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# Scleroderma

## New Zealand support group

## Autumn 2017

Welcome to the first newsletter of the year.  
I trust that you all enjoyed your Christmas break with pain free joints and at least a little jollification.

In this newsletter we have a report from Dianne, the President. She will keep you up to date with all the latest news especially the seminar coming up in May. You can find the details as you read on.

Results of the quilt raffle are shown with pictures of these wonderful quilts. There is a big talent of quilters out there.

World Scleroderma Day in June: tell us what you have planned in your area. You can read what the Wellie and Palmy ladies have planned.

Barbara gives a report on her recent holiday abroad, taking her scleroderma with her, and Jan tells us about her battles with the Ministry of Health, trying to get a fair wage for carers.

Rob tells us about his diet which, is working wonders for him and his wife.

Last there is the contacts list and a chicken story.

If you have changed your email or no longer wish to receive the newsletters, you can easily unsubscribe online and that will take you off the list.





# President's Report

## Greetings to you all for 2017

It has been a very unsettled summer so far and I am keeping my fingers crossed for some more heat for February.



President Diane and Hami at Wellington's February meeting.

We have had a small taste of it here in Wellington this week. It has been a busy time for Gordon and me on a personal note with four flower shows since September with our last one on the 4th & 5th of February, which was a begonia, fuchsia and dahlia show, a lot of work and support from all the good folk in Wellington and Lower Hutt and beyond. Barbara Spavin did very well in her flower and citrus classes too!

Judy Trewartha has been very busy raising funds for Scleroderma NZ with her beautiful quilt-making - a huge thank you to Judy for all her efforts, which are very much appreciated, and to all of you out there who supported buying raffle tickets.

Gordon and I were one of the very lucky ones to receive a winning lap quilt. It is full of lots of cheerful colours and heart-filled shapes, which makes it a very comforting quilt indeed, and it will be treasured always.

## 2017 Seminar

We are looking forward to seeing as many of you as possible at our seminar on the 6th of May here in Wellington. We have a very good line-up of speakers, good food and of course a perfect chance for us all to meet up again.

We have World Scleroderma Day coming around the corner too, this year our Wellington group is joining the Palmerston North group in an art exhibition at Square Edge in Palmerston North from 21st of June to the 18th of July. Wellington will also have a display at the Wellington Hospital between 26th of - 30th of June. We will be raffling a quilt to raise funds for an MRI machine at Wellington Hospital.

This year my main focus will be starting a lengthy process

with the health system for the common good of scleroderma patients in regards to developing a national monitoring programme. This will be a big experience I'm sure, but it I will have a very positive outcome for us all.

In the mean time I am very fortunate to have a GP and specialist immunology team to help monitor my bloods for kidney function and blood pressure.

This means every three months I will head off to the GP for the checks, this is interim, between my usual annual specialist checks. Some of you may already have these checks due to the medications you are on, but some of us are stable and may not be on any monitoring tests between specialist visits.

I highly recommend that you organise this with your GP if you are in this situation. As you all know it is very important to keep an eye on our blood pressure and kidney function along with liver function, thyroid etc. A good relationship with your GP and practise nurse is worth its weight in gold.

On the 28th of February it will be Rare Disease Day check out [www.rarediseaseday.org.nz/](http://www.rarediseaseday.org.nz/) for details.

Thank you all again for your ongoing support and friendship, we have a special caring group, which is much appreciated.

Looking forward to seeing you all in May.

Take Care and Good Health to you all.

**Dianne**



Paul Klee, a renowned painter whose death in 1940 marks World Scleroderma day. He died on 29 June from scleroderma and is buried near Bern in Switzerland.

# 2017 Scleroderma Seminar

Another seminar will be staged in the Hutt Hospital Learning Centre on 6th May 2017. It follows previous successful seminars staged by both the Wellington and Waikato support groups.

