coming.

Regards

Heather Cowled

Southern Co-ordinator

## Northern Report

It was encouraging to have such a good roll up at the last morning tea. I hope Julie and Emily enjoyed their time with us and found it worthwhile. Hopefully they will come back and again share our friendship and knowledge. For some time we have been thinking our 100's of brochures should be updated and thanks to Drs Lois and Peter Beckwith this has been done with very few changes having to be made. This is no small measure because of the superb work done in the past by a previous secretary Marilyn Rosevear. Lois and Peter were pleased and surprised at the number of brochures we have. As a result of their efforts they are now planning to produce a booklet regarding Lupus which will be done in conjunction with your Association. This will probably be given to the newly diagnosed and Doctors. All of this is very exciting and we thank them very sincerely for their enthusiasm, knowledge and hard work. Our current research association with Menzies Research Institute (MRI) is coming to an end and the results can be obtained by any interested member from the secretary. There is ongoing discussion with MRI as to the possibility of funding further research and maintaining our association with them. Lupus Awareness Week (LAW) and the launch is on Tuesday, 21st October at 2.00 pm is rapidly coming up. We have two excellent speakers Dr. R Raj, Consultant Nephrologist from the LGH and Ms L Banfield, Principal of Physio fit. Dr. Raj will be speaking on Lupus and the kidneys and Ms Banfield on the benefits of Physiotherapy for Lupus and other Autoimmune sufferers. Please put the date in your diary and try to attend. We have two beautiful quilts and numerous prizes for our raffle so please make every effort to sell your tickets when they arrive. This is our only fundraiser for the year. Do not forget the next General meeting at the Launceston Community Health Centre (Joan Marshall Wing, at 11.00 am on the 21st September, 2014.

*Continued on page 5*

## Northern Report Continued

A plate of finger food for lunch would be much appreciated. Looking forward to seeing you all soon.

Colleen McCormack,  
Northern Co-ordinator.

## North West Report

Our recent meetings were well attended with our regulars and it was good to see most in reasonable health and good cheer.

Members have asked for another lunch in September at the Gateway Hotel, Devonport at 12 noon. Pay for self.

Our Lupus Awareness Week closes at the Forth Hotel on 26th October at noon, please come a little early so as to order lunch as it is a busy lunch crowd and if we can get orders in before the crowd, all the better. We have a guest speaker in Lucianna Torrents, Pharmacist, who is very good in giving presentations on auto-immune diseases and has a special interest in Lupus. She wrote a wonderful article on Lupus and vitamin D which was published in our newsletter some time ago. On Monday 17th November we go to the Fuschia Farm, Lillico, at 12 noon where member and Lupus sufferer Narelle and her staff really look after us.

Hope to see you all at the meetings and hope you are all enjoying good health.

Denise Hartas  
North West Co-ordinator

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## 311 Lemonade Scones

3 cups SR flour

1 cup of cream

1 cup lemonade

Mix all together and cook for in a Moderately hot oven for approx 15 minutes.

*Very quick and taste delicious*



## **Successful Pregnancy Outcomes for Most Women**

*Adapted media release.: Nov 7 2011*

Promising research led by investigators at Hospital for Special Surgery may offer hope for women with Lupus who once thought that pregnancy was too risky.

Results from the Multicenter National Institutes of Health (NIH) funded PROMISSE initiative, being presented Monday, Nov. 7 and then during a press conference on Tuesday, Nov 8, during the American Rheumatology's 2011 Annual Scientific Meeting in Chicago, show that most women with stable lupus can have successful pregnancies.

"There was a misconception, based on outdated experience, that women with lupus should not try to have children," said Jane Salmon, M.D., the study's senior author and Collette Kean Research Chair at Hospital for Special Surgery in New York City. "Now that our treatments are more effective and we have a better understanding of the disease, we can identify a window when pregnancy is safe and outcomes are good for mother and fetus. Historically, women with systemic lupus erythematosus (also known as SLE or lupus) have been advised not to become pregnant because of risks to their own and their fetus' health. SLE is a chronic inflammatory disease, in which the body's own immune system attack tissues of the body and can cause complications during pregnancy.

