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# Scleroderma

## New Zealand support group

## Autumn 2018

Greetings to you all.

Welcome to the first newsletter for the year. I hope you had a great Christmas and a relaxing time in the sun. It has been lovely and warm and so good for sore joints.

In this newsletter, we have the President's report.

Dianne will keep you up to date with scleroderma throughout New Zealand.

Wellington had a great last meeting and we talked and talked and talked. It was good to get things off our chest.

We had lots of suggestions of how to cope with different situations and symptoms. The meeting lived up to be a good support group. Try one in your area.

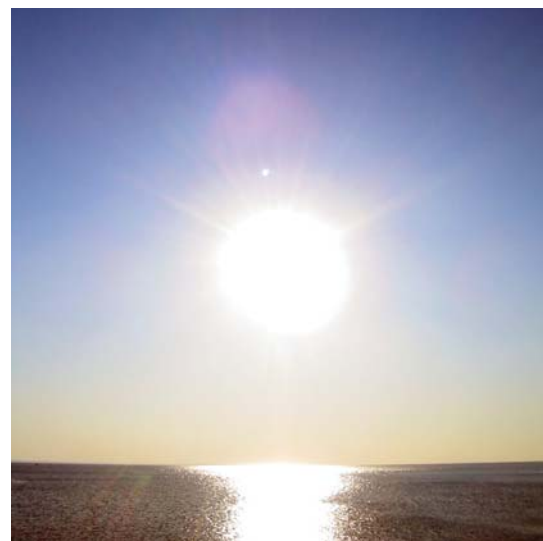
Jules has kindly offered to run for Scleroderma. Making an awareness for this disease and doing this for World Scleroderma Day.

Please support her.

An article on foot care and a reminder to fill out the survey for Dianne.

It is for our benefit in the end, so spend 10 minutes and fill it out. Remember our feet hold us up, so they are very important.

We want your contributions for the next newsletter. Please send them in with a photo and cover note and we will gladly publish.



# President's Report

February 2018

Greetings to you all, it is still sunny and warm here in Wellington but we feel concerned for various places around NZ with the flooding and land slides. I hope that your all coping well with what ever comes your way and I hope that you stay safe.

We have been saddened by the loss of one of our members Graham Aamodt here in Wellington, it was a sudden unexpected death. It has been a sad time, as he was a very jolly fellow.

There will be a memorial notice later in this newsletter.

We launched the podiatry survey on the 13th of February. There has been quite a bit work involved with this, from various people on our committee and Professor Rome who is the Professor of Podiatry at AUT .

Professor Rome has more than 25 years of experience within education. His research focus is on long-term chronic foot conditions, specifically in inflammatory arthritis. He collaborates with rheumatologists in New Zealand, USA, Singapore and the UK. We were lucky enough for Professor Rome to check our survey, and to offer advice.

A special thank you to all of you who contributed to the development of the survey.

Our main objective for the survey is to gain as much information as possible to put a good case together to lobby for free and improved foot health care for scleroderma patients. This should bring us in line with the diabetes patients who receive three free visits a year.

This a big please to ask all of you to fill in the survey. This will help us all, and improve our quality of life. I have put together a few words on foot care, later on in this newsletter, to at least give us a good start.

Wellington started with their first meeting on the 10th of February. It was nice to see our good friends from Palmerston North Catherine, Martine and Peter, to come and support our group.



We have been very fortunate this year as we have a woman by the name of Julius Ikitogia. Julius has offered to run in the Wellington Marathon to fund-raise for Scleroderma NZ Inc and to also help raise awareness. This will be part of our World Scleroderma Day awareness campaign.

Gordon and I will be walking the half Marathon as support for Julius and I think there will be a few more of us too.

I won't commit any one else by naming names :-)

I am also trying to get the Capital and Coast staff and Hutt Valley Hospital staff to join in and run, to help fund-raise and raise awareness too.

