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# Scleroderma

## New Zealand support group

## Winter 2016

Greetings and welcome to the latest newsletter. I hope you are all coping with the cold weather and feel it's safe to say 'winter is here'.

Our Southland group will be most affected and feel sure that your gloves, scarves, and jackets will be getting a good workout.

I skipped over the Tasman to visit family in Victoria, however it was no warmer there than it was here in Wellie.

Next time I must make sure that it is later on in the year.

In the newsletter this month we have a report from Dianne, the President of our Scleroderma group. We tell you what has been happening around the country with other groups and what they have been doing.

There is also a report from dietician Sarah Crawford. She spoke to our group about the dos and don'ts of eating well, the importance of reading the labels on our food packages and the act of masticating our food well. It was a good meeting and you can read her report further down.

There is the medical marijuana debate. Whether it will benefit some of us or not. Please let us know your views.

Scleroderma Day is here. Let us know what you got up to.



# President's Annual Report 2016

It is with pleasure that I sit here in our warm living room, with the fire roaring on this cold June afternoon.

Firstly I would like to thank all of you on the Committee for all your hard work over the year. Especially Maureen Kirby, our Southland Specialist Nurse, for raising a lot of money by producing and selling calendars for four charities, one being Scleroderma NZ (we received \$900) and Linda Bell, from Scleroderma Waikato, for her great effort of another movie night charity raising \$800 for Scleroderma NZ.

Also many thanks to all of our members who have donated terrific sums of money to our society. These efforts are very much appreciated.

Thank you to Barbara and John Spavin for the great informative newsletters and website that keep us connected, and to Cushla Marsters for running Scleroderma NZ facebook page, a very good job well done too.



Also a big thank you to Carolyn Barkhausen for organising some great bumper stickers for us to put on our vehicles.

I must say they stand out and are very useful when I am searching at the supermarket car park!

It has been a busy first year for Scleroderma New Zealand, with the main task of getting the society registered as a charity. This has lead to having a bank account and tax deductible receipts for donations over \$5.

We have set up a [Give-a-little](#) site where we can receive donations as part of our annual appeal on the 29th of June 2016, or at any other time.

I have approached a large number of companies throughout New Zealand for financial support and so far I haven't had any luck.

Gordon and I met with Ken Scott the New Zealand representative for Acetelion Pharmaceuticals late 2015 and unfortunately his company cannot support Scleroderma NZ now.

However, I was fortunate to receive a large number of prepaid envelopes from NZ Post for our Booklet project.

We have established a Logo which is very bright and cheerful which was developed by Jago Print in New Plymouth.

The main project now is to develop a New Zealand Edition of Understanding and Managing Scleroderma. It is almost ready for printing, and with the very kind donations from the above

we will be able to print around 1,000 copies and send to those of you who wish to receive a hard copy.

## Regional Happenings:

It has been a busy year, for a number of groups around the country, starting from the deep South.

**Invercargill:** Maureen Kirby has been getting her group together for meetings though out the year, with numbers climbing.



**Christchurch:** After many attempts I was able to get a group started in Christchurch with the help of Arthritis New Zealand and one of our committee members, Kim Tocker, who helps run the meetings. The Rheumatology Nurse, Jan, has also been a great help at informing patients in the area, so they can attend. There are quarterly meetings alternating between talks and get-togethers.

**Wellington:** Held a national seminar in May 2015, with a good attendance and informative speakers, an art exhibition to raise awareness and funds for Scleroderma NZ in June. We also have quarterly meetings, with a speaker at every second meeting, and a social get-together at every other. We will be having a get-together lunch out for World Scleroderma Day on the 3rd of July.

**Palmerston North:** Have get-togethers though out the year and generally make it down to Wellington for the talks and seminars.

**Hamilton:** Linda Bell runs a coffee group every month and a seminar every year, plus the movie night fund-raisers which have been very successful. Linda will hold her seminar in Hamilton, this year in November. Linda works very hard at fund-raising and does a terrific job, a big thank you to Linda, for all her support of Scleroderma NZ.



Continued next page

# President's Annual Report 2016 contd.

**Auckland:** Allan and Sandy Edmondson run the New Zealand PAH group, meeting, with welcomed scleroderma patients, every couple of months. Allan will be running a seminar later in the year for the PAH sector, a big effort from Allan and Sandy, they are both extremely generous with their time and kindness towards people.



