



LUPUS NEWS

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

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Merry Christmas

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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 the Hon Mr. Michael Ferguson MHA for the printing of our Newsletter and his continued support.

Editor's Apology

My sincere apology for the incorrect date and volume on the last newsletter. I had trouble getting a programme to print the last newsletter, as my computer decided to die just before it was time to set it out. Hence a new computer and Office doesn't come with Publisher, so I had to buy a new version which isn't simple any more. So I missed the date etc. when getting the newsletter out.

It was rather a shock to come back to Tassie and the cold weather. Guess we'll have to get used to it.

Congratulations to Lois and her cohorts for the members' booklet. It is a very comprehensive, yet easy to read piece of work. I hope that it will help those of our members understand our disease.

We are still having problems with our website. Apologies to those who have posted queries on it. Because our president Vic has had to move to Queensland owing to his wife's illness there has not been anyone reading and answering. At the moment it is best to write any requests to the PO Box 639 Launceston 7250 and someone will answer any queries'

LAW launch was held at the LGH on Thursday 20th October where the "Lupus A Patient Guide" was launched

Our Association is undergoing problems at the moment

If you are able to take some responsibility please talk to Bruce or Vic. But owing to Vic not being at Burnie now it will need to be one of our northern or southern Co-ordinators

Edna Brock , Editor

Please note the change in my Phone number 0419541989

At The Launch of Lupus A Patient guide.

Hon Michael Fergusson MHA , Sheryl Thomas. Representing Tasmanian Community Fund, Dr Lois Beckwith, author, and Bruce Mc Cormack



Regional Reports

Southern Report.

Greetings from the South!

Two people attended the October luncheon so there isn't much in the way of news. A special thank you to Jenny who hosted this luncheon for me. My husband and I were in South Australia with my 91 year old father-in-law. As I write I am home again but awaiting the call to return urgently. I'm sorry I had to miss the luncheon but family must come first.

Heather Cowled
Southern Coordinator

Northern

Morning tea at Kings Meadows on the 4th Thursday in the month. Please bring a plate of morning tea and have a great chat among friends.

Launch of Lupus a patient guide

The Association decided to use Lupus Week to Launch the Lupus Patient Booklet. Many thanks to Bokprint for printing and printing the banners which advertised our Association.

Thank you to the Tasmanian Community Fund for investing in the printing of this booklet, and thank you to Lois Beckwith and those members who spent time setting it up.

There were approximately 15 members in attendance. The media was well represented and Michelle O'Byrne, MHA represented the Opposition. Our patron, The minister for Health Michael Ferguson MHA launched the booklet, which has been distributed to all members, Interns at the hospital, all surgeries and Medical centres, Paramedics and the hospital pharmacy.

A big thank you to the Pathology Lab for aiding in the delivery of the booklets. If you or some members of you families would like a booklet they are available from PO Box 639, Launceston 7250. In all it was a very successful day.

For the Man Who Hated Christmas By Nancy W Gavin

It's just a small, white envelope stuck among the branches of our Christmas tree. No name, no identification, no inscription. It has peeked through the branches of our tree for the past ten years.

It all began because my husband Mike hated Christmas. Oh, not the true meaning of Christmas, but the commercial aspects of it— overspending and the frantic running around at the last minute to get a tie for uncle Harry and the dusting powder for Grandma— the gifts given in desperation because you couldn't think of anything else. Knowing he felt this way, I decided one year to bypass the usual shirts, sweaters, ties and so forth. I reached for something special just for Mike. The inspiration came in an unusual way.

Our son Kevin, who was twelve that year, was on the wrestling team at the school he attended. Shortly before Christmas, there was a non-league match against a team sponsored by an inner-city church. These youngsters, dressed in sneakers so ragged that shoestrings seemed to be the only thing holding them together, presented a sharp contrast to our boys in their spiffy blue and gold uniforms and sparkling new wrestling shoes.

As the match began, I was alarmed to see that the other team was wrestling without headgear, a kind of light helmet designed to protect a wrestler's ears. It was a luxury the ragtag team obviously could not afford.

Well we ended up walloping them. We took every weight class. Mike, seated beside me, shook his head sadly, "I wish just one of them could have won," he said. "They have a lot of potential, but losing like this could take the heart right out of them."

Mike loved kids— all kids. He so enjoyed coaching little league football, baseball and lacrosse. That's when the idea for his present came.