The event will take place on the 1st of July, Fingers crossed for good weather.

Mean while, I hope you are all keeping as well as you can and getting out and about.

Best Wishes

**Dianne and Gordon**

# Getting it off your chest

Sometimes talking a problem through can be as refreshing as a positive blood test.

The Wellington group got off to a good start for 2018 when around 20 members sat down for a chin wag.

We went around each member to let them describe their scleroderma experiences.

What could have been a fast 10-minute chat, turned out to be a fascinating exchange of advice, experiences and shared triumphs and trials.

What works? What doesn't? Who has tried something new? All got an airing.

There seems to be an overwhelming feeling of apprehension and confusion about what's going on with your body and this intruder, scleroderma. The confusion arises when patients have no idea what to ask their doctors about.

If you're not aware of symptoms and drug side-effects, how do you know what questions to ask? What do your blood tests mean?

All of these were shared. Those who have taken the time to learn a little more exchanged experiences with those who are more recently diagnosed.

Some quirky products came to light. Like the battery-powered vest that pumps out warmth for 10 hours on a full charge. Like Maori traditional healing that one member swore had much more beneficial effects than prescribed medicine. Although, wisely, she continues with both.

We learnt that there are about three thousand general practitioners in New Zealand and around one thousand people with scleroderma. So it's likely that a GP might practise for a whole career and never come across it.

The drugs you are prescribed might seem a little odd



sometimes. For example, Viagra figures in some prescriptions. One member found herself on a pain-killer for her back. She learnt upon asking (always pays to ask what a drug is for) that it's primarily an anti-depressant.

Are you on Methotrexate? Look for curly hair! It's apparently a side effect!

Amongst the advice was always to look for symptoms that might have nothing to do with scleroderma. For example, if you are chronically tired, maybe your B12 levels are low. An inability to absorb vitamin B12 is an auto-immune disease called pernicious anaemia. Some members are lumbered with that along with scleroderma.

A hundred years ago it was a terminal disease. Then a bright spark discovered that eating 2 kilograms daily of raw bullock liver would save your life. These days it's fixed simply with a regular injection at your GP.

The meeting offered a good example of a support group at work. No one was cured and the health problems that they brought to the meeting, they took away with them again. But the mood was supportive and informative and many left with a better understanding of how to cope.

# Memorial for Graham Aamodt.

## Death of Scleroderma Group member

Graham sadly died on the 20th of November 2017, suddenly from complications of scleroderma.

It has been a shock to us all here in Wellington.

I first met up with Graham in November 2016 not long after he was diagnosed with scleroderma.

I have known Pat his partner for a few years through the Johnsonville Garden Club, and it came as a big surprise one day when Pat called me to have a chat about Graham.

Pat and Graham invited me out to lunch at the Botanical Gardens, so that they could both learn as much as they could about Scleroderma.

Graham and Pat had a wonderful friendly generosity about them and invited the Wellington scleroderma group to Pat and Graham's home for a BBQ in January 2017.

We gathered around and passed on as much positive information as we could.

Graham, wanted to meet as many people as he could with Scleroderma, he was enjoying the company and I know from Pat, that he felt very supported.

We all had a terrific time that day, it brought out a whole new dimension to our group, and we all got to know each other a lot more that special day.

Graham and Pat made it to our National Seminar in May, where we all met up again. It was a real pleasure to have them there. They gave us all a lot of support, kindness and understanding. Graham always had a great sense of humour amongst all the tough times he was going through with his Scleroderma. Pat was always there for Graham doing everything possible to make life easier for him.

Both Pat and Graham have had a wonderful life together lots of good times with family and friends. We found out a whole lot more about Graham's sense of humour and caring nature towards the people he came into contact with over the years



at his memorial service on the 1st of December 2017.

At the memorial service Pat asked people to donate to Scleroderma New Zealand. Graham's Family and friends were very generous and kind and donated a sum of \$964.50 to our organisation. The donations will be very much appreciated with great gratitude.