## Preliminary Programme

9am	Registration
9.20am	Welcome
9.30 - 10.30am	Dr Charles Hornabrook, Psychiatrist
10.30am - 10.50am	Morning tea
10.55am - 11.55am	Dr Steven Innes, Gastroenterologist

5-minute stretch

12.00pm - 12.30pm	Sandra Forsyth, The Importance of Support
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12.30pm - 1.30pm      Lunch

1.30pm - 2.30pm	Dr Andrew Aitken, Cardiologist, on PAH
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5-minute stretch

2.35pm - 3.30pm      To be confirmed

Afternoon tea - to finish around 4.15pm



# Seminar Details to Note

## The Venue

The Learning Centre at the Hutt Hospital, High Street Lower Hutt (see next page)

## Times

9:00am -4-15pm

## Cost

\$20-00, which covers a catered a lunch, morning and afternoon tea, (Pay at the door on the day).

## Registrations

Registrations and any special diet information to Dianne Purdie by email [diannepurdie@xtra.co.nz](mailto:diannepurdie@xtra.co.nz) or Ph 04 479 5548

By the 24th of April.

## Accommodation

We have a few of our Wellington Members that have very kindly offered a room in their homes, to help with some accommodation or there are local motels (see map)

### Boulcott Lodge

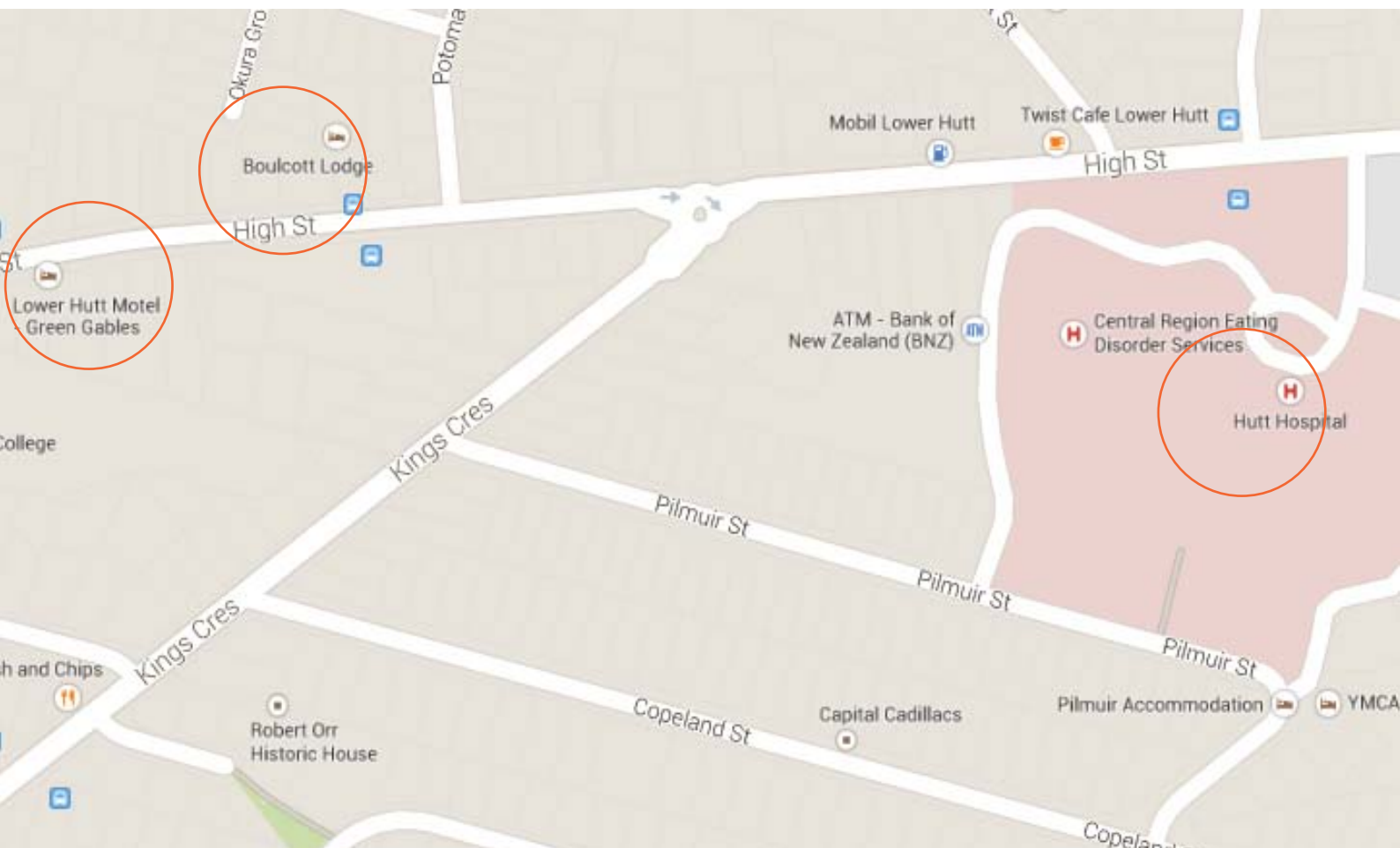
615 High Street,  
Lower Hutt 5010

### Green Gables Motel

560 High Street,  
Lower Hutt 5010

### Motel 22

22 Pharazyn Street,  
Lower Hutt



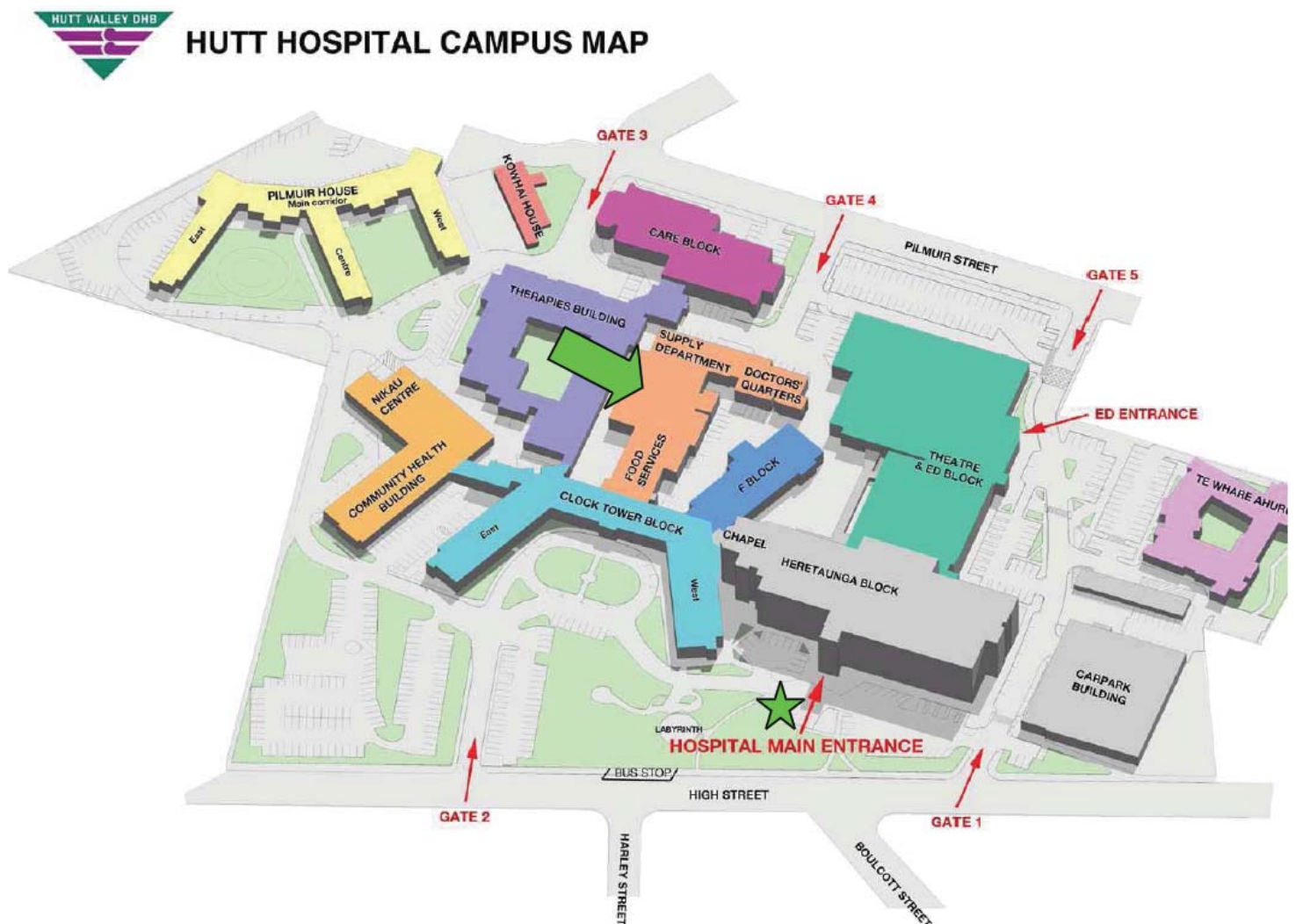


