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NUMBER 24

MAY 2015

newsletter

Scleroderma

New Zealand support group

Seminar Success

Welcome to the latest newsletter coming hard on the heels of the Wellington Seminar.

We had a good line-up of speakers and learned plenty from them about how to manage our conditions. You will read about their talks further into the newsletter.

It was good to see the out-of-towners there also as it was a big effort to get here from faraway places like Dipton, Christchurch, Hamilton, Auckland, and not forgetting our Palmy and Kapiti ladies.

We have a busy year ahead and would like your input into the upcoming events.

The first one will be World Scleroderma Day. We would like to hear what you are doing in your area.

No matter how big or small your get-together is, sharing your photos and news of your events with the rest of us will make it even better.

Dianne explains in her President's report, the Wellington region group is having an art exhibition in the foyer of the Odins gallery.

All of those who are artistic will be showing their paintings, jewellery, card-making and craft works for the week of the 21st June to the 5th July.

We encourage you to come along and support the group to see what talents the group has. The products on show can also be purchased.

Hamilton group are having a movie afternoon.



Every good scleroderma seminar marches on its stomach.

Napoleon Bonaparte



President's Column

May 2015

Greetings to you all. We have had a busy year so far with Scleroderma New Zealand becoming incorporated in February. Now, we have our structure in place.

President: Dianne Purdie (Wellington), Vice President: Allan Edmondson (Tuakau, Auckland), Secretary: Gordon Purdie (Wellington) and Treasurer: Gabrielle Conway (Auckland).

Committee members Jenny Andrews (Invercargill), Carolyn Barkhausen (Christchurch), Linda Bell (Hamilton), Adrienne Burleigh (Kapiti), Chris Carlyon (Palmerston North), Jo Harris (Wellington), Maureen Kirby (Invercargill), Jan Lowe (Kapiti), Cushla Marsters (Wellington), Tina Mclean (Wellington), Heather Milligan (Dipton), Barbara and John Spavin (Lower Hutt), Julie Rolston (Wanganui), Kim Tocker (Christchurch), Judy Trewartha (Auckland) and Lorraine Wenlock (Invercargill).

Newsletter Editors Barbara and John Spavin

Web Master: John Spavin

We had our first committee meeting on the 15th – 17th of March via email.

Decisions made:-

Financial year 1st April to 31st March.

AGM Thursday 18th to Sunday 21st June.

Registered Charity, We decided that Scleroderma NZ Inc will apply to become a registered Charity; this will give donors more confidence in our society.

Calendars We decided to support Maureen Kirby by selling her fundraising calendars for 2016. Some of the funds will come to Scleroderma NZ Inc

Memberships fees were discussed along with other possible fundraising activities. There were no decisions made on these topics and these thoughts will come up again at the next committee meeting.

Next Committee meeting, 1st to 3rd of June

We have just had an action-packed seminar in Wellington, which Barbara and John have filled you in on and the next



activity will be world Scleroderma Day held on the 29th of June.

Wellington holds an Art Exhibition at the Odlins Gallery in the Foyer Gallery in Lower Hutt from the 21 of June – 5 of July. Waikato will be holding a fundraising afternoon at the movies in Hamilton on the 29th of June.

We have also linked up to the World Scleroderma Day website worldsclerodermaday.org It makes us part of the world scleroderma community. You can give a 25 second video here where to explain how Scleroderma has affected you. You may also sign the petition at the bottom of the home page which calls for improved care for people with Scleroderma.

We are after ideas on how to fundraise. Please contact me, Dianne Purdie, on diannepurdie@xtra.co.nz and I will put your ideas to the committee.

Thanks to the committee for their sterling efforts. We have a long road to make life here better for scleroderma patients and their families. We need sound management of scleroderma, beginning with ourselves, with ongoing education and continuing good relations with our medical specialists and Arthritis New Zealand.

This is your society. Please give us your ideas and ask questions. We can help find ways to manage your scleroderma. We have a network of good listeners too. Feel free to contact me and for help. Looking forward to working with you all.

Dianne Purdie

President, Scleroderma NZ Inc

Phone (04) 479 5548, email diannepurdie@xtra.co.nz

Scleroderma Seminar 2015

Good turnout, very good speakers - success

This year's Scleroderma Seminar went off very well. We attracted delegates from many parts of both islands. Presentations were always informative, sometimes entertaining and all well received by the nearly 40 delegates. For those who couldn't attend, here is information on the business end of the seminar.