We will miss Graham dearly, he was a terrific person always cheerful, no matter what and he always made us laugh, and that is how we will remember our good friend.

Our kindest thoughts to Pat, family and friends.

Sincerely,

**Dianne and Gordon**

# Running for scleroderma

## Community Health Carer with a big heart

When Community Health Carer, Jules Ikitogia, was assigned to one of our group's members, the two became firm friends.

So much so that Jules will run a half-marathon mid-year to raise awareness and funds for Scleroderma New Zealand.

It's part of the Wellington group's effort to help mark World Scleroderma Day.

The Wellington Round-the-bays event is open to walkers, sprinter, marathoners and onlookers and Jules may have sparked interest in a few members who say they'll take part.

Jules attended the February Wellington meeting to introduce herself and explain her links to us through her community work. Word Scleroderma Day is an annual event and a chance to let more people hear about scleroderma and understand its effects on sufferers.



## Eating well with scleroderma

### The Scleroderma Foundation talks about your nutrition

The foods we eat affect our health in many ways - for better or for worse.

Fruits and vegetables are beneficial and provide energy and essential nutrients. Processed junk foods like biscuits and cola have don't and can be harmful if eaten too much.

But when a person faces a chronic disease like scleroderma, fatigue, digestive difficulties and nutrient deficiencies are common. So you need a high quality, nutritious diet.

Establishing a balanced diet that emphasizes foods that fight inflammation and provide energy, protein, vitamins and minerals is paramount.

Systemic sclerosis overstimulates the collagen-producing cells causing inflammation and an excessive buildup of collagen. This leads to hardened skin and fibrosis of internal organs such as the lungs, digestive tract and blood vessels. While there are no specific foods or nutrients capable of reducing collagen production, the foods you eat can ease your disease condition by fighting fatigue, inflammation and digestive dysfunction.

People who suffer from scleroderma are at increased risk of malnutrition even if they try their best to eat a healthy diet. Malnutrition in scleroderma is caused either by inadequate intake of nutritious foods or from poor absorption of nutrients from the gastrointestinal (GI) tract.

Individuals who eat less because they have difficulty chewing, swallowing, and/or preparing their own food may suffer from inadequate nutrient intake.

See the full essay here on how to eat well with scleroderma.



**Eating well with  
scleroderma**

[Download PDF](#)

# Invercargill calling

On 18th February the southern group got together in Invercargill for a nice lunch.

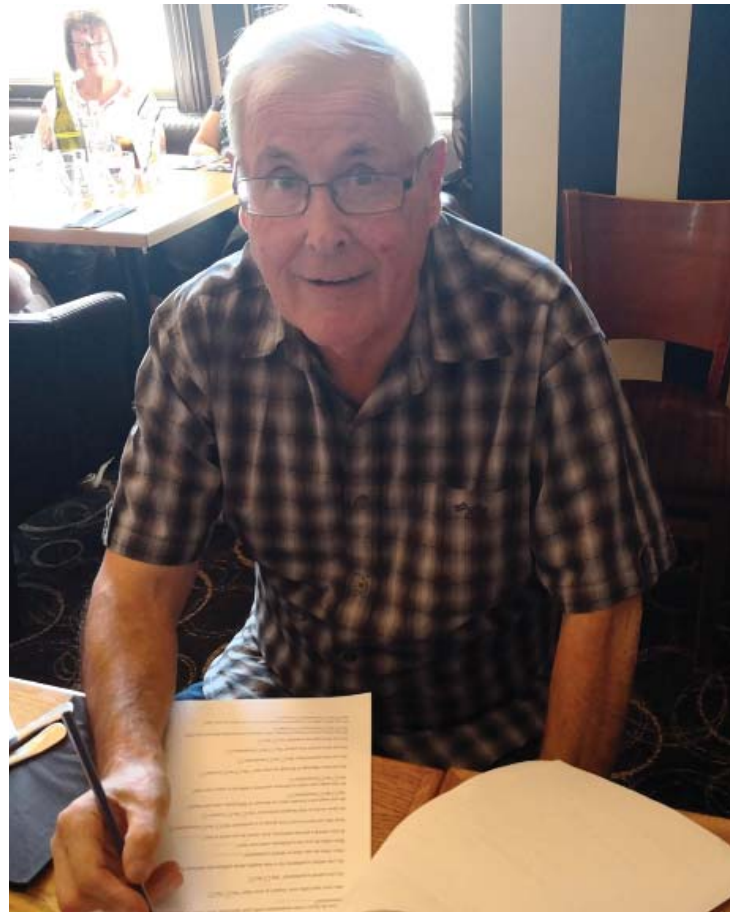
We did enjoy catching up with each other and talking about problems that those with scleroderma can understand and empathise with:

