



Incorporating LUPUS LINES

Writing Herself a New Future

Julie Green feels very alone; medication fails to ease the symptoms she has been experiencing from lupus for the past 14 years and few of her friends understand the impact of a chronic illness. Julie's cognitive functions have been severely impacted by lupus; her most frustrating symptom is that she is not able to concentrate to read.

"Reading has always been important to me," she said. "But now I can hardly read at all, I can't read an article or the newspaper in detail because I can't concentrate to get that material. That's my most frustrating

symptom."

Julie would like to keep up-to-date with advances in research through the Lupus Association of NSW but is frustrated that she finds it difficult to read the newsletter. As her symptoms are not classic ones, she would like to see greater research about lupus and cognitive function as well as any detail on links between lupus and her second condition Fibromyalgia.

Julie's journey with lupus has taught her that it's "almost impossible" for friends to understand this disease, the fact that the fatigue is so overwhelming.

"My symptoms are not life threatening which makes it hard to be taken seriously," she said. "And it's difficult for people to understand the reduction in my quality of life particularly as I look very well."

Lupus affects her skeletal muscles, brain and eyes causing overwhelming mental and physical fatigue and severe muscular pain.

"I try to tell them that it's like having a mild dose of the flu, feeling tired, not being able to concentrate but that it's not bad enough to stay in bed all the time," she said.

When she had two hip replacements

and a knee replacement, Julie learnt that people were better able to understand that healing process of surgery, physiotherapy and recuperation.

"On an ongoing basis, they don't understand," she said. "The sickness I have goes on and on. I haven't become better in 14 years."

Julie first experienced very mild



lupus symptoms that lasted only three months in 1985.

The illness went into remission for nine years but symptoms re-appeared in 1994 and were much more severe.

Finding out she had lupus meant a big adjustment for Julie

who had been a teacher who studied a Masters degree and taught science at secondary school and science teaching practices at tertiary level. But through persistence, she unexpectedly discovered a new talent.

"To my delight, I've found I have the ability to write something short, sharp and clear," she said.

As a member of the Greens political party, Julie has written succinct letters to the editor to lobby for this very important cause.

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From Hook House

Times are tough, the Prime Minister says so, the financial experts say so, and social commentators say so.

Many charities have already commented on how the down turn in the economy has affected their bottom line. These are charities that have million dollar budgets.

The Lupus Association has a budget in the range of 1-2% of most major charities and so a drop in revenue of \$1000 can mean the difference between staying afloat and going broke.

It is important, now, more than ever in our 30th year that our members get involved in all facets of the organisation.

Volunteer: There are plenty of activities to get involved in to raise awareness and help with general administration. Join the Management Committee there are two general committee places open.

Keep up to date on membership: There are lots of reasons to keep up to date *Lupus Links* among them but it also

provides much needed funds for the ongoing operation of the Association.

Fundraise: Anyone can do it. It can be big or small, with friends and colleagues or by yourself, it can be a one off or a regular thing.

Let's make the 30th Anniversary of the Lupus Association the most successful year yet! Ignore the press and let's grow in these difficult times.

Ben Jackson, Executive Officer

Dear Members

I know that for many, each year brings challenges. 2008/2009 has introduced a few more with the changed and ever-changing economic climate.

Let's hope that this testing time will pass quickly and that governments around the world will be able to lessen its impact on individuals. In the meantime, the situation will certainly have an impact on charities and the Lupus Association is no exception.

We remain convinced of the value of what the Association does and we will continue to provide support,

education and information to those living with Lupus, Sjögren's and associated Connected Tissue Disease. You can help us to serve you by staying in touch – tell us what you like about the Association or what you need and want from it. We may not be able to do all of it, but constructive feedback from you helps us to direct our activities in a way that is more likely to meet your needs. Let 2009 be the year you get involved – visit the office, respond to a survey, give us your story about living with Lupus. You never know it may help someone else.

On behalf of the Management Committee I hope you had a very Happy Christmas, and I hope that 2009 brings you peace and contentment whatever your situation may be.

"May you have enough happiness to make you sweet, enough trials to make you strong, enough sorrow to keep you human, enough hope to make you happy". Author unknown

With my very best wishes,

Judy Rough, President

The Lupus Association of NSW turns 30

In August this year the Lupus Association will celebrate it's 30th anniversary, and what a change we have made in 30 years! The Lupus Association

of NSW was first formed in 1979, in a small meeting room in Royal North Shore Hospital. From meagre beginnings the association has grown to over

1100 members Australia-wide.

Keep an eye out for feature articles in *Lupus Links* and special events to be held throughout the year.

The Lupus Association of Tasmania

In the last quarter the Lupus Association of Tasmania has been on the ball finding out more about sticky blood and rheumatology. Dr Murray was the recipient of research funds from the

Association and presented some of his findings to the group.

The Association was also invited to their Patron, Kerry Finch MP's Christmas

lunch, which was a great success. The LAT's 4th Thursday of every month meetings have also kicked off for 2009 and will continue as usual.



Lupus/Scleroderma/Sjögren's SA

The LSS is entering a new era with a number of long time committee members retiring. The new President, Barbara McDonald is looking to fill a number of important positions that still

remain vacant: that of Secretary and of Vice President .

Recognition must go to Dr Geetha Chandran a Rheumatologist at Queen Elizabeth Hospital who has taken on the

role of Medical Advisor to the LSS.

Diary dates for this year are the 10th of February and 19th of March. The Guest Speaker in February will be David Crisci a Compounding Pharmacist.



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Chairman's Report

We have had an extremely busy few months. Our October "Forum" was extremely successful. Ninety six lupus patients, members and family support, packed The Bruce Hunt Lecture Theatre and listened to our guest speakers, Dr Peter Hollingsworth, Dr Madelyn Chan, Dr Daniela Ulgiati, Dr Jean Foster and Franke Durack, with great interest.

The feedback was very positive with most people providing information on our short questioner which will be evaluated soon. An initial glance through them looks very interesting.

I must thank the doctors for their time and the excellent presentations, Norma, Greg, my wife Stephie for handling the registrations and Gretchen for her excellent organisation of the Forum.

Then came our trip to the South West from Albany through to Bunbury to meet with our members who are not able to come to the city for meetings etc. One big difference from a similar trip 10 years ago was the lack of doctors and services now available in country centres. One lady, in a town that had only access to a doctor once in three weeks and it was difficult to get an appointment, has had to sell up and move to a larger growing centre to have access to good a good medical service and hospital. It was a very worthwhile and informative trip. Our next one will to our near northern centres.