Dr John Carter: Stem Cell Transplant for Scleroderma

In a European trial to treat systemic scleroderma patients with stem cell transplants, about 10% of people died from the treatment.

The survival rate after 5 years was about 80% and 65% for those who did not have a transplant. After 10 years it was about 70% and 50% respectively.

Dr John Carter, consultant haematologist at Wellington Hospital's blood and cancer centre, talked about stem cell transplants generally: what they are, how they work and how they can be effective.



His speciality is stem cell transplants. He declared at the outset of his talk to the seminar that such procedures, while common in the treatment of blood cancers, are rarer for scleroderma.

He says scleroderma is difficult to treat as it can involve lung, heart, skin and joints. Perhaps reflecting the difficulty, figures for the US in 2011 showed that of nearly 20 thousand stem cell transplants, categorised by disease, scleroderma was lumped in with "other", which totalled fewer than 500.

Doctors trying to kill cancer cells or correct the misdirected immune process obliterate them with high-dose radiation, in combination with chemotherapy. Stem cells die too in the treatment but are reintroduced by a transplant. The theory is that the transplanted supply of stem cells will repopulate the body with healthy cells and end the disease.

Transplants are common in the treatment of blood cancer sufferers. For those who have the treatment early in their disease, the survival rate after 6 years is about 60%. It decreases for those treated with more severe or advanced symptoms, the extreme of which is 20% survival after 6 years.

Dr Carter says the mortality rate from the transplants alarms rheumatism and autoimmune specialists who are unused to such a toll.

Stem cells produce immune cells but they make up just 1% of the body's cells. Dr Carter says the modern way to retrieve stem cells is to extract them from blood. Stem cells can be sourced from a patient's own blood, from siblings or unrelated donors. In earlier years doctors sucked them from the pelvic bones using large needles in a short but painful procedure.

The blood stem cells used are CD34 positive cells.

Dr Carter says use of stem cell transplants to treat autoimmune diseases like scleroderma, multiple sclerosis and Crohn's disease could be performed in New Zealand but the rheumatologist or other specialist would need to recommend it. Some Kiwis travel overseas to have it done. It's not cheap. In Moscow, it can be had for \$US40 thousand, in Singapore for \$US 80 thousand and in the United States, \$US200 thousand.

Scleroderma Seminar 2015

Dr Richard Steele: Overview of treatment for systemic sclerosis

It's not great to have scleroderma and its associated ailments but thank your stars you are living now and not a couple of hundred years ago.

For then, Dr Richard Steel says, doctors probably killed more patients than they successfully treated.

Dr Steele is a clinical immunologist in Wellington and says modern medicine bases itself on clinical trials and high quality evidence.

Doctors and medical researchers grade the quality of evidence according to how rigorously they gathered it, ranging from level 1: high quality randomised trials across many studies down to 5: expert opinion.

Treatment for scleroderma is based on this evidence.

Scleroderma's problem is that it's relatively rare so it's difficult to recruit enough people for an authoritative trial. Scleroderma also manifests itself in so many different ways, Dr Steele says, so how do you know that treatments will work for all sufferers equally?

He says doctors have only a moderate understanding of the treatment because the disease attacks in so many different ways and can start slowly and lessen equally slowly. It's difficult in a trial to measure the efficacy of a treatment. But through it all, the evidence-based approach is paramount.

Trials for treatment are more and more becoming multi-national so there are greater numbers of patients to test. However, a cure is a long way off, he says, because of the slow progress to understand it coupled with its rarity.

Treatment day-to-day for patients with scleroderma starts with doctors evaluating the possible symptoms:

- Raynaud's.
- skin sores,
- organ involvement,
- overlap with other auto-immune diseases and
- a hunt for the tell-tale auto anti-body profile associated with some sub-groups of systemic sclerosis.



Because scleroderma varies in its effects so much, doctors tailor their treatment to the individual.

It begins with an inflammatory period, which lasts for several years and after that Dr Steele says it becomes more difficult to treat. So he says doctors focus of early treatments on the inflammatory part of the condition.

"If we can treat that aggressively and effectively then maybe we get less of the fibrosis and the other more permanent problems associated with systemic sclerosis," he says. Early treatment often depends on the GP recognising what their patient has and referring them to a specialist or the patient being assertive enough to have the possibility of scleroderma examined.

Dr Steele ran through the various ways that scleroderma manifests itself and the types of drugs and treatments brought to bear against it. He explained cases in which a range of immunosuppressives are used to treat the disease from its outset and as it progresses.