Drs. Salmon together with Jill Buyon from New York University Medical Center, and their collaborators evaluated 333 pregnant women with lupus from the PROMISSE Study (predictors of Pregnancy Outcome: Biomarkers in antiphospholipid antibody Syndrome and Systemic Lupus Erythematosis), which seeks to identify biomarkers that predict poor pregnancy outcomes. The research team found that 80 percent of lupus patients had favourable pregnancy outcome.

Patients with Lupus may be free of symptoms for long periods of time and then experience a disease "flare," when symptoms such as rash, joint pain, chest pain, swollen legs, bruising and/or fatigue suddenly appear.

"Most women with stable lupus, defined as limited disease activity and no flares during the time of conception and the first trimester, had successful pregnancies," explained Dr. Salmon, who is also the principal investigator of PROMISSE Study. "We learn from these results that timing is a most important element for successful pregnancy in women with lupus and that avoiding pregnancy during periods of increased disease activity is essential."

In the study, two categories of pregnancy were evaluated: the health of the mother and the fetus. The research team studied development of mild, moderate, or severe increases of lupus activity, or flares, in expectant mothers. For the fetus, the study examined the worst outcome— death— or situations in which the well being of the child would require extended hospitalization in a critical care unit.

Of the 333 women with lupus studied, 63 had poor outcomes. Ten percent of mothers experienced preeclampsia, a serious complication characterized by the onset of high blood pressure and appearance of protein in the urine. Ten percent experienced mild or moderate flares at 20 weeks and eight percent experienced flares at 32 weeks or had newborns of small gestational size – smaller in size than normal for the baby's sex and gestational age, commonly defined as a weight below the 10th percentile for gestational age.

*Successful Pregnancy Outcomes For Most Women With Lupus: cont.*

None of the women in the study was pregnant with more than one fetus, took more than 20 mg/d of prednisone, or had abnormally high excretion of protein or impaired kidney function. The women who experienced complications had more active lupus at 20 and 32 weeks and higher levels of antiphospholipid antibodies.

#### References

Article adapted by Medical News Today from original press release.

The PROMISSE study was funded by the National Institute of Arthritis, Musculoskeletal and Skin Diseases of the National Institutes of Health in 2003 to identify biomarkers that would predict poor pregnancy outcomes in lupus patients. To date, the PROMISSE investigative team has enrolled 647 volunteers who are monitored with monthly checkups and research laboratory studies looking at genes and circulating proteins that may predict the course of pregnancy. PROMISSE will continue through 2013 with \$12.3 million in support over ten years from the NIAMS and the office of Research in Women's Health. Dr Salmon and co-investigators from 11 academic centers will continue to examine a broad range of genes and molecular pathways that can affect pregnancy in women with lupus, and it is anticipated that their findings will have applications for the prevention of miscarriage and preeclampsia in healthy women.

The PROMISSE Study is coordinated by Dr. Salmon; Other investigators include Michael Lockshin, M.D., and Lisa Sammaritano, M.D., at Hospital for Special Surgery; Jill Buyon, M.D. at University School of Medicine: Ware Branch, M.D., at University of Utah Health Sciences Center; Carl Laskin, M.D., at Mt Sinai Hospital in Toronto, Canada; Joan Merrill, M.D., at the Oklahoma Medical Research Foundation; Michelle Petri, M.D., MPH, at John Hopkins University School of Medicine; Mimi Kim, D.Sc., at Albert Einstein College of Medicine; and Mary Stephenson, M.D., at the University of Chicago.

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## Closer to Understand Autoimmune Diseases

Science Daily (Mar.5 2012) - University of Alberta researcher Troy Baldwin is a step closer to understanding why the body's immune cells, called T-cells, sometimes attack perfectly healthy cells causing autoimmune diseases like diabetes.

Baldwin, a researcher in the Department of Medical Microbiology and Immunology, and graduate Alex Suen looked at a specific molecule, known as BIM, which is vital in regulating T-Cell death. He explained that when BIM was removed from auto-reactive T-Cells, rather than being killed off and eliminated from the blood, the T-Cells actually survived and were rendered inactive.

Baldwin, whose study was published in the *Proceedings of the National Academy of Sciences*, says his research also found there is a mechanism that controls T-Cells beyond the reach of BIM. Looking specifically at T-Cells that target the pancreas, which is a cause of diabetes, Baldwin explains that the auto-reactive T-Cells that survived in the absence of BIM weren't able to Kill the insulin-producing cells in the pancreas.