That afternoon, I went to a local sporting goods store and bought an assortment of wrestling head gear and shoes, and sent them anonymously to the inner-city church. On Christmas Eve, I placed a small white envelope on the tree telling Mike what I had done, and this was his gift from me.

Mike's smile was the brightest thing about Christmas that year. And that same bright smile lit up succeeding years. For each Christmas, I followed the tradition— one year sending a group of mentally handicapped youngsters to a hockey game, another year a cheque to a pair of brothers whose home had burned to the ground the week before Christmas, and on and on.

The white envelope became a highlight of our Christmas. It was always the last thing opened on Christmas morning, and our children—ignoring their new toys—would stand with wide-eyed anticipation as their dad lifted the envelope from the tree to reveal its contents. As the children grew, the toys gave way to more practical presents, but the small, white envelope never lost its allure.

The story doesn't end there. You see, we lost Mike last year to dreaded cancer. When Christmas rolled around, I was still so wrapped up in grief that I barely got the tree up. But Christmas Eve found me placing an envelope on the tree. And the next morning, I found it was magically joined by three more. Unbeknownst to the others, each of our three children had for the first time placed a white envelope on the tree for their dad. The tradition has grown and someday will expand even further with our grandchildren standing to take down the special envelope.

Mike's spirit, like the Christmas spirit will always be with us.

Thank you to Nancy Gavin. Taken from Christmas Stories, Inspirational Stories, Originally published in December 1982



Dr Michael Andrew
Williams



Dr Rebecca Gregory

Lupus and the Eye

Dr Rebecca Gregory, Foundation Doctor, Northern Ireland and Dr Michael Andrew Williams, Senior Lecturer / Honorary Ophthalmology Consultant, Queen's University of Belfast and Belfast Health and Social Care Trust

Lupus can affect almost any organ in the body, and the eyes are not exempt. Doctors who specialise in eyes and vision are ophthalmologists, and ophthalmologists describe the visual system as consisting of eyeball, optic nerve and brain. Lupus can affect any of these components of the visual system. The potential symptoms and signs therefore are wide ranging. In general, like lupus elsewhere in the body, the course of ophthalmic involvement is one of relapses interspersed with periods of remission. This narrative review will consider two aspects of lupus and the eye: the effect of the lupus itself, and the effect of medications for lupus.

Starting with the disease itself, the eyes are said to be the 'window to the soul' and ophthalmic problems can be an indicator of disease flare up. There are four main manifestations of lupus in the eye. Firstly, the most common is dry eye. One in three people with lupus have dry eye compared to one in ten of the general population. Although very rarely vision threatening, the impact of dry eye on quality of life can be significant. Several studies have attempted to assess in a standardized way how troublesome different conditions are, using a measure called 'utilities'. Mild dry eye, requiring only intermittent treatment, is judged to be about as troublesome as mild angina, while severe dry eye is about as troublesome as severe angina. While some have criticized such studies' methods, findings like these do highlight that for many people, dry eye isn't a trivial problem. A definition of dry eye is a 'syndrome of decreased tear production and increased tear evaporation'. The cornea is the clear window forming the front of the eyeball, and normally a tear film covers the surface of the cornea. Tears evaporate, and the tear film is restored with each blink. Dry eyes can be caused by a deficiency of any of the three elements which make up normal tears: the aqueous component, the mucin component which helps the tears stick to the corneal surface below, and the lipid layer which forms the most superficial layer of tears, and retards evaporation of tears between each blink. When tear quality or quantity is insufficient to protect the cornea below, symptoms occur: burning, stinging and grittiness of the eyes, and a degree of blur. 'Reflex watering' occurs when the corneal surface becomes especially irritated. Thus occasional eye watering, occurring for example when outside on a windy day, when tear evaporation is happening quickly and the surface of the eye dries as do clothes hanging on a washing line on a windy day, ironically can have dry eye as the underlying cause.