He covered Raynaud's, which he says is not just about hands and feet but about core body temperature. A life in the tropics should fix the temperature but that's not possible so patients should always dress warmly, never smoke and try to avoid stress.

As if to illustrate the variety of ways in which scleroderma attacks the body, Dr Steele ranged over potential effects on the heart, lungs, kidneys and even erectile dysfunction. He canvassed the treatment, types of drugs and severity with which it can affect a patient.

We may not live with the seat-of-the-pants medicine of 200 years ago but the breadth and scope of scleroderma is still a big challenge for modern medicine. A cure eludes it but Dr Steele says significant progress has been made with a greater variety of treatments and better scientific evidence to guide us.

Scleroderma Seminar 2015

Dr Beth Henderson: Dental Care for Scleroderma

The side effects of scleroderma affect teeth and gums in many ways.

Dr Henderson presented a grim list of how teeth suffer from lack of saliva, reflux and an inability to manipulate a toothbrush to clean them effectively. She concentrated her talk on dental problems and ways to deal with them.

Up front was dry mouth. Dr Henderson says sufferers are susceptible to tooth decay and gum disease. The saliva can turn acidic. Alkaline saliva is preferred as acid attacks tooth enamel. She says fibrosis of the oesophagus can make reflux a problem as it's highly acidic and erodes tooth enamel.

She says dentists and dental hygienists can't cure the problem but they can help a patients who see them regularly to manage it.

She says professionals have recently recognised the importance of saliva's role in protecting the teeth and mouth tissues. She helps patients fight dry mouth with aids such mouth washes. She gave as example, BioXtra and Oral 7 as rinses that she had found to be beneficial. While they're not commonly available at chemists, they can be bought online. There are gels that help keep the mouth moist.

Dr Henderson recommends chewing sugar-free gum to

stimulate an alkaline environment.

Gastric reflux, strongly acidic, attacks tooth enamel. It can destroy the top layer of enamel to expose softer dentine, which, she says, erodes much faster than enamel. Teeth eroded to the underlying dentine are difficult to fix because they're soft and fillings won't adhere to them.

Management includes chewing gum, a mouth rinse using baking soda (a teaspoon in a glass of water). She recommends sipping the baking soda solution throughout the day, especially after meals. To overcome the taste, Dr Henderson says just drop a small amount of almond or peppermint flavouring into it.

High levels of plaque can result from patients who have difficulty cleaning their teeth or a dry mouth. Plaque encourages decay around the tops of the teeth and can occur quickly. It harbours acid-producing bacteria that exacerbate problems already inflicted by reflux and a dry mouth.

To remove them, Dr Henderson says she uses Curasept, an anti-bacterial mouthwash. She then uses a selection of high-dose fluoride toothpastes and tooth mousse to replenish minerals in the enamel.

Gum disease is associated with scleroderma. It's acidic saliva that brings on plaque, which, in turn, irritates the gums. The gums can swell and release toxins and affect the bone structure around the teeth. It may not be obvious to the patient, another reason for regular visits to the dentist.

Dr Henderson told the seminar that she prefers electric toothbrushes, particularly if dexterity is a problem. She recommends either Braun or a Philips' Sonicare. If you prefer a manual toothbrush, she says use the smallest head that you can find. The bristles should be flat, not trimmed in a jagged pattern. She recommended flossing too, calling it, "mandatory".

To help patients with tightened skin and lips around the mouth, she has exercises design to retain elasticity, such as pursing of lips and exaggerated smiles while leaving the lips to cover the teeth. She recommends that patient carers should accompany the patient at the dentists so they can learn about the tooth-cleaning regime.

Dr Henderson says it's most important that people with scleroderma visit a dentist and dental hygienist regularly, to can catch problems early, before they become serious. She says many dentists are unfamiliar with scleroderma so let them know about the particular problems you experience.



Scleroderma Seminar 2015

Dr Rob McLachlan: Living with a chronic illness

A chronic illness can last from a couple of months to become lifelong. Often, it's treatable but not curable

DR Rob McLachlan, a senior registrar, says half of all consultations in primary health care are for a chronic illness. Research in the United States suggests that 7 out of every 10 deaths each year are from a chronic illness.

Those with a chronic illness are two-to-three times more likely to develop stress, depressive and anxiety conditions.

Responses

Dr McLachlan says the response of many who have contracted a chronic illness is a feeling of distress because of the massive changes to living day-to-day. There can be a feeling of guilt too, say with a disease like diabetes where patients might feel bad about eating habits that they fear could have led to the disease.

