

■ Welcome.....	1
■ President's Report.....	2
■ Southland News	3
■ Stay Warm	4
■ Quality of Life.....	5
■ Christchurch Meets	6
■ Aged care Workers.....	7
■ Auckland Group Sets Up	8
■ PAH.....	9
■ In the News.....	10
■ Micronutrients.....	11
■ Contacts	12

Scleroderma

New Zealand support group

Spring 2017

Greetings to you all.

Welcome to the latest newsletter for spring. The days are getting lighter however not quite warmer yet.

In this edition of the newsletter we have our President's Report. You can read what she has to say about the state of Scleroderma NZ Inc.

Dianne also has a lot of information on the importance of keeping ourselves warm during the cold days of winter and ways to keep warm.

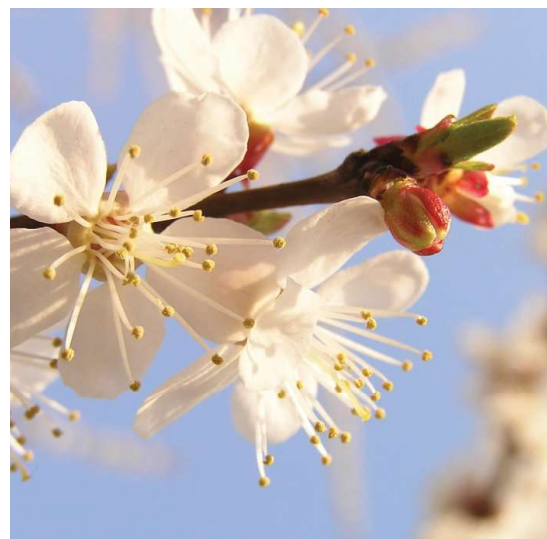
There is news from around the country from the different regions and what they are up to. It's good to see the different groups popping up and getting together to help each other.

We have photos of the various groups. It's nice to put a face to some of the names who help those with scleroderma around the country.

Read Jan's battle with bureaucracy to get better wages for relief care workers. It's an ongoing struggle.

Also read Allan's solution for keeping his medical records on himself and his wife Sandy.

We report on an interesting item on Scleroderma sufferers' likelihood of developing micronutrient deficiencies. Something we all need to keep an eye on.



President's Report

August 2017

Hello all, well we have great hints of spring. The daffs are out and blossoms are standing out amongst the green native forest here in Wellington, along with quite a few spring bulbs, giving lots of vibrancy.

Our membership is growing. We now have 144 members from North of Auckland to Invercargill.

The new Christchurch group is doing well and meeting every couple of months and the Auckland Central group had their first meeting on the 27th of August. It will also meet every couple of months. Well done to both groups for getting together and supporting each other.

Palmerston North, Invercargill, Hamilton, South Auckland and Wellington are all meeting regularly and supporting their members very well.

For World Scleroderma Day the Palmerston North Support Group worked hard at putting together a vibrant art exhibition at Square Edge Art Gallery, which was held over a period of three weeks. Catherine Thompson did an interview with the Manawatu Standard newspaper telling her story, along with a video clip. It was a brave thing to do and was much appreciated by us all. We gained some new members from the coverage. A couple of us from Wellington joined in with the art exhibition, which was an absolute pleasure.

The Wellington group put up an educational display at the Wellington hospital over the week of the 29th of June and managed to attract a few people who were interested in our books.

Gordon and I have just completed an International literature review on monitoring for renal complications with scleroderma. It's now in the hands of Dr Rebecca Grainger. She said it reinforces the need for home blood pressure monitoring. There will be some advice coming about how often this should be done.

We sent a letter to the health spokesperson, of each major

political party, asking them:-

"Would your party ensure that scleroderma patients are cared for with the best monitoring systems, and the most effective drugs, to help extend these patients' lives so they live the best life possible?"



We received a couple of acknowledgements from the parties and a letter from the office of Dr Jonathan Coleman, the Minister of Health, saying that he was getting advice from his officials.

A big thank you to Barbara and John for their continued support with the production of our wonderful newsletters and web site and to all of you out there for your support of Scleroderma New Zealand.

The aim of the society is to work together to benefit and support all people in New Zealand with scleroderma, and their families and caregivers. We're here to provide information about scleroderma and as much practical help as possible.

Please feel free to contact me any time if you need any help or someone to talk too. I can also link you up with supportive people in your region.