Thank you to the many people who have returned their survey sheets. They are still coming in the post and we intend to analyse the data next year. Results will be published when completed.

The Board, Norma and myself hope you enjoyed a happy and healthy festive season and hope 2009 is a good year for you all. David Henderson.

Disclaimer: The Lupus Group of W.A. (Inc.) does not recommend or endorse any products, drugs, treatments, procedures, medical or health professional in this newsletter. We suggest you discuss this information with your doctor or specialists.

Donations

The Lupus Group of W.A. (Inc.) depends on your good will and generosity. Please remember donations over \$2.00 and over are tax deductible.

The following people are thanked for their donations of \$10.00 or more. Z. Pilgrim, E. Stone, B. Walters, I. Chan, J. Foster, B. Morley, J. Papp, J. Cooke, S. Larter, G. Warren, J. McCormick, D. Turner, S. Carme, G. Lumsden, L. Barker. J. Okas, K. Sullivan, O. Powell, M. Laws, L. Braimbridge, C. Lenson, M. Schmiedte, J. Douglas

New Board

Jodi Abbott has resigned from the board, we wish to thank her for all her support over the years. Wishing her all the best for her coming marriage in the New Year. Health and happiness for the future, At the recent AGM the following were elected to the board for October 08 to October 2009. Chairman, David Henderson. Secretary, Chris Hawkins, Treasurer, Greg Warren with Dr Madelyn Chan, Stephanie Henderson, Dr Daniela Ulgiati, Marie-Anne Neveu and David Fienberg as board members. Dr Jean Foster was invited as a member of the board and accepted in November.

New Members

Elizabeth of Kensington, Hong of Nedlands, Rachael of Albany Sheryl of Inglewood, Helena of Bunbury, Cindie W. Leederville, Denise of High Wycombe, Janine of Joondalup, Sylvie of Karrinyup, Julie-Anne of Palmyra, Rachael of Kenwick, Elaine of Gosnell, Joanna of Armadale, Silvana Spearwood, Kitty of Lesmurdie.

Fundraiser for Amy

The as very successful and would like to thank all members who donated. We were able to give Amy's family a cheque for \$1700 before Christmas with more funds coming in. The Halton family would like to thank the Lupus Group for their generosity which provided such a wonderful Christmas surprise.



Fundraising Update

The Gift of Generosity

Thankyou to all of the organisations and individuals who gave generously between 1 October and 31 December '08



Small Business Donors: Kelly Davidson Graphic Design, Home Instead Senior Care, The Makeup Business (ERA product range), Andrew Cutrupi - Tiler.

Major Donations: Michael & Helen Carapiet

Donations \$200 or more: Jennifer Brown, Lucie Reynolds

Donations \$50 - \$199: Margaret Murray, Andrew Ferie, Lynne Seccombe, Chris Hanger, Narelle Heather, Margaret Cowles, Deborah Wells, Allan Sturgess, Grace Player, June Lewis, Gail O'Brien, Malee Lipman, Rosalind Carter, Gillianne Price, Hilary Hunt, Maya Zelazo, Pamela Wormald, Rosemary Rowe, St George Senior Citizens Club, Raelene D. McFadyen, Joe Tomal, Helen Jones, Christine Ross, Dr John Glass, Marietta Sargeson

Other Generous Donors: Bern Story Consulting Services, Carole-Anne Claxton, Clarisse Burgess, Karen Hamerton, Heather McGlew, Karen Turley, Tania Leiblich, Stacey Gee, Ros Wang, Nola Dunn, Janice Morgan, Shirley Patricia Gaskill, Helen Legge, Lynne Battle, Anne Taylor, Annie Porter, Christene Cole, Gerald Cundell, Richie Stores, Marian Bevan, Margaret Blundell, Sally Midgelow, Nicole Yammine, Marcia Canty, Nicky Wade, Marie Jones, June Matthews, Jan Robilliard, Deborah Galea, Ruth Penman, Joan Swan, Christine Leek, Amy Wong, Peter Davies, Rosalyn Clare, James McQuiggin, Angela Tsang, Mary O'Bryan, Janette Nix, Joan Pearson, Maggie Dutton, Dorothy Marie Spillane, Elisabeth Hamilton, Lyn Sicard, Margot Sawyer, Peshurst Ladies Probus Club, Heather Oliver, Wendy & Natasha Drady, Robin Cunial, Sally Hordern, Joy Hill, John Nott, Leila Walker, Vicki Furey

Andrew Cutrupi joins Small Business Donors

Andrew Cutrupi works hard for his money. He is a tiler by trade and runs a small business in southern Queensland and northern NSW, he even travels as far as South Australia to get the job done. He tiles industrial, commercial and residential sites and has been in the trade for 16 years.

Andrew is also passionate about increasing the profile of lupus in the community. One of his close friends is living with lupus and he sees how it affects her everyday life. "I am inspired by what she does, she is very dear to me and I want more people to get involved in supporting lupus".

Andrew is good to his word. His next goal is a series of supporters in the construction industry. "There isn't enough known about how devastating this disease can be so anything I can do to help I will", says Andrew.

Andrew has joined the Small Business Donor Programme but has also made further very generous donations to increase awareness of the disease. You will find a free bumper sticker in this issue of Lupus Links and this is Andrew's doing. "The Lupus Association have been really good to deal with, I wanted to raise awareness and they gave me plenty of options to choose from. I think bumper stickers is a great way for people to be made aware, especially now traffic is getting so bad in the major cities" says Andrew.

The Lupus Association of NSW Inc does not endorse doctors nor does it endorse products, nor does it necessarily hold the position of guest writers. We can however suggest options that are available to you and things that have worked for others that you can consider in conjunction with medical advice. The Lupus Association of NSW Inc can also provide information that may impact on treatment differently for different patients. Lupus and associated autoimmune diseases are very individual in how they effect people and we recommend ongoing and complete dialogue with a medical practitioner that you are comfortable with, while considering information in *Lupus Links*.



Fundraising Update

Home Instead joins Small Business Donors

In Sydney Home Instead Senior Care has three branches in New South Wales. David Carver, Michael McAviney and John Quirk run the branches in Hunters Hill, Bondi Junction and Pymble respectively. Home Instead Senior Care understands lupus and Sjogrens patients because they are there to help with issues like respite and convalescent care, light housekeeping, personal care and companionship.