Grief can be present for the life-style that has gone with the diagnosis. It can start with denial, progress and bargaining and anger and remain as sadness.

Coping

The first step to begin to cope with a chronic illness is to face up to the diagnosis, Dr McLachlan says. Once that's done it leads to a better long-term psychological adjustment. He says it works, as studies have shown, particularly in women with breast cancer.

"We know that if you look at their psychological health 3 years after diagnosis ... and they've demonstrated an aversion to this from a few months to several years then they're worse off than if they'd faced up to things from the outset," he says.

He says methods for coping include learning about your condition. It doesn't matter how old you are, everyone has the ability to understand their condition better.

Interact with health professionals to learn how to get the best out of your treatment under them. Dr McLachlan says accepting your condition and that it may be chronic is not resignation. He says the nature of a chronic illness is not just psychological; not just social and not just biological - it's a combination of all three and it's different for everyone.

Getting the best from your medical appointments is important,



Dr McLachlan says. He has a checklist that he titles 'Come prepared':

- List of questions/concerns to address
- Bring your medication list/tablets-not just the ones you need replaced.
- Consider bringing someone to the appointment
- (don't make another appointment straight afterwards ideally)
- Let us know if you need to leave by a certain time.
- Appointments can be moved/linked
- Investigations can be done closer to home.

He says to manage those elements of your life that you have control over. Eat healthily, exercise as you can and don't forget to pursue hobbies. If you find you spend time with people who are not supportive of you, spend less time with them.

Find support:

- Let go of unnecessary obligations.
- Time off work/alter hours.
- Seek financial support.
- Do not be afraid to ask for help of family, friends, health professionals.
- Support groups; join people with similar experiences whether scleroderma-specific or not.

Scleroderma Seminar 2015

Dr Lisa Judd: Care of Skin for Scleroderma



Countering the effects of scleroderma on skin involves a range of ointments and ultra violet. But they are all aimed at symptoms, not cures.

Dr Judd ranged over medicinal treatments for some of the symptoms. Some treatments can be used against skin hardening, dilated blood vessels (telangiectasia), itches, calcinosis, ulcers, Raynaud's and ulcers.

Symptoms she says you can't counter include absence of sweating, nail changes, pigmentary changes and skin atrophy.

For skin hardening, she listed a dozen or so medicines and treatments and discussed Imiquimod and Calcipotriol in detail. Of these two, she says Imiquimod has been used in localised scleroderma with some success. However, there are only a small number of case reports. Dr Judd says Calcipotriol has had mixed results but remains untried for systemic sclerosis.

Phototherapy

Ultraviolet light can be effective in the treatment of localised skin disorders and Dr Judd explained the different intensities and wave lengths that she works with to treat patients.



Scleroderma affects skin from the surface to deeper down. Of the two main ultraviolet wavelengths that the sun shines on us, ultraviolet A (UVA) rays have a longer wavelength, which penetrate deeper than ultraviolet B (UVB). It's the

UVB rays that cause sunburn. Dr Judd says although they can't penetrate as deeply as UVB, a form of light called narrow-band UVB is commonly used here. Facilities in New Zealand for UVA treatment are limited and expensive.

Ulcers

There are measures you can take to reduce the effects of skin ulcers. Dr Judd listed:

- Keep warm
- Avoid restricting circulation with tight clothes
- Protect from injury
- Don't smoke
- Moisturise

Raynaud's

Patients with Raynaud's can aggravate their condition by using a soap-based cleanser. Dr Judd advises them to use a soap-free cleanser. She says there are many on the market, for example, from Neutrogena and Aveeno .

She says when it comes to choosing a moisturiser, get one that works for you. There is no list of best or most effective although those designed for eczema sufferers are often most effective.

As general measures she advises:

- Keep warm, especially hands and feet
- Wear mittens or gloves for handling frozen foods
- Use a fleecy steering wheel cover
- Avoid cold water
- Don't smoke

Dry Skin

Dr Judd's advice for those with dry skin is similar to her advice for Raynaud's. Use a soap free cleanser eg aqueous cream, emulsifying ointment, or numerous commercial brands that are more pleasing to use. Examples are Aveeno cleansers, Cetaphil, QV, Neutrogena and the like.

Again, there is no clinical grounds to recommend one moisturiser over another - choose the one that you like best.