Scleroderma New Zealand has a phone tree with people in different regions around New Zealand who have offered their contact phone numbers to help support others. You can contact me and I will put you in contact with a local person.

If you would like to be on the phone tree list please let me know.

Take care all of you and many thanks again for all your support. You are all wonderful people.

Dianne.

News from Southland

Thanks so much to Jenny for organising a social get together for 14 of the Southland group for lunch in Gore.

We will bring you a group photo before everyone disappears next time - there is just too much talking going on!

We as a group decided it is up to us to educate health professionals such as our doctors, dentists, opticians etc about Scleroderma with the help of the Scleroderma booklet.



Graham keeps up with the extended family news from his second cousin Betty, (everyone knows everyone in Southland).

Our rheumatologists travel from Dunedin (or we travel to them in Dunedin) for appointments. That's not ideal, but with SDHB budget constraints, it is the way it is.

Several members voiced their concerns that they were not getting the care they should be. One member said iloprost infusions are a battle to receive. In the past when Southland Hospital had a specialised rheumatology nurse (Maureen Anderson) it was a positive portal to go through. Alas that nursing position doesn't exist any more.

Another member said she is having problems being looked after by the podiatry clinic as scleroderma appears not to be recognised as a legitimate problem to be treated by them.

We decided to keep meeting as a social group, meeting for lunch 4 times a year.



David, Anne, Jenny, Gwenda, Linda and Lynette still talking after lunch is long gone

Keep Warm

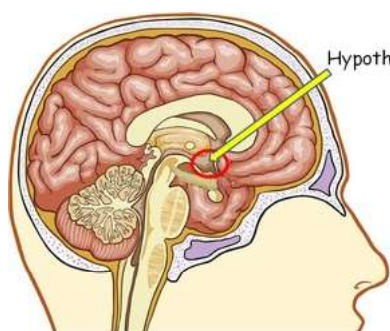
Dianne told the Wellington group's August meeting about the importance of staying warm to combat Raynaud's.

Have you ever wondered how your body temperature stays at 37°C whether you're in the sun or standing in snow?

Your body has mechanisms to regulate heat loss and gain, to protect your vital organs.

Cold is communicated to brain centres by blood and skin cold receptors. The brain centres are the hypothalamus and the higher cortex of the brain.

The hypothalamus is located below the thalamus, just above the brain stem. In humans, it is roughly the size of an almond.



It's your very own thermostat! When you get hot, you sweat and its evaporation cools you. Your blood vessels dilate to radiate heat from the skin surface. When you cool, you might shiver and your

vibrating muscles cause heat. Blood vessels constrict to reduce surface heat loss.

But when you contract scleroderma, there's an imbalance in this thermostat. It's an exaggeration of the normal responses to environmental temperatures. Many (but not all) scleroderma sufferers also develop Raynaud's.

In Raynaud's reaction to cold changes and becomes extreme. Nerves supplying muscles in blood vessel walls cause it to contract, leading to narrowing of the blood vessels in a process called vasoconstriction.

The body produces an excess of molecules that promote vasoconstriction and a shortage of those that promote relaxation of the blood vessel.

In other words, with Raynaud's, your reaction to cold is triggered even though it's not cold. As this cycle repeats, damage to the vessels increases.

Raynaud's affects small and even large vessels in many organs, such as the heart, lungs, kidney and gastrointestinal tract, this is called internal Raynaud's and it's why you need to keep your

core warm.

In scleroderma, there's evidence that immune-mediated injury can lead to constricted blood flow.

Repeated episodes of Raynaud's create a cycle of vascular injury and propagation of the disease. It reduces blood flow and impairs tissue oxygenation.

Management of Raynaud's

Avoid cold, reduce emotional stress don't smoke.

Reduce the number of Raynaud's attacks by taking preventive action.

Remember: fewer attacks means fewer problems.