When Mr Carver first approached the Lupus Association on behalf of Home Instead Senior Care he didn't realise that a close family friend was a member and volunteer. As his understanding grew of the Association so did his conviction that Home Instead Senior Care and the Lupus Association had some real synergies.

"There are some real synergies with what we offer. People with lupus and Sjogrens just can't get everything done sometimes and that is where we come in", said Mr Carver.

Home Instead Senior Care caregivers provide one to one support to help older, disabled or disadvantaged people retain an independent lifestyle in their own home for as long as possible. From a few hours a day, up to 24 hours - seven days a week, including weekends and holidays.

"There are parts to the job that are not taxing like companionship and other light duties which would suit a member of the Lupus Association, and they can choose to do it part time", said Mr Carver.

Its not just about providing a service it is also about opening up opportunities for casual or part-time work. Carers are required to perform the duties described previously but also perform duties such as meal preparation, medication reminders and transporting clients to medical appointments or shopping trips.

Mr Carver will be speaking at support group meetings and the Health and Wellness Seminar in March if you would like to find out more.

The Makeup Business joins Small Business Donors

For make-up artist Karen Playel, a trip to the United States in 2003 to visit her daughter has certainly proved to be not only a career-changing , but also life-changing one. Karen's daughter, an entertainer, introduced her to a new airbrush make-up which everyone in the industry was talking about. Karen visited a make-up store and was demonstrated ERA® Spray Make-up, a range of spray foundations, which provide an airbrush make-up application without the need for the traditional airbrush machine.

After returning home to Sydney, Karen wondered if Classified Cosmetics, the developers of the product, would ever release it in Australia. After 3 years of dialogue, Karen received an email from the company's President, requesting a telephone meeting to discuss distribution in Australia, where they offered Karen the distribution rights. Two-and-a-half years' later, Karen managed to break into the fashion industry with the product, but has discovered its' benefits for those with more specialised coverage needs – from portwine birthmarks, post-trauma scarring from injury such as burns, and surgery, vitiligo, pigmentation, rosacea, acne, and of course lupus.

"It's been an interesting journey. There is a lot more attention being paid by the medical profession to the benefits of coverage for those with chronic illness with skin conditions and post-trauma injury, and the beneficial impact it can have as part of someone's rehabilitation, improving self-esteem, confidence and also to regain some control over their circumstances if they choose. The perception that make-up is 'fluff' or a vanity thing is luckily becoming a thing of the past.

Karen most recently spoke at the Australasian Dermatology Nurses' Association Information Day at Westmead Hospital, held workshops for The Burns Support Foundation, and conducted in-service demonstrations at Royal Perth Hospital at the request of Dr. Fiona Wood, which the Lupus Association WA Executive Office attended, and also Brisbane Hospital.

Karen can be contacted on (02) 9802 2231 or 0419 251441, or via her website: www.themakeupbusiness.com.au.

Annual Report Now Available - Ask For Yours Now!



Lupus Awareness Month

Diagnosis: Lupus

The last of the 2008 Diagnosis: Lupus Seminars was run in Orange at the end of October and Dr Peter Cheung (right) was again on hand to deliver it to the GPs present. The seminars were born of a survey done last year where members told us that it took on average between two and a half and three years to be diagnosed with lupus. In some cases it was reported to have taken almost 20 years to diagnose.

In total over 60 GPs or allied medical staff attended the seminars and gave excellent feedback as to how much they learnt about the disease.

We must again acknowledge the generous support of the Maroubra Seals Club, the Toongabbie/Seven Hills RSL and Orange Ex-Services Club for supporting the event.



Patient Education Seminar in Orange

The final Lupus Awareness Month Patient Education Seminar was run in Orange at the Orange Ex-Services Club.

Guest speakers included local politician, John Cobb, whose session was more like a lupus workshop than a speech. Everyone walked away wiser and convinced that their local member knew more about lupus than he did before he walked in. Next was optometrist Jake Hansen who walked the participants through the different aspects of eye care required of a lupus patient and Dr Derek Davies spoke on dermatology and covered skin issues that autoimmune patients may experience. Geoff Thomas spoke on his experience with lupus and his ride around the USA promoting awareness of the disease.

Thanks goes to the Wellness Pharmacy for donating the lucky door prizes. To Hogans Pharmacy special thanks for supporting the Seminar through advertising in the local papers and a door prize. John Hannaford must be thanked for all of his effort in bringing this event to fruition.



Healing Lupus: A Spiritual Approach

We were delighted to have the CEO from the Lupus Association of NSW speak at the Healing Service in St Andrew's Cathedral, corner George and Bathurst Streets Sydney on 22nd October 2008 during Lupus Awareness month. This was one of the Cathedral's usual Wednesday night Healing Services, but with a special focus on Lupus. Ben Jackson informed us about Lupus and the work of the Lupus Association of NSW and recent medical research. It was an opportunity to recognise and give thanks for the people and organisations who work so tirelessly to provide better outcomes for people diagnosed with this disease.

The Healing Ministry prayed for the Association and its members, for volunteers, the medical profession and nursing staff. Prayers of healing and support were said for all people suffering this disease, as well as for their carers. Lynette Medway who is a long time member of the Association, gave a testimony of her recovery from Lupus disease and for the Healing Ministry's support and teaching, as well as the Lupus Association's education seminars.
Rev Christopher Allan, Healing Ministry Leader, St. Andrew's Cathedral Healing Ministry

Medical Update

Brain Fog - What is it? and How do I deal with it?

Adapted from an article by Elaine Alexander, MD, Phd. in the October 2008 edition of *The Moisture Seekers*.

What is Brain Fog?

Brain Fog is a lay term to describe fluctuating mild memory loss that is inappropriate for a person's age. It may include forgetfulness, spaciness, confusion, decreased ability to pay attention, an inability to focus, and difficulty in processing information. Remember that gradual cognitive decline from early adulthood is a fact of life. Brain Fog can occur in auto-immune diseases like lupus or Sjögren's Syndrome, but other factors also might cause these symptoms and should be considered by you and your doctor. Especially in patients over 65-70 years of age, a major cause of cognitive dysfunction can be side effects of drugs and drug interactions.

What can I do about Brain Fog?

There are three main areas where you can work to help minimise the chance of experiencing brain fog:

Look after your health, train your brain and lead a balanced life.

In looking after your health you need to develop a close working relationship with your doctor(s), always report changes in cognition/memory and mood (depression, anxiety), and make sure your physician knows about all the prescription and OTC medications you are taking.