# Find the Hutt Hospital Learning Centre

## From the main entrance:

- Walk past the volunteers' desk, ATM and florist.
- Turn left at the hospital directory board
- Walk down the corridor past the chapel entrance to the clock tower building.
- After ENT (ear nose and throat) go up the stairs on your left.
- At the top of the stairs, turn left
- Down the corridor, the library and learning entrance is on your right-hand side.

Best access to the parking building is from gate 1 on High Street.



# Quilt Raffle

## Judy Trewartha's finely worked quilt proves a popular fund-raiser

Many thanks go to Judy for her big fundraising effort for Scleroderma NZ Inc, Judy raised \$808.50, which is a tremendous effort and much appreciated by us all.

The very Lucky winners were :

Alison and Michael Norman from Scleroderma NZ for the first prize



and second prize went to Gordon and Dianne.



Third prize went to one of Judy's Warkworth quilting friends.



Thank you so very much your quilt will be treasured Judy.

# World Scleroderma Day 2017

For World Scleroderma Day/Month we were lucky enough to secure gallery space at Square Edge in Palmerston North.

We have to drop our art work off on the 21st of June and pick up our unsold art work on the 18th of July. The cost is \$94-00 for the hire of the Gallery and no commission on any works sold for less than \$500-00 a piece. The cost of the gallery is to be shared among the artists contributing to the display.

Artists are welcome to donate the sales to Scleroderma NZ Inc if they choose, but that's not necessary as our purpose is to raise awareness for Scleroderma.

There is no theme, just what you feel like creating / painting etc.

We have at least 3 ladies in Palmy and two from Wellington/Kapiti, who have expressed interest. The gallery is expecting us to deliver around 4 pieces of work each and they will choose the best three pieces from each artist.

The gallery will hang our work, which is a blessing, as it is very difficult when choosing what to put next to what in a gallery trying to bring out the most of each piece of work.

So we are keen for anyone else who would like to add some of their lovely creative pieces: photography, painting, fabric jewellery etc. Even a poem on the wall would be great. So if you interested please Dianne know.

For World Scleroderma Month in Wellington, we are having a display at the Wellington Hospital from the 26th of June to the 30th of June. Here Dianne will put up our usual write up about scleroderma and Paul Klee. Dianne has offered to make a bright, cheerful quilt to raffle for the Wellington Hospital, as they are fundraising for a new MRI. She thought it would be nice to give back to the community, while raising awareness about scleroderma. If we have any more keen quilt makers out there, who would like to donate to the raffle please feel free.

Any other ideas for Wellington or other regions close by please come forward, It would be lovely to hear what you have to say.