- medication,
- calcified heart valves,
- leg ulcers running rampant (a district nurse recommended a tincture of iodine, which seems to be helping – I will follow this up for the next newsletter),
- PAH and everything in between!

Seeing we had a 'captive audience' we filled in the podiatry survey. Thanks Dianne for getting the survey coordinated and copies down to us.

Thank you again Jenny for your fantastic organisation in getting us together.

**Heather**



Neil ticks the podiatry survey boxes



Racheal on the birth of baby Shae Rian McIntosh on 30-1-2018 weighing 6lb1oz and 49.5cm long.

# Foot care for scleroderma .

## These feet are made for ...

While we are on topic with our recent survey, I thought it would be a good idea to send out a few pointers on how to look after our feet along with some of the problems we may have.

These include Callus's, corns, toenail thickening ,toe deformities, Calcinosis –( calcium deposits in the skin of your feet) ,ulcers on the feet and or toes, painful feet and foot joints, sore toes, thinning of the pads of our feet, blood vessel damage, Raynaud's, ingrown toenails and toenail infections.

We may have a poor gait because of our foot problems which in turn could give us back and hip problems.

It is important to make sure your specialist has a look at your feet when you have your visits, as good feet will improve our well being and give us less problems for the future. We need to exercise for various reasons, in particular for scleroderma patients, it is our life line to keep our body flexible and our

organs in good working order, especially for people with lung problems.

A foot health check from your podiatrist would be terrific value and hopefully in the future we will have some free visits to the DHB podiatrist.

While searching the internet I couldn't find a lot of advise about caring for your feet with scleroderma, but I did come across the below information from Scleroderma and Raynaud's UK.

There are many things you can do to look after your feet. Here are a few pointers:

- Moisturise your feet as often as you can, ideally three or four times a day, being careful not to leave any cream between your toes. Something quite simple such as aqueous cream is a popular choice (this may be bought at the chemist or may be available on prescription).
- Inspect your feet daily – as you moisturise or put on your footwear, take a note of any changes in the skin. If you are concerned seek medical advice.
- Choose footwear that doesn't rub and allows plenty of room for adequate socks or tights. A thick sole may help protect against the cold, and the use of a thermal insole is recommended if your footwear can accommodate one.
- Some people with systemic sclerosis experience a feeling of 'walking on pebbles', particularly when walking on uneven surfaces. This may be due to changes in the fibro-fatty pad that normally protects the ball of the foot. This discomfort can be relieved with the help of a podiatrist. They can provide appropriate padding or the use of footwear with a thick sole that will add a layer of protection to the ball of the foot.
- Scleroderma can lead to an increased incidence of in-growing toes nails, which can be both painful and prone to infection. Ideally cut your nails in a line straight across the free edge of the nail. Nails may become thicker or you may experience difficulty managing to physically reach down and manipulate clippers. Seek help from a podiatrist.
- Whatever your concerns are about your foot health, it's worth asking to be referred to podiatry services for a full podiatric assessment.