Scleroderma Seminar 2015

Robyn Tuohy, Arthritis New Zealand Educator



Robyn outlined the role of Arthritis New Zealand in supporting groups such as Scleroderma New Zealand.

She says the organisation seeks partnerships with like groups

Robyn says up to 580 thousand people in New Zealand are living with some form of arthritis.

She was keen to find out the specific concerns of scleroderma sufferers. She will include Scleroderma New Zealand in her newsletter subscription list so members can become aware of the services her organisation has available, even if some aren't specifically for scleroderma.

Arthritis New Zealand runs courses of interest to scleroderma patients including living a healthy lifestyle and help with self-management. Developed at Stanford University, it takes a maximum of 15 participants each course. It's held in different parts of New Zealand, the Wairapapa, Horowhenua, Counties-Manukau and Hwews Bay.

Arthritis has a nationwide support network and assigns local educators, some of whom have spoken in past years at the regular meeting that we have held in Lower Hutt.



They don't resemble blotting paper but the audience at the scleroderma seminar soaked up many tidbits of knowledge in the day-long event.

World Scleroderma Day - Hutt Art Exhibition

We are planning an event again this year to mark World Scleroderma Day. It will be a static display of art and craft in a Lower Hutt gallery

Those of you who would like to participate in this exhibition, are very welcome.

We will be having mixed media with whatever you choose.

Crafts include:

- painting,
- mosaics,
- embroidery,
- jewellery,
- pottery
- photography,
- floral art and
- poetry.

Whatever you think would look good is welcome.

Our theme will be sunflowers, to brighten up winter, however we will be happy with what ever you would like to put in.

We will take over the Foyer Gallery, at the Odlin's Gallery in Lower Hutt, which is a small space, but a good start for us.

Here are the details

Set up on Wednesday the 17th of June

Opening night will be Saturday night the 20th from 5pm-7pm

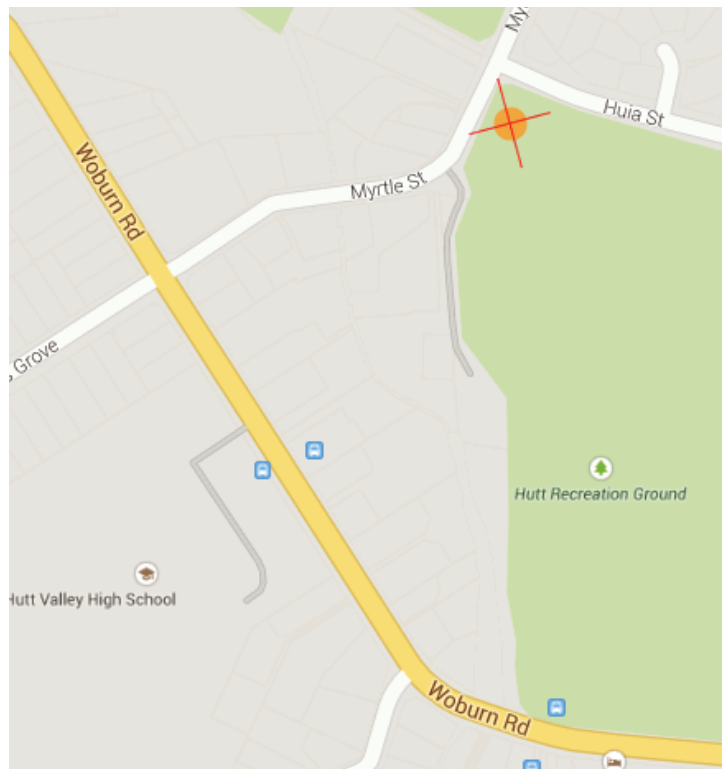
General opening to the Public will be from June 21st - July 5th

We will have to take our art down on the 5th of July after 4:30pm

We are very fortunate as the Muriel Hopper Hutt Art Awards Exhibition will be on at the same time, this is the big exhibition for the year for the Hutt Art Society, so we will get a big spin off from this.

See the website on www.huttart.co.nz/#!whats-on/coi

They have their opening night on Friday the 19th of June.



Kiwi specialist features at Eu. conference

The UK's Raynaud's and Scleroderma Association is staging a conference this year to mark World Scleroderma Day. The first speaker up at this international event is a Kiwi who graduated from Otago University.

According to the biography in the conference information pack, Professor Neil McHugh graduated from Otago University Medical School and completed physician training before specialising in the sub-specialty of rheumatology.

He has had research fellowships at the Walter Elisa Hall in Melbourne (1985), Yale University Medical School (1990-1991) and the National Heart and Lung Institute (2002-2004).