- Put your gloves on before you get Raynaud's.
- Keep your home warm 22 degrees C. This includes your entire home (even the loo).
- Eat well; eat enough; eat often to keep your blood-sugar levels constant.
- Use thermal gloves, socks, and boots, hand and foot warmers, thick-soled shoes and boots
- Exercise as much as possible to improve blood supply to the skin

The aim is to avoid this:



Quality of life! – despite my illness

An oldie but a goodie from the archives of Scleroderma Queensland



CHANGE:

- | | |
|--|--|
| • change happens!!! | • change can bring stress and anxiety |
| • sometimes it's planned and sometimes it isn't | • change can challenge our sense of safety, predictability and control |
| • change can bring gain, excitement, new insights and learning | • change can challenge the assumptions we make about our world |
| • change can bring loss and grief | • change is a transitional time which cannot be avoided |

FIGHTING SPIRIT:

- | | |
|---|--|
| • rise to the challenge of your illness - face it | • care for yourself |
| • seek valid information and be involved in choices | • manage your stress |
| • be positive and optimistic, and realistic | • maintain as usual a life style as possible |
| • stick to what you know, not what you imagine | • *acknowledge and express your emotions |
| | • *seek joy |

10 COMMANDMENTS FOR SELF CARE Anonymous

- | |
|--|
| • Thou shalt not be perfect, nor even try to be |
| • Thou shalt not try to be all things to all people |
| • Thou shalt leave things undone that ought to be done |
| • Thou shalt not spread thyself too thinly |
| • Thou shalt learn to say "no!" |
| • *Thou shalt schedule time for thyself, and thy supportive network |
| • *Thou shalt switch off and do nothing regularly |
| • *Thou shalt be boring, untidy, inelegant and unattractive at times |
| • Thou shalt not even feel guilty |
| • Especially, thou shalt not be thine own worst enemy but be thine own best friend |

Christchurch Get-together

Barb Dench reports that their recent meeting went really well and that she came away feeling so happy having talked with others with similar problems to her own.

Barb says that although the members are all different, they have that common bond. The others in the group were and myself.



Chris Bates, Carolyn Barkhausen, Glynnys Hemi and Barb Dench share their experiences and progress at the recent Christchurch get-together

Wellington's Mid-Winter Meeting



At Wellington's August meeting, the theme was a mid-winter's meal. While the wind whistled around cold streets we sat in air conditioned comfort and feasted on nice food. Dianne gave a talk on Raynaud's - the dangers and how to minimise them.

Aged Care Workers

Aged care workers and the ETU union recently won pay equity. As they should have. But those who provide relief care are still out in the cold on about \$3 an hour.

Support group member, Jan Lowe has been battling courts and bureaucracy to win a better deal for relief carers.

Now seems timely to remind the Ministry of Health that the (mainly) women who provide relief care for full time carers, earn slightly over \$3 per hour, - although due to MoH semantics it is called an allowance, not a wage. As these women do not get a wage they therefore are not workers. A total of \$75 for 24 hours of time worked or \$37 per 12 hours is not even an allowance.

Not wanting to detract in any way from the hard work done by all involved with the aged care issue, surely now it's time for Jonathon Coleman and the MoH to do the right and honourable thing and address the issue of pay rates for carer relief.

The work is the same as for aged workers, just done in the home instead of a facility.

Working with elderly people who have a wide variety of disabilities, from broken bones to severe dementia carries the same responsibilities and duty of care expected from all aged care workers in institutions and private homes. The rate of this "allowance" has been unchanged for the past 25 years.

Does anyone know of any private employer, who with Government approval, could pay their workers obscenely under the minimum wage? I don't.

We tried at the Supreme Court to rectify the situation last year and the judgement came through last month. Dame Sian Elias was the lead judge and with her was one other woman and three elderly gentlemen. The two women (judges) concluded that we were workers and should be given the same employment rights as caregivers through an agency and home care workers had.

Unfortunately, the three male judges deemed that we were NOT workers in the normal sense and the Ministry of Health was not our employer, any more that the Health Boards. And by their majority, we lost.

It is not over yet. The dissenting judges went on the strict wording of the law so we need a law change and that's what we'll lobby for.

I feel angry when I hear Bill English say how National has helped bring pay parity to home care workers. No one is hearing about or mentioning the 35,000 carer relief workers on \$3 per hour under the current and previous governments. .

I am committed to seeing this through and at present I am

phoning all MPs from each party and telling them about the injustice of this situation.

No one I have spoken with thus far has been aware of this and there have been "promises" to look at it if elected.

'Scuse my cynicism !

NZ Council of Trade Unions awards Jan

At the New Zealand Council of Trade Unions' Women's Conference this year I received an award: "To Jan Lowe for her leadership on equal pay."



The award is given to three women per year so I feel blessed and humbled by it -- I am one of thousands of women who are trying to make life easier for women in the work place so for me it is an accolade and recognition or all of them and all they do too.