# Holiday Happiness

## Have scleroderma - will travel - Barbara's Asian and European adventure

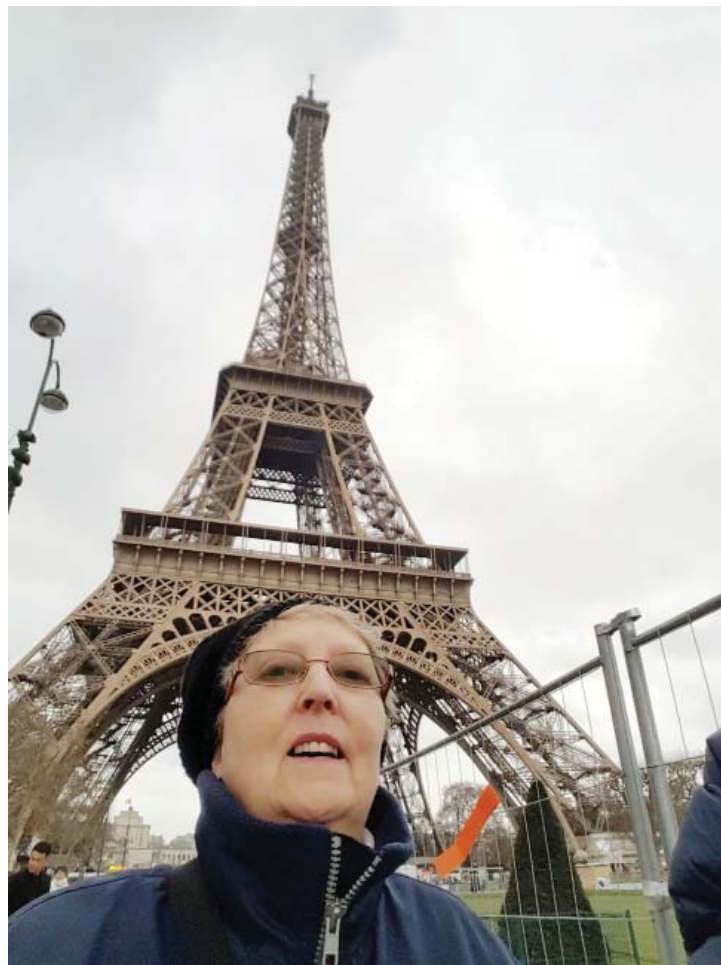
Armed with trepidation and a 3-litre click-clack of medication I went through customs. "Put your things on the conveyer belt, shoes off, belt off, jacket off, wait, get scanned, then proceed." Then, plonk your butt onto a seat and put them all back on. Through the first check point - there were to be many more. I took a lot of medication for the 5-week trip. I took an extra week's worth because you just never know.

Travelling on Air New Zealand I thought the seats were very hard. I sat on the little neck-pillow they provide, which helped, but I still had sore hips when I arrived at Ho Chi Minh City. I didn't mind the travelling, other than being boring. I also wore compression socks to reduce swelling in my feet and ankles but it took me 15-minutes to get them on. Another negative from Air New Zealand was that I had ordered a 'special' meal suitable for my dietary needs, but never got it.

If scleroderma makes your joints ache, I recommend the kind of climate we met in Vietnam: around 32° with 80%+ humidity. I was almost pain free. I paced myself there, doing only what I could manage and it paid off. Food can be a problem with me, but I was lucky. My daughter lives in Vietnam and a local friend wrote in Vietnamese that I couldn't eat onions. My daughter photographed it and texted it to me. In restaurants I showed it to waitresses to sort out a meal I could safely eat.

Through the customs strip-tease again and from the heat of Asia to the wintery cold of Europe was a big shock. Sitting on an open-topped, double decker bus in Paris in -2° with a wind chill factor of probably -8° while taking photos was difficult. Having Reynaud's would give you quite a bit of trouble. Your gloves would be off and on the whole time and fingers and toes would be white and numb. Lucky me, that's one I don't suffer from but my hands still froze.

Thermals, boots, gloves and hat were essential as we moved east for Christmas in the Czech Republic. Prague is a beautiful city in which everyone is rugged up. It takes so long to get all your clothes on, but you truly need them. As we walked round the Christmas markets in the old town square, drinking mulled wine, it was a world away from Christmas in NZ.