Inquire about your hormonal status, thyroid function, and blood pressure.

Lead a balanced life by rejuvenating with sufficient sleep. If after 8-9 hours of sleep you are still tired, tell your doctor. Minimise stress and anxiety; this can be done by setting realistic expectations, by planning ahead by finding a balance between work and leisure.

Take breaks throughout the day and learn relaxation exercises and practice them at regular intervals. Limit multi-tasking and focus on one task

at a time. Have a good old laugh every now and then, it is often the best medicine. Share your feelings.

In terms of your diet reduce caffeine and alcohol. Manage effectively musculoskeletal and joint pain and exercise regularly. Adequate physical exercise enhances cognition/memory.

Train the brain! "If you don't use it, you will lose it." Boost your brain power by continuing to work into retirement (part time), by learning new skills, volunteering, by engaging in social and mentally stimulating activities and by establishing new friendships and relationships.

Take your body to the gym and don't forget to visit the "BRAIN SPA" - both will improve brain function.

Suggested reading: *The Memory Bible*, by Gary Small, MD, Director of the UCLA Center on Aging.

50 Years Without a New Lupus Drug

Thursday, November 20, 2008 marked an unfortunate anniversary. It was 50 years ago that the U.S. Food and Drug Administration (FDA) last approved a drug to specifically treat lupus.

The Lupus Foundation of America (LFA) brings increased attention to the need for safer, tolerable and effective lupus treatments through its Zero in 50 campaign. Today, there

is great cause for optimism. There are more lupus researchers and pioneers in biotech and pharmaceutical companies than ever before working to develop new treatments for lupus. We believe through continued partnerships on all fronts we can accelerate the pace of discovery and ultimately end the suffering caused by lupus. The LFA is on the front lines of this effort to advance the science and medicine of lupus and to bring

down barriers that have impeded progress in lupus research.

You can read more about this new campaign, and what 50 years without a new lupus drug means to them, and learn how you can take action at the website www.lupus.org/newsite/pages/zero-in-50.html

Share your story and tell us what 50 years without a new lupus drug means to you.

Medical Update

Vitamin D, for Don't miss out

by Wendy Gilbert. Wendy is not a doctor but is a registered psychologist and a long time Lupus patient.

Why do we need sunshine?

Sunlight helps to generate Vitamin D which is essential to build healthy bones and helps increase calcium absorption and bone density. Vitamin D is converted from cholesterol in the blood by sunlight and helps increase the calcium in the intestine, building stronger bones.

The Facts

Australians receive about 99% of their vitamin D from sunlight production, a function that's inhibited by wearing sun screen. Sun exposure, when SAFE, is the most 'ideal' way to obtain Vitamin D, especially during the summer months. As many Lupus suffers are unable to expose themselves to sunlight and UVA light, a good vitamin D supplement is crucial. There is very little in food alone.

What Happens if You Don't Get Enough?

It is important to find the balance in all of your body's inputs but there are physiological consequences of vitamin D deficiency. The fear of cancer has lead many Australians to be 'overly' cautious due to the fear of developing skin cancer. However, emerging research has linked lack of vitamin D to colon, breast, and prostate cancer, diabetes, and Multiple Sclerosis.

Lack of vitamin D levels leads people exposed to bone disease, such as osteoporosis and it's potentially debilitating affects such as fractures and other cancers, suggests Professor Peter Ebeling, Medical Director, at Osteoporosis Australia.

SLE and Vitamin D Deficiency

The cross-sectional studies between vitamin D deficiency and disease severity and susceptibility is not entirely known but is of growing interest. Some links between the two have been indicated.

Vitamin D is a steroid hormone that plays a crucial role, not only in calcium metabolism and bone density but also plays important roles in other bodily systems, including effects on muscles, vasculature, reproduction, cellular growth and differentiation, malignancy and the immune system. Rickets, depression, and other 'mental' disorders have also been indicated. Vitamin D's potential, as a therapeutic agent is as said above, of increasing interest among Rheumatologists. Why live with depression, or more intense depression if lack of vitamin D may be a contributing factor.

New Hope for those 'at risk' or who have Osteoporosis

Teriparatide (Forteo) treats Osteoporosis in a different way than other drugs used for Osteoporosis. The drug causes new bone formation. It is apparently the latest and more useful drugs, to be available in March 2009. It has been approved by the FDA (Food and Drug Administration) for treatment of Osteoporosis and post menopausal woman who are at risk of having fractures. There are some seemingly minor side effects and the long term side effects of the use of teriparatide are not fully known as yet.

Bone metabolism is a complex process. Bone remodels throughout a persons life so that there is new bone being made along with bone resorption. Among the substances that affect bone metabolism and increase the risk of osteoporosis, include prolonged use of corticosteroids, alcoholism, smoking, and in men, hypogonadism.

Unlike other osteoporosis drugs, it actually causes bone density to increase more rapidly. Teriparatide's mechanism of action is too clinical to explain in simple terms but it is a synthetic form of the naturally occurring parathyroid hormone (PTH). Please discuss it with your doctor for clarification on its mechanism of action if you wish to.

Existing treatments for osteoporosis are medications that currently prevent resorption. These include Bisphosphonates alendronate (Fosamax), Resedronate (Actonel), Salmon Calcitonin (a nasal spray) and Raloxifene (Evista), a selective estrogen receptor modulator. Actonel is available not only with the calcium tablet included but also with vitamin D, hence combining all three-Actonel Combi- Actonel, calcium, and vitamin D. This makes it more cost effective as vitamin D, even prescribed, can be costly but is essential if your levels are very low.

Medical Update

Early Immune System Error Challenges Basic B-Cell Biology in Lupus

New York City - A researcher at Tufts University School of Medicine in Boston with funding from the Lupus Research Institute - USA's only organization exclusively devoted to pioneering innovative science in lupus - has made a startling discovery. Thereza Imanishi-Kari, PhD, reports that early mutation of immature, undeveloped B cells may prevent them from becoming a source of tissue-destroying antibodies.

The discovery challenges long-held dogma and changes basic views of B-cell biology in lupus. Until now, scientists thought that only "mature" B cells could mutate their antibody genes. With LRI Funding, Imanishi-Kari has discovered that B cells also mutate during their early development. The early genetic altering of antibodies could prevent the developing cells from making an early immune system error - a mistake in 'tolerance' - that causes autoimmune diseases such as lupus. This discovery offers a new direction for research into autoimmunity. It may explain why the immune system in lupus makes a basic mistake: It fails to recognize its real enemies and turns on itself- a core error in the autoimmune process. The study results may also pave the way to new strategies for preventing lupus.