Dry eye is diagnosed simply by taking the patient's history, and by examining the tear film and corneal surface. Simple additional tests, such as 'Shirmer's test', can aid the diagnosis but are not essential, and interesting research has been done examining tear pH and protein content to investigate 'dry eye syndrome' further. Dry eye can be episodic, occurring either when symptoms are produced by environmental triggers (such as air of low humidity in an air conditioned office or in an airplane cabin), or during times associated with less frequent blinking (for example when concentrating on a computer screen). Chronic dry eye persists continuously, although can be aggravated by the same triggers as episodic dry eye. Treatment of dry eye can start with simple measures such as correcting the office temperature. However most people with dry eyes use artificial tears. There are many different types of artificial tear, all applied to the front of the eye and all designed to reestablish normal tear quality and quantity. They vary in terms of their constituents and properties. Some are aimed at people with mainly aqueous deficiency for example, while others aimed at people thought to have insufficient lipid in their tears. They also vary considerably in viscosity: the thickness of the artificial tears determines how long it takes for them to evaporate from the eye. At one end of the viscosity spectrum, watery tear drops are easier to apply but don't last long, needing to be applied many times daily, while at the other end of the spectrum the thickest artificial tears can last all night, but are so thick that they blur vision. However sometimes artificial tears aren't enough and the patient still has symptoms. Normally tears are continuously produced, and continuously escape through four small drains in the eyelids leading to the nose, called the nasolacrimal ducts. In dry eye, tiny plugs can very easily be placed into two or more of these duct openings in the eyelids to block a proportion of tear drainage, and thereby aid retention of tears on the eye surface.

The second ophthalmic problem lupus can cause 'red eye'. Inflammation of any of the structures at the front of the eye can cause red eye. Keratitis is inflammation of the cornea. While this is rare in lupus, it can be associated with a serious potential side effect called 'guttering', when thinning develops at the edge of the cornea. At its worst, the cornea can thin right through and a small pinpoint perforation can occur. If noted, the ophthalmologist should realize that corneal guttering indicates the lupus is active throughout the body and therefore eye drops aren't enough—'systemic' steroid treatment is needed, for example as tablets or intravenously rather than just eye drops. Another cause of red eye in lupus is scleritis: inflammation of sclera, the white protective outer coat of the eye. The sclera has a rich supply of sensory nerves, and thus the pain of scleritis can be severe, to the point of being incapacitating. Scleritis pain is centered on the eye, but can radiate to the head and jaw and can be mistaken for other conditions. The characteristic feature of scleritis pain however is that it's worse at night, classically waking the patient from sleep. The presence of scleritis should again alert the ophthalmologist to the fact that the patient's lupus is active everywhere, and so systemic treatment is again appropriate.

The eyeballs usually move in tandem and when they don't, the result is the third potential ophthalmic manifestation of lupus: double vision. Momentary double vision is fairly common in anybody, for example when tired or sick. This is normal and with a couple of blinks it clears. However in lupus approximately a third of people have eye movement problems, often because of lupus affecting the muscles that control eye movement, and sometimes associated with pain on looking to the side. This often improves with treatment of lupus.

Finally vision loss in lupus can occur when the retina of the eye is affected. The retina is the equivalent of the camera film of the eye, the part which turns light into nerve signals, and it lines the back of the eyeball like wallpaper lines the inside of a room. Retinal involvement is said to occur one in ten people with lupus. The characteristic complaint is loss of vision often occurring over days, but also distortion of straight lines like lampposts, or difficulty reading even with reading glasses on. In lupus it is specifically the blood vessels in the retina that become inflamed, termed retinal vasculitis. Mild retinal vasculitis may not cause any symptoms, but can cause signs apparent on examination of the eye. If the retinal vasculitis is progressive, then the retinal arteries become constricted and eventually close, leaving the retina deprived of oxygen. The eye responds by sprouting new blood vessels. This is not a good thing however, as these new blood vessels are abnormal. They have a tendency to bleed, and lack the supporting scaffold of tissue that normal blood vessels have. Treatment for retinal vasculitis is initially steroids in some form or other, such as tablets. Treatments for leaky blood vessels in the eye include treatment of the underlying lupus, but also laser to adjacent and surrounding retinal tissue. The laser is not the same as that given to people who want rid of their glasses, but is the same as that given to some with diabetic retinopathy. It is termed 'retinal laser photocoagulation', and is usually completely painless, and usually effective at causing the new retinal blood vessels to regress before they bleed.

Two of the mainstay treatments for lupus are steroids and hydroxychloroquine (for example Plaquenil®). Although these treatments can be very effective in keeping lupus in remission and minimizing eye problems, the medications themselves have side effects that can affect the visual system. It is important to be aware of these potential side effects for appropriate action can be taken early.