Gabrielle Conway, our treasurer, has just set up an Auckland facebook page to bring people in the Auckland area closer together. This will help those who cannot get out easily to have contact and perhaps a coffee meet and greet at sometime in the future. A terrific idea, and it looks to be running very well.

Media Coverage took a quick swing in February this year when Tina McLean from Wellington took centre stage on TV 3 with an interview on how difficult it is to deal with packaging when you have a disability with your hands. Tina talked about scleroderma and did a very good interview. This interview

was held as part of a campaign by Arthritis NZ about the dangerous and poor packaging we all have to deal with.



As mentioned earlier about Maureen's Calenders, it was a huge effort, a lot of red tape to go through, and the producing of the

calenders along with having to sell the great lion's share of them.

Maureen did all this while holding a specialist Rheumatology Nurse position at Southland Hospital and running a family, and I'm sure numerous other tasks, a huge effort. These calenders generated an interview with the Southland Times where Maureen brought about awareness for scleroderma. This was on the 21st of December 2015.



Kapiti Access Radio interviewer Sandra Forsyth, one of our members, interviewed Adrienne Burleigh, one of our committee members, about scleroderma. It was a

terrific and a very well thought out interview. This was on the 24th of June 2016, to raise awareness for World Scleroderma Awareness Month.

Arthritis New Zealand held a workshop for volunteers who would like to be contacts for newly diagnosed people with arthritic conditions.

It was great to see three of us from Scleroderma NZ attending, Linda from Palmerston North, Nicky from Christchurch and myself here in Wellington. We will be the first contact people for anyone with Scleroderma who is newly diagnosed that contacts Arthritis New Zealand. Arthritis NZ has 15 educators to cover all of New Zealand, so volunteers have become a valuable asset to their society.

We are not expecting a lot of patients to come our way, but we will be ready and waiting to guide and help them. We fulfil this service for Scleroderma NZ through our web site also.

Whether you are newly diagnosed or not, you are very welcome to write into me [diannepurdie@xtra.co.nz](mailto:diannepurdie@xtra.co.nz) or phone 04 479 5548 for any help or advice you may need, or just a listening ear can help big time too.

To end this report I wish you all very well keep your core warm it is most important!!! And thank you all for your support.

**Dianne Purdie**

## The Association's AGM - Officers Elected

The AGM held this week elected the following as its officers.

**President:** Dianne Purdie (Wellington)

**Vice President:** Allan Edmondson (Auckland)

**Secretary:** Gordon Purdie (Wellington)

**Treasurer:** Gabrielle Conway (Auckland)

**Committee:** Jenny Andrews (Winton) Carolyn Backhausen (Christchurch ) Linda Bell (Hamilton) Adrienne Burleigh (Kapiti) Chris Carlyon (Palmerston North) Jo Harris (Wellington) Lorraine Holbrook (Invercargill) Maureen Kirby (Invercargill) Jan Lowe (Kapiti) Cushla Masters (Wellington) Tina McLean (Wellington) Heather Milligan (Dipton) Julie Rolston (Wanganui) Barbara Spavin (Wellington) John Spavin (Wellington) Kim Tocker (Christchurch) Rob Tomkies (Greytown) Judy Trewartha (Auckland)

# Healthy Eating

"Everything you eat affects you."  
Consultant Dietitian, Sarah Crawford  
talks food and health at the May  
Wellington meeting.

Sarah's talk ranged over modern eating habits, how they affect you and how those with a disease like scleroderma can help themselves by eating the right food.

She says a modern supermarket has up to 20,000 products. Choosing from them wisely can take some study.

She had a ton of good advice about diet - from breakfast to lunch, dinner and snacks and how to reduce side effects.

## Reflux

When you chew food, chew it 20 times before swallowing. It's very important, particularly for those with reflux. It's important too, she says, to sit at the table and chew that food instead of rushing through a meal. And if you like chips, you're setting yourself up for reflux.

To reduce reflux, eat smaller meals and eat more often, up to 6 times daily, rather than the traditional large, 3 square meals a day.

## Fibre

Eat high-fibre foods like porridge or rolled oats at breakfast. Food high in fibre eases constipation and won't affect bouts of diarrhoea. Check the ingredients on the your breakfast cereal's packet and avoid those with high levels of added sugar. She says Coco-Pops, Fruit Loops and Nutri Grain are the cereals with the highest levels of sugar on the New Zealand market.