"Our findings show that the immune system can influence adaptive autoimmunity much earlier than had been previously thought," Imanishi-Kari said. She and her colleagues are also looking at the role of the protein interferon in forming these immature B cells.

Lupus Research Institute, September 19, 2007

Do Bacteria Have Itchy Trigger Fingers?

Could bacteria be the culprit in triggering lupus?

Dr. Jochen Mattner thinks so. He discovered a bacterial trigger of autoimmune liver disease that has implications for lupus. With funding from the Lupus Research Institute, the Cincinnati Children's Hospital doctor helped to confirm a long-held suspicion that certain bacterial or viral infections can elicit strong immune responses that prompt autoimmune illnesses such as lupus. Dr. Mattner reported in May's *Cell Host & Microbe* that the common gut bacterium *Novosphingobium* triggers autoimmune liver disease in mice.

Dr. Mattner and co-authors illustrate how the bacterium, due to its unique cell wall antigens, activates specialized immune system white blood cells that provide help for autoreactive B cells. When extended to humans, the findings imply that straightforward antibiotic treatments might prevent or halt the autoimmune process in genetically susceptible individuals.

Are common germs triggering lupus?

They might be.

Dr. Marko Radic at the University of Tennessee has discovered that a bacterial or viral infection can trigger chemical modifications to proteins on immune system cells that in turn prompt autoimmune assaults. Published in February's *Journal of Immunology*, the discovery could explain why autoimmune diseases often first appear following an infection.

How about chronic viral infections?

It's possible, according to Dr. Zhixin (Jason) Zhang at the University of Alabama, who now has 5 years of funding from the National Institute of Health to take his Lupus Research Institute-funded breakthrough to the next level.

Studies in Dr. Zhang's Birmingham laboratory indicate that almost half of the DNA-binding antibodies in lupus are byproducts of antibody editing, which is also seen in different types of chronic viral infections. Dr. Zhang will now examine if excessive editing of the antibody-encoding genes is indeed taking place in people with lupus.

Adapted from Lupus Research Institute, May 25, 2008

Medical Update

A Case of Drug Induced Lupus

Late in 2008 there was a phonecall that came into the Lupus Counselling and Information Line from a concerned mother: her son had lupus. She had spoken to her specialist already and they believed it was drug induced lupus. They were due to go in and see the specialist in the following weeks to confirm the diagnosis, however, understandably she wanted as much information as she could find so she was well prepared.

Drug-induced lupus erythematosus is an autoimmune disorder that is brought on by a reaction to medication and resembles systemic lupus erythematosus (SLE) in many respects. Drug-induced lupus affects men and women equally. It results from a hypersensitivity reaction to a medication. The drug may react with cell materials, causing the body to form antibodies that attack the body's own healthy cells. There are a list of medications that may cause this reaction, here are the associations based on the presentation Dr Peter Cheung gave to the Diagnosis: Lupus Seminars.

Definite associations: Hydralazine, Procainamide, Minocycline, Chlorpromazine, Isoniazid, Penicillamine, Methyl-dopa, Interferon-alpha.

Possible associations: Anticonvulsants, Quinidine, Propylthiouracil, Sulfonamides, Lithium, Beta-blockers, Nitrofurantoin, Sulfasalazine, Diltiazem, Hydrazine, Interferon-gamma, TNF inhibitors.

Symptoms tend to occur after taking the drug for at least 3 to 6 months, and the most common symptoms are those that affect the joints (arthritis), heart, and lungs. Other symptoms associated with SLE, such as lupus nephritis and neurological disease, are rare.

The mother in question was given some information by her specialist that she forwarded onto the Association so we could have a better understanding of how drug induced lupus was affecting the patients diagnosed with the disease. The data was for 25 individuals aged between the ages of 15 and 39 but predominantly in the late teens and early twenties. The reaction to the lupus-causing-drug varied enormously from "Arthritis, antinuclear antibody" to "Disabling arthritis, myalgia, fever, antinuclear antibody". The good news for these patients however was the common theme of "recovery on drug withdrawal". Common thought is that it can take up to 6 weeks after ceasing to take the drug, for symptoms to fully dissipate.

It is always important to communicate all medications with your medical team so that they have, at all times, the maximum information to make the best decisions on your health care.

Lupus Research Reaches High School

My name is Hannah McVicar and in February this year I was diagnosed with SLE. I am seventeen and I'm currently in Year Twelve at St Andrews Cathedral School in Sydney. Thankfully, I was diagnosed early and, although I have been unwell, my Rheumatologist has now prescribed the right combination of medication and I'm able to live a relatively normal life. As part of one of my subjects at school I have to complete a personal interest project. I have decided to focus on Lupus and the affect the disease has on families of those who suffer from the disease. Hopefully, once I have finished the study, it will assist in raising awareness about Lupus in the wider community as well as the need for understanding and providing support. In the next Lupus Association newsletter I hope to include a brief survey. This, along with a number of interviews, will form the basis of my research. I would like to ask for your support in taking a few minutes to complete and return the survey when it arrives in the next newsletter.





Natural Help for Insomnia

By Aimee Magrath BHSc (Nat.), N.D., Dip. Nut., Cert. IV Rem. Mass., M.A.T.M.S.

About Aimee: Aimee was diagnosed with SLE as a young teenager and struggled with ill-health throughout her schooling years. Now, more than 15 years on, Aimee is a qualified naturopath and nutritionist, working from a practice located in the heart of Pennant Hills. She has been medication free for over 10 years now, managing her condition with a combination of natural therapies. For members of the Lupus Association and their families, Aimee donates 10% of the initial consultation fee to the Lupus Association NSW.

Fatigue is one of the most common, and most debilitating symptoms experienced by lupus patients. Often patients feel tired all the time, and no matter how much sleep they get, it's never enough. However, some patients, though feeling so tired, find it difficult to get to sleep, causing further detriment to their health and increasing their fatigue levels further.

Some Triggers For Insomnia:

Restless Legs Syndrome – a condition marked by uncomfortable urges to move the legs often worse at night. Iron deficiency – if you think you may not be getting enough iron, particularly vegetarians and women who have heavy periods, speak to your doctor about having your iron levels tested. Hormonal changes such as those that occur pre-menstrually and during menopause. Stress alters the body's hormone levels and can interrupt with normal sleep cycles. Anxiety and worrying can also upset sleep patterns. Pain – if pain is keeping you awake, speak to your doctor or practitioner about pain-reducing therapies. Food sensitivities – sensitivity to some foods may cause sleeping difficulties.