He has been a Consultant Rheumatologist at the RNHRD since 1991 where he leads the connective tissue disease service and he is currently Professor of Pharmacoepidemiology at the University of Bath. He is the current lead of the ARUK clinical study group for spondyloarthritis. His research interests include the characterisation of autoantibody formation in scleroderma.

That's a long way from Dunedin!



Have scleroderma (and bike), will travel

When she last featured in our newsletter, Yvonne had just completed the Otago Rail Trail. She wanted to get out and not be tied down by scleroderma.

She has been at it again. This time in the Pureora Timber Trail, which she rode in March this year. "The trail is 85km long," Yvonne says, "We took 2 days riding it, staying overnight at a lovely rustic place called Blackfern Lodge."

"The Lodge isn't on the trail (It added an extra 12km to the trip, including a whopping hill!). There are suspension bridges spanning high ravines - pretty scary riding across for the first time!"

The picture shows Yvonne on the highest bridge - , 53 metres up.

"Highly recommended for all," she says.

Achieved something? Share it with members.



We are now: Scleroderma New Zealand Incorporated

A brisk email storm in March settled on a group willing to act as committee members.

Your committee has settled into a routine to run the support group on a more formal basis than has existed over the past 6 years.

A financial year has been settled on as 1 April to 31 March, in keeping with most businesses.

The committee meets by email and spread meeting over a few days to give all members a chance to participate.

Dianne Purdie advocated incorporation as a means to try to secure charity status (in progress at present) and to attract donations.

The group's annual general meeting will be held in mid-June.

Inaugural committee members and office holders



President:	Maureen Kirby (Invercargill)
Dianne Purdie (Wellington)	Jan Lowe (Kapiti)
Vice President:	Cushla Masters (Wellington)
Allan Edmondson (Auckland)	Tina McLean (Wellington)
Secretary:	Heather Milligan (Dipton)
Gordon Purdie (Wellington)	Julie Rolston (Wanganui)
Treasurer:	Barbara Spavin (Wellington)
Gabrielle Conway (Auckland)	John Spavin (Wellington)
Committee:	Kim Tocker (Christchurch)
Jenny Andrews (Winton)	Judy Trewartha (Auckland)
Linda Bell (Hamilton)	Lorraine Wenlock (Invercargill)
Adrienne Burleigh (Kapiti)	
Chris Carlyon (Palmerston North)	
Jo Harris (Wellington)	

Sclderoderma Waikato Movie Fundraiser

Thursday, June 11 @ 8:30 pm - 10:30 pm | \$15



Where: Metro Cinema Centreplace– 12 Ward Street Hamilton (Cinema 3)

When: Thursday 11th June at 8:30pm

Ticket Price: \$15 each

For Booking or any further enquiries please phone or email:

Linda Bell 07 853 5434 or Mob: 027 548 1214 Email: linda.bell@hotmail.co.nz



www.scleroderma.org.nz

Lab reports

A woman brought a limp parrot into a veterinary clinic. She laid her pet on the table, The vet put his stethoscope to the bird's chest. "I'm so sorry, Polly has passed away," he said.

"Are you sure?" The owner wailed. "She might only be in a coma or something."

The vet shrugged, turned and left the room, returning in a few moments with a beautiful black Labrador.

As the bird's owner looked on in amazement, the dog stood on his hind legs, put his front paws on the examination table and sniffed the parrot from top to bottom.

He then looked at the vet with sad eyes and shook his head, "no."

The vet escorted the dog from the room and returned a few moments later with a cat. The cat jumped up and delicately sniffed the bird. The cat then sat back. It too shook its head "no" it meowed and walked out of the room.

The vet looked at the woman and said, "I'm sorry, but, as I said, your parrot is most definitely 100% certifiably dead."

He then turned to his computer terminal, hit a few keys and produced a bill, which he handed to the woman.

The parrot's owner, still in shock, took the bill. "A HUNDRED AND FIFTY DOLLARS!" She cried. "A hundred and fifty dollars just to tell me my bird is dead?"

The vet shrugged. "If you'd taken my word for it, the bill would only have been \$20, but ... with the Lab Report and the Cat Scan ... it's \$150.00.



Noticeboard



Next Wellington
Meeting:
1 August 2015 -
1.30pm

Waikato
Film Viewing
June 11 8.30pm

Your News
We're keen to get news
from: Auckland, Hamilton,
Palmerston North and
Southland groups