"Our future work is going to look at the mechanisms controlling these cells," said Baldwin. "Even though T-Cells are present in the body and should be able to target, in this case, the pancreas and cause diabetes, they don't."

Baldwin says understanding why these cells don't target the pancreas and why they are inactive could lead to new therapies to control auto-reactive T-Cells and help people with autoimmune diseases.

"Something is telling them not to become active," said Baldwin. "If we can figure out what that something is we could then potentially use that information to try and either suppress cells that would normally become activated and cause autoimmunity or, vice versa, we could now take T-Cells that are not active and make them more active."

Baldwin says cancer therapies, for example, are one instance where physicians want to boost T-Cell response. "If we turn that suppressive mechanism off, then perhaps we can make a cell that wouldn't normally respond, responsive," he says.

The next step will be to begin searching for the other mechanisms that regulate T-Cells.

First we want to try and understand if there are other cells that are controlling this auto-reactive population, or if it is something in the cells themselves that is preventing them from being active," said Baldwin.

"If we can break those control mechanisms, then we can understand how autoimmune diseases can progress," added Suen. "That will give us an idea of what to target to generate therapies to either try to prevent breaking that control or enforcing that control more strictly."

Printed from the internet <http://www.science daily.com/releases/2012/03/1203061900.htm>



## 55 Years of Living With Lupus By Lois Beckwith

By age ten I knew I was different but I didn't understand why, and I didn't share this realization with others. But my school friends knew, they nicknamed me Lumbago. I didn't have a clue as to what it meant but I liked the sound of the word.

As I progressed through primary school it was the late 1950s, a pattern started to emerge. I was outstanding in sport, fast, well co-ordinated and a high achiever in all competition, but I had days when I was lethargic, emotional, depressed, stiff, and could hardly move. It would come and go and be quite disruptive in what I wanted, and needed to do. As it became more noticeable I was presented to local physicians, to be firstly labelled as growing pains, then puberty blues and then on to tennis elbows, etc., etc.

I learnt to cope teaching myself to write with both hands so I could swap from hand to hand when cramping and pain would take over. I couldn't sit or stand in one position for any length of time. I would volunteer for any classroom task so I could stretch at regular intervals. People described me as always active and busy, sometimes "hyper". To add to this I had another problem; school was a nightmare. My earliest recollection is spending my lunch time writing spelling on the blackboard as punishment for not being able to spell or pronounce words I had never heard. Teachers then, were pretty cruel to dyslexia students, they showed little empathy, no understanding, and putting it frankly, intimidating to the extreme. Every day brought new stress. I spent an inordinate amount of time trying to rote learn every word I needed to pass tests in every subject. It was and is incredibly frustrating to know the answers but not be able to share it. This experience may have helped trigger my onset of LUPUS. High school was physically hard with lots of sitting and writing. I was given extra time to write my exams so there was some acknowledgement that I was struggling. After the final exams the pressure lifted and I felt different, the symptoms seemed to settle and I could relax about exposing my dyslexia. I had actually matriculated and gained University entrance and a studentship. Then I floored everybody, I applied for physical Education at Melbourne University. I wanted to study physical movement from a Norman perspective (not treatment) and I knew that I would be able to cope. Many tried to talk me out of it but that only made me more determined. I was in remission and I didn't even know

### 50 Years with Lupus *continued:*

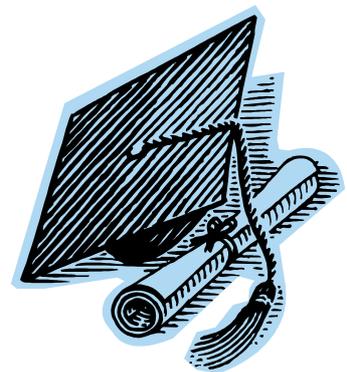
The full story. I did have some lingering signs and I learnt not to get to a fatigue stage otherwise the aching could creep back. At age 40 I was pushing too hard in my business, working long hours, lots of sitting and writing and I "hit the wall". I couldn't get out of bed, couldn't think or remember, ached constantly and couldn't drive a car. The first diagnosis of Ross River virus was disregarded after Systemic Lupus Erythmatosis (SLE) was evident in my blood tests. This long term disease now had a test and a name. It was a long 2 years of slow recovery and I have now had 25 years of living with adult LUPUS. I have predominately connective tissue problems which indicate what I can do and enjoy. Other problems are slowly creeping up on me which is attributed to LUPUS and long term drug usage. During my working life very few people had any idea of my condition and I preferred it that way.