Dietary Help:

Avoid alcohol – a small amount can help induce sleep initially, but often disrupts deeper sleep cycles later. Avoid caffeine after 3pm. This includes tea, coffee, chocolate, coke. Avoid heavy meals three hours before bedtime. In the evening, eat foods high in tryptophan, a substance which encourages sleep. These foods include bananas, dates, tuna, turkey and yoghurt.

Herbs & Supplements That Can Help:

'Sleep is the golden chain that ties health and our bodies together' – Thomas Dekker

Magnesium & Calcium – have a relaxing and calming effect on the body and mind.

B complex – taken in the morning, it can help your body better utilise energy throughout the day and provide the correct nutrients for inducing sleep. Do not take at night.

Melatonin – a substance naturally produced in the body that helps regulate sleep-wake cycles. Can be useful for short-term use for sleeping problems and also jetlag.

Flower Essences – 'White Chestnut' is great for those people who lie in bed unable to switch their minds off.

Herbs – Valerian is perhaps the most widely known and used herb for sleep. It has a relaxing effect on the body and promotes sound sleep. Kava is my favourite herb for insomnia that is related to stress and anxiety (this herb is only available from a practitioner). Other sleep-inducing herbs include passionflower, hops, chamomile, californian poppy, lemon balm and skullcap.

Herbal teas – for mild insomnia, a therapeutic sleep tea mix can be of benefit, including 'Sleepytime tea', or chamomile, valerian or passionflower teas can work well.

Nutrients that I find most helpful in relieving restless legs syndrome include Magnesium, Vitamin E and B vitamins (particularly folic acid). Calcium, potassium, zinc, iron, lecithin and fish oil may also be beneficial.

Lifestyle & Environment:

When it comes to sleep, our bodies like a consistent routine. So establish a set of habits and follow them each night to help promote a healthy sleep cycle.

Aimee consults on a wide variety of conditions, with a special interest in allergies, lupus and chronic fatigue syndrome. She treats people of all ages, from infants to the elderly, using a diverse range of modalities including herbal medicine, nutrition, iridology, counselling and flower essences.

This is intended as general information only and it is not recommended that you self-prescribe nutritional or herbal supplements.

If you would like any further information, please contact: Aimee Magrath FAMILY NATUROPATH

In Balance Health 9 Hillcrest Road Pennant Hills 2120 P: 9980 9991 E: aimee@inbalancehealth.com.au

M: 0414 297 165 W: www.inbalancehealth.com.au



Local Support and Volunteering

Get Involved in Local Support

Support groups are a great way to learn more about lupus. They are also a great forum for communicating information, emotions, and physical problems and successes. Support groups are a two way street so if you need the support of such a group or if you believe you can provide support to others then get involved in your local group.

Blacktown

The Blacktown group Christmas Party took place on the 3rd of December. Come to celebrate were some of the group's stalwarts and their families as well as new members of the group who chose Christmas as their first meeting. Special thanks to all those who helped with the fundraising on the day, the Executive Officer had three goes at the lucky Christmas dip to bring presents back to the staff in the office.

Canberra

The Canberra meeting commenced with some easy introductory Tai Chi exercises for about 1 hour under the guidance of an instructor from the Tai Chi Academy. They then had an interesting discussion period which covered many different aspects of how Lupus had effected various attendees. Don't forget to help out at the BBQ at Buntings Fyshwick from 9am – 4pm on Saturday 4th April. Please contact Judy 6166 6258 if you are available.

Sutherland

The Sutherland group Christmas Party took place on the 11th of December at the Cronulla RSL. New year plans were discussed with possible topics for upcoming meetings. The Sutherland group will have an external speaker in February and March.

Tweed Heads

After being kicked off by a flying visit from Ben Jackson back in October at the request of Beryl Klingsporn, the Gold Coast/Tweed region held its second Lupus/Sjogren's support group meeting on 3 December. There were about half a dozen of us in attendance. Kelly apologises that the Lucky Door Prize was not drawn on the day, but the prize will be saved and drawn at the next meeting. A change of venue and possibly a different time-slot was discussed and options are currently being considered. Kelly Davidson on 02 6676 2646 or 0417 703 834 for information and to be put on a contact list so that you can be personally advised of any upcoming local meetings.

Central Coast

The Central Coast kick-off meeting was held on the 6 December. Nadene Veitch travelled all the way up to Mingara Recreation Club to hold a meeting where 14 people showed up to give each other their support.

It was a busy agenda with much to talk about from both a practical perspective as well as a support perspective. Nadene addressed the group on how a group functions and the responsibilities of its members and then went on to talk about topics like loneliness, meditation and even grief and loss.

If you are interested in a support group on the Central Coast then call Nadene at the Association on 1800 802 088

Health and Wellbeing Seminar 3rd March

This is a special 30th Anniversary Seminar to be held as well as the patient Education Seminars in October.

Where: Hook House, 55 Wicks Rd, North Ryde

When: 3rd March, 2009 from 1.00pm to 4.00pm

Topics: Tai Chi, Home Care - what is available?, Vitamins and Nutritional Supplements, Coping with Grief & Loss and Remedial Massage. Lucky Door Prizes drawn on the day.

The Seminar costs \$5.00 to attend for members and \$10.00 for non-members. Afternoon tea will be provided.

There are only 40 places available, so book quickly. Transport can be arranged for 4 or more people travelling from the same location. Great for a support group get together.



Seeing the Light

By Verna Cunliffe

Flick the switch and the light comes on - that is all there is to it. Far from it! Thousands of people are adversely affected by artificial light – fluorescent, halogen and LED. Unfortunately, many light-sensitive people are unaware that the uncovered fluorescent lights in their workplace and shopping centres are making them ill.

Artificial light has many components; Ultraviolet B, Ultraviolet A, Blue light, Red light and in fluorescent and halogen – electromagnetic circuitry. Fluorescent lights have large peaks and troughs in emissions and are harmful to light sensitive individuals.

As a lupus sufferer, I am affected greatly by the UVB emissions from the sun, but also from uncovered fluorescent lights, particularly in Shopping centres, Offices, Hospitals and Doctor and Dentists surgeries. UVA affects me as well, from photocopiers and digital photo printers in shops. To make matters worse I am affected by blue light- for example: any light in the blue end of the spectrum, that is; fluorescent, halogen and LED.