After Prague we went by train to Vienna. It was good transport, warm, with good seating and a view of the countryside. Vienna was just as cold as Prague. Thermals needed again along with gloves, scarf and hat. If we went out at night I got a cab and met the others there. I was too slow to walk and that was a lot easier than being exhausted by the time I got to the restaurant. During the day we did our own thing so I paced myself, without problems. The shops sold plenty of warm clothing, so if you forgot something then there was plenty to choose from.

From Vienna we flew to the slightly warmer climes of Cannes. No thermals needed here but still gloves and scarf. Temperatures were above zero, only just, but the chill was not the same as before. The streets were on an incline going down towards the Mediterranean Sea. An effort coming up, and using another set of muscles. *contd next page*



## Holiday Happiness *cntd.*

But slowly slowly gets you there and back again. I spent a week there and went for a day trip to Monaco. This is a lovely place, densely populated and wealth exuded everywhere you looked. I enjoyed looking at the super yachts all 3 stories of them, expensive cars and all the well-known brand shops. Oh how the other half live.

I was sad to leave Europe, but went back to Vietnam for a week with our daughter's family in Da Nang, where she lives. Da Nang is not as hot as Ho Chi Minh, but still warm at about 25°, again with high humidity. My bones could thaw out and I ditched the warm clothes and got back into t-shirts

once more. That was so good. The holiday wasn't without its problems.

I had sore joints from all the walking, and the problems that go with eating a different diet, but nothing that caused me deep concern. I was never questioned about all the medicine I carried, customs' sniffer dogs bypassed me, but I did carry copies of the prescriptions just in case. Also I had had an infusion of Rituximab about 3-months previously so that kicked in at the perfect time. I was as good as I could have been. Don't think you can't do it?. Try it, go for it and the worst that can happen is you come home sooner.



A little mother-daughter bonding over a glass of New Zealand's Oyster Bay wine in Hoi An, a very old and picturesque village just south of Da Nang.

## Tips for travelling

The US Center for Disease Control and Prevention has an advice section for people with chronic conditions who plan to travel: <https://wwwnc.cdc.gov>

Seek a pre-travel consultation with your doctor or specialist 4 - 6 week before you go.

Take a doctor's letter on office letterhead, outlining medical conditions, medications prescribed - include generic names, and any equipment required to manage the condition.

Pack medications and medical supplies in original containers in carry-on luggage and carry a copy of your prescriptions.

Ensure sufficient quantities of medications for the entire trip, plus extra in case of delays.

Insure against illness, health care abroad and medical evacuation

Seek a health plan from your doctor to manage anything from minor to serious events.

Wear a medical alert bracelet or keep medical information with you

Stay well-hydrated, wear loose-fitting clothing, and walk and stretch at regular intervals during long-distance aeroplane travel



# A Carer in Court

For decades full-time carers, paid by the Ministry of Health, but not recognised as employees, have scraped by on the equivalent of \$3 an hour. Support group member and former full-time carer, Jan Lowe, called enough.

Carer relief is a part of the health system that gives the full-time carer of an incapacitated person a break.

Often the person cared for will have Alzheimers or other serious disabilities. After an assessment, the full time carer is given so many hours a year and has to choose a relief carer of their choice. This may be for a few hours at a time or specific days a week. The Ministry of Health pays for these hours.

The relievers do not come under any other home-care organisations. The Ministry has said they are not "employees", rather "informal independent contractors" or "volunteers." It says that they receive an "allowance", not a wage, therefore they were not workers for the Ministry.

But they pay just \$75 for 24 hours, or, a little more than \$3 per hour. To Jan's knowledge, this hasn't changed since she first worked as a carer 25 years ago. With the help of the Service and Food Workers Union (SFWU), she went to the Employment Court seeking redress - and won. Finally they were employees, not receivers of an allowance.

The Employment Court found that relief carers were employees. It said they did the same tasks and had the same responsibilities as the full-time carer and the same as formal care-workers in rest homes or home-care organisations.

As often happens, an appeal followed and the Ministry won round two, in the Court of Appeal, a year ago. The Ministry

claimed successfully that it could not afford to pay the minimum wage and, anyway, it wasn't a job - carers were not employees. The carers were back to receiving an allowance, not a minimum wage.