# Podiatry survey

## Scleroderma NZ Inc National Podiatry Survey 2018.

We are surveying members to assess the needs of scleroderma patients in New Zealand. Currently there are at least three DHBs in New Zealand that provide a free podiatry service for scleroderma patients.

### Why we are doing it

Scleroderma New Zealand wants to encourage all DHBs to provide a free service for all scleroderma patients, as our foot health is most important.

At present most of our scleroderma patients have to pay anything from \$50 to \$90 per private podiatry visit.

Currently diabetes patients in New Zealand receive three free visits per year at a hospital-based podiatry service.

To advocate for free podiatry care for scleroderma patients in New Zealand we need to canvas our scleroderma community to find how many of us need access, the general health of our feet and corrective footwear needs.

Once we have this information we can use it to put up a case to the Ministry of Health for a free service for us all.

This survey is comprehensive and sometimes clarification may be needed.

If you feel comfortable you are welcome to add details to your questions, with your contact details.

If you have any other questions about the survey please feel free to email Dianne Purdie, President of Scleroderma NZ at [diannepurdie@xtra.co.nz](mailto:diannepurdie@xtra.co.nz)

The information that we collect in this survey will be anonymous and confidential.

You are welcome to add your name and contact details if you wish, but if you prefer to remain anonymous that is absolutely fine.

We would very much appreciate your participation in this survey to help improve the foot health for all scleroderma patients.



### How to take part

#### First option

An online survey that will take you about 12 minutes to complete.

<https://www.surveymonkey.com/r/RMM978Q> you can do this easily online, it will take about 12 minutes.

#### Second Option

Print off the survey from our website and post it to:

Dianne Purdie  
19 Thatcher Cres,  
Crofton Downs,  
Wellington 6035,  
or scan and email it back to Dianne.

#### Third Option

Email [diannepurdie@xtra.co.nz](mailto:diannepurdie@xtra.co.nz) and she can print a survey off and post it to you.

Post your completed survey back to Dianne at the above address.

Many thanks to Heather Milligan and Jenny Andrews for looking after the Southland group this weekend. I believe you will be all taking part in the survey.

I would very much like to thank you all in advance for completing this survey, the more of you who attempt it, will give us good grounds to work with the Ministry of Health to obtain some free podiatry visits for us at our DHBs.

Many thanks to all of you, who have helped with the development of this survey, it is much appreciated.





A woman walks into a doctor's office.

She has a cucumber up her nose, a carrot in her left ear and a banana in her right ear.

"What's the matter with me?" she asks the doctor.

"Aha," The doctor replies, "You're not eating properly."

## 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.

# Noticeboard



## Wellington Meeting dates

Saturday 12 May 2018 1:00 pm to 4:30 pm

Saturday 11 Aug 2018 1:00 pm to 4:30 pm

Saturday 10 Nov 2018 1:00 pm to 4:30 pm

Venue: Russell Keown House, Queens Drive, Lower Hutt

## Christchurch meeting dates

Thursday 22nd of March 2-4pm

Thursday 24th of May 2-4pm

Thursday 19th of July 2-4pm

Thursday 20th of September 2-4pm

Thursday 22nd of November 2-4pm

Venue:- Mc Donalds Merivale 217 Papanui Rd, Merivale, Christchurch in the free community room, as long as you buy a coffee at the Mc Cafe.

## Contacts

Scleroderma New Zealand Inc.

**President:** Dianne Purdie

[diannepurdie@xtra.co.nz](mailto:diannepurdie@xtra.co.nz)

**Newsletter:** Barbara Spavin

[barbara@spavin.com](mailto:barbara@spavin.com)

Does your area plan a meeting? For times, venue and directions to all meetings that we know about:

[www.scleroderma.org.nz/calendar/](http://www.scleroderma.org.nz/calendar/)