Now retired I am much more open. My hands and wrists are dysfunctional. The fancy new drugs didn't work for me, the side effects were not worth it. So good old exercise, massage, pressure gloves and wrist bands along with some pain killers and lupus specific drugs maintain my quality of life.

Putting pen to paper makes one think back and also examine one's life outcomes. I can honestly say I am pleased with my life, that I was able to meet all my aspirations including six years of University, a successful career in the professions and then business. When I talk with other LUPUS sufferers I am reminded to accept the barriers, to be persistent and to enjoy what you do have.

Lois Beckwith

*Thank you to Lois for permission to print this inspiring story of her life. As a fellow sufferer I can empathise with her in that my life followed a similar pattern. Ed*



## Meet Molly

She's a gray speckled pony who was abandoned by her owners when Hurricane Katrina hit Louisiana. She spent weeks on her own before finally being rescued and taken to a farm where abandoned animals were stock piled. While there, she was attacked by a dog and almost died. Her gnawed right front leg became infected, and her vet went to LSU for help, but LSU was overwhelmed, and this pony was a welfare case. You know how that goes. But after Rustin Moore met Molly, he changed his mind. He saw how the pony was careful to lie down on different sides so she didn't seem to get sores, and how she allowed people to handle her. She protected her injured leg. She constantly shifted her weight and didn't overload her good leg. She was a smart pony with a serious survival ethic.

Moore agreed to remove her leg below the knee, and a temporary artificial limb was built. Molly walked out of the clinic and her story really begins there.

'This was the right horse and the right owner,' Moore insists. Molly happened to be a one-in-a million patient. She's tough as nails, but sweet, and she was willing to cope with pain. She made it obvious she understood that she was in trouble. The other factor, according to Moore, is having a truly committed and compliant owner who is dedicated to providing the daily care required over the lifetime of the horse.

Molly's story turns into a parable for life in Post-Katrina Louisiana. The little pony gained weight, and her mane finally felt a comb. A human prosthesis designer built her a leg. The prosthetic has given Molly a whole new life, Alison Barca DVM, Molly's regular vet, reports. And she asks for it. She will put her little limb out, and come to you and let you know that she wants you to put it on. Sometimes she wants you to take it off too. And sometimes, Molly get away from Barca.'It can be pretty bad when you can't catch a three legged horse,' she laughs.

Most important of all Molly has a job now. Kay the rescue farm owner, started taking Molly to shelters, hospitals, nursing homes and rehabilitation centres. Any where she thought that people needed hope. Wherever Molly went, she showed people her pluck. She inspired people, and she had a good time doing it.

'It's obvious to me that Molly had a bigger role to play in life,' Moore said. She survived the hurricane, she survived a horrible injury, and now she is giving hope to others.' Barca concluded, 'She's not back to normal but she's going to be better. To me, she could be a symbol for New Orleans itself.'

*This article was sent to me via e-mail . I felt it would be a good story to share with you all. We often need some thing to lift our thoughts. Ed*



**For Your Diary**

**Morning Teas for Northern Members**

4th Thursday of the month  
Joan Marshall Wing  
Kings Meadows Health Centre



**Southern Members**

October 8th  
Esus Café  
12 Noon  
Please ring Heather for Booking  
[6272 3096]

**North Western Members**

September 17th  
Gate Way inn 12.noon pay for self 6431 6042  
November 17th  
Fuschia Farm Lillico  
12 noon pay for self

**General Meeting**

September 21st  
11.00 am  
Joan Marshall Wing  
Kings Meadows health Centre  
Please bring a plate of finger food.

**Lupus Awareness Week Launch**

October 21st 2014  
2.00 pm  
Joan Marshall Wing Kings Meadows Health Centre  
Members Please bring a plate of afternoon tea

**Close of LAW**

Forth Hotel.  
26th October 12.00noon .  
Members, Please come a little early to help prepare.  
Good Guest speakers at both sessions.