So Jan and the union went to the Supreme Court this month to argue their final chance for legal redress.

Jan says the Ministry's stance was about semantics and was totally unjust.

"They pay for the service without being responsible for holiday or sick pay or any of the other rights that formal workers have" Jan says.

Their 'allowance' has been unchanged for at least 25 years - \$75 for a day (24 hours) or \$37.50 for a half-day (12 hours). This equates to just over \$3 per hour.

"How can they, a government department, justify that in any way?" she says.

Jan's goal is that the whole issue will be looked at objectively by the Supreme Court and that relief carers will become part of the formal home-care working system.

She's now awaiting the Supreme Court's decision.



# If you have a moment darling?

If the way to a man's heart is through his stomach, can you reach scleroderma the same way? Support group, member, Rob Tomkies thinks you can.

First, he had to convince his wife.

"I have been researching food relationship with scleroderma. I think a change in food regime for 4 weeks will give some relief."

"Ok, good idea to try anything that will help"

"The regime is basically a Paleo diet with some additions. I will list them for you:

- No dairy which includes cheese, yoghurt, milk and the like.
- No gluten: Bread or anything made with wheat or barley.
- No sugar. Limit juice intake to maybe 1 glass per day.
- No alcohol.
- No nightshade plants - potato, tomato, chilli, eggplant, tobacco and capsicum.
- No processed meat.
- Only one coffee per day.
- Add fermented food, such as gherkins, olives and pickled cabbage."

"You know what the outcome of this restrictive diet will be ... no wife! Also, why no nightshade they are recognised as good antioxidants?"

"Antioxidants in normal people but toxic to auto-immune-affected people."

So, we did it and I think it is a huge success, so much so that we are basically sticking to the regime. I lost the steroid fat and we both trimmed down. Our energy levels picked up, we slept better and funny as it might seem our memory improved. On the web the diet is referred to as a kidney and liver detox regime.

Yes, still got the same wife.





# Palmerston North Celebrated Christmas



and Wellington met last week..



A pair of chickens walk up to the circulation desk at a public library and say, 'Buk Buk BUK.'

The librarian decides that the chickens want three books, and issues them.

Around midday, the two chickens return to the circulation desk and say, 'Buk Buk BuKKOOK!' The librarian issues the chickens another three books and the chickens leave as before.

The two chickens return to the library in the early afternoon, approach the librarian, looking very annoyed and say, 'Buk Buk Buk Buk Bukkkook!'

The librarian is now a little suspicious of these chickens. She gives them what they request, and decides to follow them - out of the library, out of the town and to a park.



She hides behind a tree and sees the two chickens throw the books at a frog

in a pond, to which the frog says "Rredit Rredit Rredit..."

# Noticeboard



Next Wgtn  
Meeting:  
**Seminar**  
**6 May**

## Find a Scleroderma support group near You

**Auckland:** Allan Edmondson Email-  
[allanedmondson@xtra.co.nz](mailto:allanedmondson@xtra.co.nz)

**Hamilton:** Linda Bell Email:-  
[linda.bell@hotmail.co.nz](mailto:linda.bell@hotmail.co.nz)

**Palmerston North:** Chris Carlyon-  
[ningandalley@clear.net.nz](mailto:ningandalley@clear.net.nz)

**Invercargill:** Heather Milligan  
03 248 5147

**Wellington / Christchurch:** Dianne Purdie-  
[diannepurdie@xtra.co.nz](mailto:diannepurdie@xtra.co.nz)

## New Support Groups

If you would like a support group in your area please contact Dianne Purdie 04 479 5548 or email [diannepurdie@xtra.co.nz](mailto:diannepurdie@xtra.co.nz) and I will be happy to help you set one up.

## Contacts

Scleroderma New Zealand Inc.

**President:** Dianne Purdie

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**Invercargill:** Jenny Andrews Ph 03 236 0068

Heather Milligan Ph 03 248 5147