Can it be any worse than that? Oh Yes! I am affected by the electric circuitry in Compact Fluorescent lamps (CFLs) and Halogen lamps, and the peaks and troughs in emissions from these lamps. Only the old fashioned incandescent globe suits me! What a shame the world is phasing incandescent globes out in favour of CFLs. This means that light sensitive individuals like me, cannot go out or participate in 'outside our home' activities.

The Phase-out of incandescent globes in Australia has already begun. What can I do about that? Go out and buy hundreds of old fashioned incandescent bulbs. Yes, that's right - every time I open my cupboard to get something out fall dozens of packets of globes – I am set until I am ninety years old – if I make it!

Not only individuals with lupus are affected (in various degrees) by fluorescent, halogen and LEDs but many other people; Chronic Fatigue Syndrome, Electro-sensitive individuals and people with Macular Degeneration disease, to name a few.

I have been very active writing to the Department of Environment on behalf of all these individuals, so that our Government is aware that the Phase-Out policy severely affects the health of thousands of Australians. The UN Charter forbids Governments from placing any man, woman or child in danger, and that is exactly what the Phase-Out policy will do. So if you don't like the cold colour of fluorescent CFLs and think this is making you feel a bit off colour – think again, it may be really making you off colour!

Lupus Butterflies Swim Cole Classic

Walking 14 kilometers from the city to Bondi is not enough for the Lupus Butterflies. They have also decided to tackle the open water swim between Shelley Beach and Manly Beach on the 1st of February. The Cole Classic has been a premier open water swimming events for 26 years. It is now the perfect occasion for the Lupus Butterflies to raise money for the Association's education and awareness programmes. To support the Lupus Butterflies in this very cold swim visit www.everydayhero.com.au/Lupus_Butterflies. Donations are accepted after the event.

New Merchandise: Golf Umbrellas

Have you been caught in the latest storm or has this summer's heat been getting to you when you are out and about? Well thanks to Andrew Cutrupi who has very kindly sponsored these Lupus branded golf umbrellas the solution is near. These huge umbrellas give plenty of protection from mother nature in all her forms and only cost \$35.00 for members and \$40.00 for non members from the office or from your local support group. Due to postage and handling costs of nearly \$20.00 they will only be available direct from the Association. There are only 40 left so phone (02) 98786055 to make your order today.





Sjögren's Syndrome

Is a lip biopsy 100% accurate?

by Philip C. Fox, DOS reprinted with permission from the March 2008, *The Moisture Seekers*

The short answer is "yes... and no!" The lip biopsy, technically a labial minor salivary gland biopsy, is the single most accurate means of diagnosing the salivary exocrine component of Sjögren's syndrome. However, it is not sufficient alone to establish a diagnosis of the entire syndrome.

In Sjögren's syndrome, there are characteristic changes in the minor salivary glands that can be seen when the tissues are fixed, stained and examined microscopically. Specifically, certain salivary cells are lost (acinar cells) and prominent collections (foci) of inflammatory cells arise which cluster around other salivary (ductal) cells. This is termed by pathologists a "peri-ductal mononuclear cell infiltrate with acinar dropout."

The pathologist actually assigns a score to the lip biopsy based on the amount of inflammatory infiltration. While the changes seen are characteristic of Sjögren's syndrome, there are other conditions, such as graft-versus-host disease, hepatitis C and HIV-salivary gland dysfunction, in which a lip biopsy may appear similar on a routine exam. It is important to rule out these situations during diagnosis. If the changes in the minor glands appear to be the result of Sjögren's syndrome, one must still have evidence of other exocrine involvement (lacrimal gland) in order to establish a definitive diagnosis of Sjögren's. The lip biopsy is accurate in diagnosing salivary involvement in Sjögren's syndrome and is a critically important part of the clinical evaluation.

The question that often arises is what does it mean when the symptoms and other tests are very suggestive of Sjögren's syndrome - but the lip biopsy is negative? Patients may have dry eyes and a dry mouth, both subjective complaints and measurable decreases in tears and saliva, but the lip biopsy does not show the characteristic tissue changes or there are changes present but they are too mild. Patients - and their doctors - ask, "is this Sjögren's syndrome?" There are a number of reasons why the lip biopsy may be negative. First, the individual may not have Sjögren's syndrome. There are many causes of dry eyes and mouth, and it is important to search for these as a possible explanation. It would be a mistake to overlook another condition. Second, one could have Sjögren's syndrome but minimal labial minor gland involvement. With time, a subsequent biopsy might be found to be positive. It is important to remember that the current classification criteria for Sjögren's syndrome do not demand a positive biopsy to be considered a definitive case of Sjögren's. The presence of specific serum autoantibodies (SS-A (Ro) and/or SS-B (La)) may substitute for the positive lip biopsy as a required component. So, you may be diagnosed with Sjögren's syndrome without a positive lip biopsy.

Additionally, there are a number of possible technical explanations for a negative biopsy. There may be an insufficient number of minor glands in the specimen. This is often dependent on the procedure used and the experience of the surgeon. (The pathologist needs at least 4-6 minor glands for accurate reading.) Also, all minor glands in an individual are not involved to the same extent. One often can see areas of intense involvement adjacent to relatively normal-appearing tissue. Therefore, the results may be skewed due to sampling error - that is, by chance the sample may be a section with little inflammation. If the specimen had been taken an inch to either side, the results might be different. This is why obtaining a representative number of glands to examine is important. It is also possible that medications the patient has taken could influence the specimen, particularly anti-inflammatory agents. Finally, studies also have shown that different pathologists may score the same tissue differently. In practice, grading biopsies is not an exact science, unless extremely detailed and time-consuming methods are used. If the results of the biopsy do not match the clinical picture, it may be worthwhile to have the specimen re-read.

So, while a positive lip biopsy in a patient in whom confounding conditions have been ruled out is a very reliable indicator of the salivary component of Sjögren's syndrome, a negative finding does not eliminate the possibility of a diagnosis of Sjögren's. Diagnosis can be difficult, since there is no single test for Sjögren's syndrome and the condition can present in so many different ways. Regardless of the cause, symptoms and signs must be managed and good communication with your doctor is essential. The lip biopsy is a very important tool in the evaluation of Sjögren's syndrome, but it represents only a part of the diagnostic picture.