Steroids can be given in several forms, from eye drops, to injections beside the eye or into the eye, to tablets, intravenous drips or intramuscular injections. The form in which they are given depends on many factors, not least the reason why they are being given. Suppressing the immune system, with steroids (or with 'steroid-sparing agents') is like walking a tightrope: immune system suppression may settle a flare of lupus, but can leave the door open to infections, including eye infections. For example steroid eye drops should never be used without medical supervision, as they can allow reactivation of herpes simplex virus in the cornea, resulting in ulceration and a red, sore eye. Herpes simplex corneal ulcers require ophthalmic assessment and usually antiviral eye ointment.

Most side effects of steroids are related to the dose and duration of treatment. An ocular side effect of steroids is cataract, specifically 'posterior subcapsular' cataract. The symptom of cataract is gradual painless blurring of vision. Cataract can also commonly cause glare with oncoming headlights, particularly in darkness when the pupils are bigger. Early cataracts can also, transiently, make the eye more short sighted. Cataracts can be treated with surgery, and although no operation is free of complications, including cataract surgery, it is generally successful. However the only reason to undergo cataract surgery is if the patient's symptoms are sufficient to interfere with day-to-day life: otherwise cataracts do no harm if left, other than slowly progressing. Cataracts can be detected during routine eye tests.

Raised eye pressure sufficient to potentially damage the optic nerve is known as glaucoma, and another potential ocular side effect of steroids is 'steroid induced glaucoma'. It is not related to dose or duration of steroid use, but is an idiosyncratic side effect, seemingly random. The treatment for glaucoma consists of eye drops and rarely eye surgery is needed, but often the eye pressure declines back to normal levels if or when steroid dose is reduced.

Another medication used for lupus is hydroxychloroquine. Ophthalmologists are familiar with hydroxychloroquine as it can rarely cause toxicity to the retina. Toxicity eventually causes the central retina (also called the 'macula') to take on a characteristic "bull's eye" appearance, and at the bulls eye stage damage to the central vision is irreversible. The challenge is to detect toxicity before this stage. Risk factors for hydroxychloroquine retinal toxicity include duration of treatment (particularly use for seven years or more), daily dose (the maximum dose advised depends on lean body weight), preexisting kidney or liver impairment or a preexisting macular problem. In 2009 the UK's Royal College of Ophthalmologists published recommendations for screening, including guidance on when to refer to an ophthalmologist. The guidelines are publically available online. It is advised that at the clinic where hydroxychloroquine is started, the patient should be asked about any visual symptoms and have near vision checked. If any concerns arise, then the patient should attend their optician, as the symptoms may be for reasons entirely unrelated to hydroxychloroquine or lupus. The optician can then refer to the ophthalmology clinic if necessary. If a patient notices new visual symptoms while on hydroxychloroquine, they should both speak to the doctor who prescribed the medication (as suddenly stopping it may cause a flare up) and also attend their optician. In 2011, the American Academy of Ophthalmology published their revised guidelines. It should be emphasized that retinal toxicity due to hydroxychloroquine is possible, but extremely rare.

Finally anecdotally people often worry that using their eyes, by reading or watching television excessively, may harm their vision. However this is not true: the gift of vision is there to be used, so enjoy the views you choose!

Summary

Lupus and its treatment can affect the visual system in a variety of ways, and it is important to be vigilant of visual symptoms in lupus, as early detection of problems and appropriate treatment may prevent potential damage to the vision. Regular eye checks will help maintain healthy eyes now and in the future.

Figure 1. Examination of tear film and corneal surface



Figure 2 Near Vision Testing



Thank you to Lupus News and Views UK for permission to print this article

from Summer 2014, Vol no. 103.

Arthritis and Exercise

Arthritis can cause pain, stiffness and often inflammation in one or more joints or muscles. Regular gentle exercise can reduce some of the symptoms of arthritis and improve joint mobility and strength.

People with arthritis should choose their type of exercise carefully. Be guided by your doctor or a health professional such as a physiotherapist or exercise physiologist.

Osteoarthritis is common

Osteoarthritis is the most common form of arthritis. Normally the two bones of a joint are cushioned with a strong flexible tissue called cartilage. In osteoarthritis the cartilage deteriorates, causing pain and stiffness.

Cartilage doesn't have a blood supply. It relies on synovial fluid moving in and out of the joint to nourish it and take away waste products. Exercise helps this process, reducing some symptoms of arthritis.