At the ceremony I found that I needed to give a speech after receiving it - somewhat of a shock and no time to write anything.- and that too got a good review, even though I cannot remember anything I said!

Auckland Support Group Up and Running

Michelle and I have had a whirl wind couple of months trying to get the Auckland support group up and running, but our hard work has paid off. .

There were 10 of us at our first meeting and we have a few more that couldn't make it but will be at our next meeting.

We discussed what everyone would like from the support group and what type of speakers they would like to hear. It was great just being in a room with so many people that understand what each of us is going through. We are working with a few members who are a bit "lost" in the system to ensure that they get the best care possible.

We also discussed fund raising and have a few things in the pipeline including a Give-a-Little page.

We are really working on get the word out there and to get scleroderma recognised.

sclero.akl@gmail.com

<https://www.facebook.com/groups/sclero.akl/>

or Ann on 021-0277-4544 or (09) 550-5690



Callan (front) and Ray



Front kneeling - Michelle; Middle left to right - Bronwyn, Judy, Simone, Ann; Back Left to right - Judith, Ngaire & Ali

Keep Track of PAH

The US Pulmonary Hypertension Association has issued a guide to help patients with PAH keep track of their medical appointments, called Empowered Patient.

The Association says tracking the results of medical appointments for pulmonary hypertension is challenging and requires a well-organized approach.

On its website, the Association breaks the process down into sections that cover:

- looking after documents,
- questions and notes,
- medical records,
- travel with PH,
- education and resources.

It wraps it all up in what it calls the complete toolkit. Each section consists of a PDF that you can write to on screen and then save onto a thumb drive to accompany you when you are out and about.

This is advice similar to what Allan from the Auckland PAH Association advised Wellington members at a recent meeting. He swears by its usefulness. See his checklist below.

Find the toolkit here:

<https://phassociation.org/patients/living-with-ph/empowered-patient-online-toolkit/>



Allan Edmondson's Records Recipe

For the last 6 years Both Sandra and Allan have worn a USB stick around their necks with information that they believe is critical should they lose their power of speech due to an accident or illness.

Allan says, "I have several simple folders on the USB and each folder contains a PDF file/s."

- Advanced Care Plan (ACP)
- Blood Type

- Doctor GP/Specialist
- Drivers Licence
- ICE Contact (In Case of an Emergency)
- Insurance Data
- IRD Number (Tax)
- Marriage Certificate
- Medical Equipment (CPAP)
- Medical History
- Medication
- NHI Number (Hospital Number)
- Passport
- Residential Address



Making News

Scleroderma support groups raising their profile with local media. The good thing about Internet news coverage is that local is local no longer. Stories are readable throughout the country.

Palmerston North has an arthritis specialist after a long wait.

There's a snippet from the story elsewhere in this newsletter but it's an example of support group member, Catherine Thompson, being a tireless advocate for people with scleroderma.

ps://www.stuff.co.nz/national/health/94374276/palmerston-north-to-get-arthritis-specialis...

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Palmerston North to get arthritis specialist after long wait

GEORGIA FORRESTER
Last updated 17:59, July 4 2017

A female rheumatologist would be starting at Midcentral DHB in late July.

123rf.com

national headlines

- Mystery over Heather Bills' death
- Tourist must stay in NZ
- Do the debates matter?
- Taking time to give back
- Ardern's fans may harm her cause
- Women in politics
- Wine company leaves debts
- Auckland CBD to be redesigned
- Ref calls football match off
- Mobster on run uses blonde wig
- Suspicious fire at hotel
- Helmet saves cyclist from injury
- All signs point to new route
- School children sent home
- Cynical truth about the '\$11.7b hole'

most popular

viewed	shared	commented
Truth or false? Fact-checking the second leaders debate		
New Zealand-born mum Chervonne Magaoa dies giving birth to triplet boys		
Man whose body found by Canterbury river		

Auckland support group starts up for scleroderma.

It's good work by the group's organisers to gain press coverage of their recently revived Auckland group.

Michelle and Ann have made a strong start and there should be potential to reach a lot of people with scleroderma in greater Auckland, considering the size of its population.

s://www.stuff.co.nz/national/health/96400960/support-group-set-up-for-aucklands-scler...

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stuff National World Business Opinion Sport Entertainment Life & Style Travel Motoring Log in Join

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Support group set up for Auckland's scleroderma sufferers

Last updated 16:42, September 1 2017

The Auckland scleroderma support group met for the first time at the end of August.