Product Reviews

Bio Oil Review Comes in Positive

In our previous Newsletter, it was announced that the Lupus Association and Bio-Oil had initiated the first Lupus Association Product Review. 20 participants put Bio-Oil to the test where they were required to apply Bio-Oil consistently on a targeted area for an 8 week period. The aim being to ascertain if the product could be used as a possible solution to alleviate the skin related side effects experienced by our members.

Of the twenty participants who began the trial we have established that eighteen participants completed the full 8 week period. At our request participants have completed a questionnaire and in so doing have provided us with the much awaited feedback of their experience.

In general Bio-Oil was used across the sample for a number of conditions namely dry skin, itchiness and damaged skin (scarring). An overwhelming 83.3% of the participants experienced great results and gave Bio-Oil an overall rating of either very good (4) or excellent (5) on a 5 point rating scale.

Participant comments showed that they found Bio-Oil soothing on their skin, reduced redness and aggravated skin and left their skin feeling healthier and more nourished, 88.9% stated that they would happily recommend Bio-Oil to others, and 100% of the participants reporting that they would definitely continue using Bio-Oil. So for those of you who are intrigued and would like to try some for yourself, go to the Bio-Oil website www.bio-oil.com where you can request a sample sachet through the "Contact Us" page.

Members said: "You have to be quite patient with the results, but you do get results!" - Edith, Mt Macdonald. "Good product and did what I expected. However, I do prefer non-perfumed products." - Nadene, Northern Beaches. "I was quite impressed with the improved visible appearance to the skin and particularly the fingernails. Bio Oil had a mild pleasant perfume, and while a little greasy initially, it was rapidly absorbed into the skin. It is a very affordable product, and I certainly will continue to use it." - Ros, Central Coast.



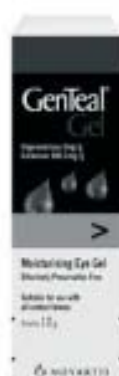
If you suffer from sore, dry, gritty, or irritated eyes, then you may have Dry Eye.



GenTeal

Mild to Moderate Dry Eye:

- Gentle, soothing relief from Dry Eye⁴
- Multidose convenience without preservative irritation³
- Can be used with contact lenses³



GenTeal Gel

Moderate to Severe Dry Eye:

- Long lasting relief that soothes and protects⁴
- Crystal clear, non-smearing ophthalmic gel³
- Preservative-free in the eye³

Always read the label. Use only as directed. If symptoms persist, see your healthcare professional.

1. Abietz J. Dry eye: an update on clinical diagnosis, management and promising new treatments. Clin and Exp Optom 2001; 4:18 2. Noecker R, Bucci F, Sheppard J. Treating ocular surface disease through medical therapy. Ophthalm Times 2002; 27: 4-15 3. Chalmers R. A review of the metabolism of hydrogen peroxide by external ocular structures. ICLC 1995; 22: 143-147 4. Tauber J. Efficacy, tolerability and comfort of a 0.3% hypromellose gel ophthalmic lubricant in the treatment of patients with moderate to severe dry eye syndrome. Curr Med Res Opin 2007; 23: 2629-2636. 5. GenTeal Product Monograph 2007. Novartis Pharmaceuticals Australia Pty Limited, 54 Waterloo Road, North Ryde, NSW 2113, Australia. ABN 18 004 244 160 Phone: 1800 635 202 Medical Information and Communication: 1800 671 203.



The Butterflyer

Upcoming Support Group Meetings

ACT

Last Tuesday of Every Odd Month

Dates 31 March
Time 7.00pm
Venue Southern Cross Club, Phillip
Agenda Informal Meetings
Contact Judy Hunt (02) 6166 6258

Blacktown

Third Monday of Each Month

Dates 16 February, 16 March, 20 April
Time 10.30am to 12.30pm
Venue Blacktown Workers Club, Campbell St, Blacktown
Agenda The Makeup Business, Home Instead Care guests
Contact Carol Page 9671 4878 or 0403 304 833

Central Coast

Regular Meetings TBA

Dates Notifications will be sent in the mail.
Time 1.30pm to 2.30pm
Venue Central Coast Venue TBA
Agenda Informal Meetings
Contact Nadene Veitch (02) 9878 6055

Northern Beaches

Last Saturday of Every Month

Dates Meetings are run 2-3 times per year and are
Time advertised locally.
Venue Rotates please contact Coordinator
Agenda Patient Education Mornings
Contact Marissa Giuffrida (02) 9948 8133

Sutherland

Second Friday of Every Month

Dates 13 February, 13 March, 17 April (10 April is Easter)
Time 10.00am to 12.00 noon
Venue The Boardroom, Lvl 4, Sutherland Hospital
Agenda The Makeup Business, Home Instead Care guests
Contact Narelle Baker (02) 9567 8351

Tweed Heads

Third Monday of Every Even Month

Dates 16 February, 20 April
Time 4.00pm DST
Venue The Tweed Hospital, Community Room
Agenda Informal Meetings
Contact Kelly Davidson 0417 703 834

Local Support Contacts

Metro

ACT
 Judy Hunt 02 6166 6258
Blacktown
 Carol Page 0403 304 833
 02 9671 4878
Blue Mountains
 Keren Dando 02 4739 4412
Eastern Suburbs
 Margaret Kennedy 02 9665 0060
Northern Beaches
 Marissa Giuffrida 02 9948 8133
Sutherland
 Narelle Baker 02 9567 8351
 Jimali McKinnon 02 9521 2216
Wollongong
 Jill Bannister 02 4256 6730
 Melissa Murphy 0419 243 745

Country

Bathurst
 Kerry Armit O'Neill 02 6332 5153
Byron Bay
 Sue Edwards 02 6685 4440
Coonabarabran
 Loy Frater 02 6843 1022
Cootamundra
 Robyn O'Keefe 02 6942 3223
Dubbo
 Marlene Wheeler 02 6884 0564
Gold Coast/Tweed Heads
 Kelly Davidson 0417 703 834
Gosford
 Bev Keats 02 4324 5517
Goulburn
 Julie Woodward 1800 802 088

Country

Hastings Region
 Malee Lipman 02 6582 3951
Hunter Valley/Newcastle
 Karen Hansen 02 4937 2834
Kempsey
 Gayle Joyce 02 6566 8025
Northern Beaches
 Marissa Giuff
Sapphire Coast
 Christine Gough 02 6494 4169
Scone/Muswellbrook
 Barbara Wakem 02 6545 1798
Taree
 Margaret Wilkinson 02 6552 1246
Wagga Wagga
 Susan Davies 02 6926 3669