Exercise can relieve symptoms

Regular, gentle exercise can have many benefits for people with arthritis. Exercise can:

- Facilitate joint nourishment
- Ease pain and joint stiffness and improve flexibility
- Build muscular strength and improve balance
- Reduce joint deformity and improve posture
- Prevent or manage osteoporosis (Thinning of the bones) by maintaining bone density
- Improve overall health and fitness and lower stress levels
- Help maintain a healthy body weight

Different types of exercise

An inflamed, hot or painful joint needs rest. However, too little exercise can cause muscle weakness, pain and stiffness.

People with arthritis should do some form of physical activity every day. This may include:

- **Mobility exercises** –such as stretching, to maintain or improve the joint's range of motion and flexibility.
- **Strength exercises**— such as weight bearing exercises, to build muscle strength and provide stability to the joint and improve your ability to perform daily tasks.
- **Aerobic exercises** - such as walking or cycling, to improve cardiovascular fitness.

Useful exercises

Many different types of exercise are suitable for people with arthritis, including:

- Dancing
- Swimming or water exercise classes
- Walking or Nordic walking (walking with ski poles)
- Chair exercises
- Low impact aerobics
- Strength training
- Tai Chi

General cautions and suggestions

Your doctor or health or fitness professional can provide you with advice specific to you. General suggestions on safe exercising include:

- See your doctor before starting any new exercise program. If you have had a joint replaced, find out from your surgeon or physiotherapist which movements you should limit or avoid
- Don't exercise a painful, inflamed or hot joint. You can move the joint gently through its range of movement several times to help reduce stiffness and improve circulation.
- Start gently and increase the intensity of your exercise program gradually over weeks or months
- Warm up thoroughly beforehand. Cool down after exercise with gentle, sustained stretches
- Pay attention to good technique and try to move smoothly. Don't force a joint beyond a comfortable range of motion
- If your joint feels particularly painful afterwards (for longer than two hours after an exercise session), reduce the intensity of your next exercise session
- If an activity causes you pain or increases your pain beyond what is normal then stop this activity
- Increase incidental activity in your lifestyle. For example, walk to nearby shops instead of driving.

This article is found on Better Health Channel, Victoria. To learn more go to www.betterhealth.vic.gov.au on the internet. Thank you to Better Health Channel for permission to print.

Christmas Pudding Fantasy

A report has reached us from Westbury
 A report that went off with a bang
 An explosion occurred in the vestry,
 Where the pudding eaters gang
 Were holding their Christmas digestry
 Of puddings. (Weight watcher go hang)
 It appears one member named Marie
 Had pinched the best pud of the lot
 And had eaten the pud in a hurry,
 Which was greedy. You can't say 'twas not.
 Soon her eyes opened wide and went starry
 And she dropped to the floor with a flop
 She started to swell and grow fatter
 Till she filled all the room floor to top,
 So they had to retreat, didn't matter
 For they carried their puds and the lot
 Then some fool lit a match, the mad hatter,
 And poor Marie went off with a POP
 A pop, did I say? Those who heard it
 Said, more like a cannon blast
 Satisfactory explosion I'd word it.
 For Marie blew up pretty fast.
 Internal combustion, the verdict
 Our Marie did nothing by half
 The rector rushed in all excited.
 "Was that the cannon I heard?
 He was not going off till we'd lighted
 Our candles. Now this is absurd"
 So they told him how Marie, ignited
 Had gone off with never a word.
 They found bits of Marie still sticking
 To the ceiling and curtains and floor
 At least she was no longer kicking
 Nor writing poems, what's more
 So they just closed the door on it sticking

This notice which quite said it all. This room contains all that remains of
 Marie Dazeley who so crazily scoffed a pud. Which surely would have fed a
 score or no doubt more. So she exploded, and we know this room contains
 all that remains of Marie dear. It's all in here.

Now the moral, of course , of this story
 Is go easy on Christmas Pud
 Don't go stuffing it down like our Marie
 Or it never will do you no good.
 Be like me, eat not more than one hourly

By Marie Dazeley

For Your Diary

**Please join us at 154 Windermere Road
For our Christmas luncheon**

Bring a salad, Meat and Christmas Pudding provided

At the above address at 11.00 am

**Please try and make it, we never know what is around the
corner**

Love to have you all

**Have a Happy
Christmas**

Christmas 1993

Well, Christmas is here once more.
I've cards and letters by the score.
Little angels adorn my Christmas tree
'Tis a very strange place for them to be!
But on that very first Christmas Day
This was the message they came to say,
"Goodwill to men and peace on earth".
Lord as we remember your simple birth,
May our lives be free from self and sin,
Fit for you to dwell therein.

By Marie Dazeley