Supplied

national headlines

- Women in politics
- Wine company leaves debts
- Mystery over Heather Bills' death
- Auckland CBD to be redesigned
- Ref calls football match off
- Mobster on run uses blonde wig
- Suspicious fire at hotel
- Helmet saves cyclist from injury
- All signs point to new route
- School children sent home
- Cynical truth about the '\$11.7b hole'
- Hooked on a fish he doesn't eat
- Homicide probe after body found
- School a 'supermarket' for thieves
- Rights and wrong, wrong, wrongs

most popular

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Truth or false? Fact-checking the second leaders debate		
New Zealand-born mum Chervonne Magaoa dies giving birth to triplet boys		
Homicide investigation launched after man's body found by Canterbury river		

Systemic Sclerosis Patients Likely to Develop Micronutrient Deficiencies

Researchers in Switzerland say that patients with systemic sclerosis are likely to be deficient in certain micronutrients, and the deficiencies correlate with their disease.



Micronutrients are essential dietary components that play a role in collagen synthesis and wound healing, key players in systemic sclerosis.

The study found that patients with systemic sclerosis can experience nutritional impairment and malabsorption at the intestine, which can lead to deficiencies in certain nutrients and micronutrients.

Researchers say that almost half of the 176 scleroderma patients studied (43.7%) had low levels of at least one of the micronutrients analysed, while 19.3% of the patients had

multiple deficiencies. The most common micronutrient found to be deficient was selenium (21.9%), followed by folic acid (16.6%) and prealbumin (15%).

The authors concluded that patients with systemic sclerosis are more prone to become deficient in micronutrients, especially selenium, folic acid and prealbumin, and that these deficits correlate with clinical aspects of the disease. The team emphasizes that clinicians and healthcare providers should be aware of the need to monitor micronutrient levels in this patient population. See more detail and links to the study [here](https://sclerodermanews.com/2015/12/15/systemic-sclerosis-patients-likely-develop-micronutrient-deficiencies/):

<https://sclerodermanews.com/2015/12/15/systemic-sclerosis-patients-likely-develop-micronutrient-deficiencies/>

Palmerston North gets arthritis specialist

Palmerston North Hospital has employed a new rheumatologist, the Stuff website reports, bringing much-needed relief to patients suffering from chronic pain.

MidCentral District Health Board confirmed a female rheumatologist was to start in late July. The hospital lost two rheumatologists in 2016 after a retirement and resignation

Stuff quoted support group member, Catherine Thompson as being 'appalled' by the long wait. She said during the time

there was no specialist in the district, some patients travelled to Wellington and one to Auckland for treatment.

The hospital says it's challenging to recruit people with the qualifications and skills during, at times, national and international shortages.

Hospital services operations director Lyn Horgan said there was a nationwide and international shortage of specialist rheumatologists.

Spring Nosh

Here's a cheery
Spring dish to lift the
spirits

Ingredients

1 cup cooked, cubed chicken
3 -4 cups salad greens
1 can mandarin orange,
drained, reserve liquid
1/2 cup toasted sliced almonds
1/2 cup crispy Chinese
noodles

Dressing

4 tablespoons oil
1 1/2 tablespoons low sodium
soy sauce
1 tablespoon brown sugar

2 tablespoons mandarin
orange liquid
2 teaspoons toasted sesame
oil
2 tablespoons rice wine
vinegar
1/4 teaspoon yellow
mustard
1/8 teaspoon ground ginger
1/4 teaspoon garlic powder
1 tablespoon sesame seeds

Directions

Mix dressing and toss with
salad.

Serve at once.

Credit:

<http://www.food.com>

Noticeboard



Next Wellington Meeting:

11 November

Next Auckland Meeting:

29 October

For times, venue and directions to all meetings:

www.scleroderma.org.nz/calendar/



Find a Scleroderma support group near You

Auckland: Allan Edmondson Email:-
allanedmondson@xtra.co.nz

Hamilton: Linda Bell Email:-
linda.bell@hotmail.co.nz

Palmerston North: Chris Carlyon
ningandalley@clear.net.nz

Invercargill: Heather Milligan
03 248 5147

Wellington / Christchurch: Dianne Purdie-
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
and I will be happy to help you set one up.

Contacts

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Newsletter: Barbara Spavin

barbara@netco.co.nz

Invercargill: Jenny Andrews Ph 03 236 0068
Heather Milligan Ph 03 248 5147

www.scleroderma.org.nz