To avoid excess sugar, Sarah recommends choosing from rolled oats, rice bubbles or cornflakes. If you like your cereal sweet, use fruit. If you prefer milk, use Calci-Trim milk, which is also low in fat and it adds calcium to your diet to aid bone density. Vitamin D - it comes free with sunshine - enhances the absorption of Calcium.

She says a high-fibre diet includes 25 - 30 grams of fibre daily. Most people eat between 18 and 20 grams.

## Toast

All bread is not what it seems, Sarah says. Many that imply



a high fibre content are, in fact, low in it. She recommends sticking with whole grain and whole meal bread. She says white bread is more difficult to swallow and it's low in fibre.

As a spread, Sarah recommends ProActiv margarine but warns that using fewer than 5 teaspoons-full a day negates its benefits and is just a waste of money.

## How you eat

Sarah recommends eating smaller meals, more frequently to cope with reflux. She says it's important not to over-eat.

Citrus drinks like orange and lemon juice, cranberry and tomato juice and can upset the gut and exacerbate gastric reflux.

Caffeinated drinks like coffee dilate blood vessels and can irritate the gut, particularly for people with scleroderma (and it gets worse as you age). She says it's worth trying decaffeinated coffee, either plunger or instant coffee. A cup of tea is fine, as is green tea.

Vegetables like the onion family, that includes garlic, chives, spring onions, onions and leeks affect many people adversely, not just those with scleroderma.

Avoid foods high in fat. Big meals of fatty chips or fried food will set you up for a bout of reflux. Sarah says that a bag of crisps, for example, is the equivalent of a potato with 10 teaspoons of fat. The problem is the fat, not the potato.

# Healthy eating contd.

## Eat your vegies up

Eat five-to-seven servings each day of fruit and vegetables. Instead of a biscuit for morning tea, try some fruit. Modern, manufactured biscuits are high in fat.

Vary the fruit, say, a pear, banana or feijoa for variety. For vegetables, eat potatoes, kumara, pumpkin, silverbeet and frozen vegetables.

A mixture of the above will ensure you get your five servings each day. A tip: tomato sauce, Sarah says, is not a vegetable so you can't count that.

Sarah advises eating your evening meal at least 2 hours before you go to bed. If you're tempted to eat before you sleep, clean your teeth and remember that the late night cuppa has caffeine and may keep you wide awake.

## Some food to avoid

Sarah says some foods are hard to swallow for people with scleroderma. For example, an overcooked hard-boiled egg and red and white meat that hasn't been finely cut. Be aware that processed meats like ham, salami and sausage all have a high fat content.

NUTRITION INFORMATION				
Servings per package: 36				
Serving size: 33g approx. (2 Biscuits)				
	Avg. Qty. per Serving	%DI* (per Serving)	Avg. Qty. per 100g	Avg. Qty. per Serving with 2/3 cup skim milk (170mL)
Energy	482kJ	6%	1460kJ	766kJ
Protein	4.0g	8%	12.1g	11.0g
Fat, total	0.5g	0.7%	1.5g	1.0g
- saturated	0.1g	0.4%	0.3g	0.4g
- trans	0.0g		0.0g	0.0g
- polyunsaturated	0.3g		0.9g	0.3g
- monounsaturated	0.1g		0.3g	0.3g
Carbohydrate	21.7g	7%	65.9g	30.4g
- sugars	0.9g	1%	2.6g	9.6g
Dietary Fibre	3.2g	11%	9.7g	3.2g
Sodium	11mg	4%	275mg	159mg

When you look at food labels to ascertain the levels of fibre, sugars and fat that they contain, look down the "average quantity per 100 grams" to work out the percentage of content. Because the size of servings (and spoons) differ so much, the amount per 100 grams is simpler to work out. It's the same too, when you're dealing with liquids.



# News From Waikato

Our movie fundraiser went well. It attracted about 67 people, mostly family and friends and some Scleroderma members.

We raised \$800 for Scleroderma NZ.

The coffee group is going well . We meet once a month at Westfield Shopping Mall, Chartwell at the Robert Harris Café.

We also go out for Lunch when a group member has a birthday.

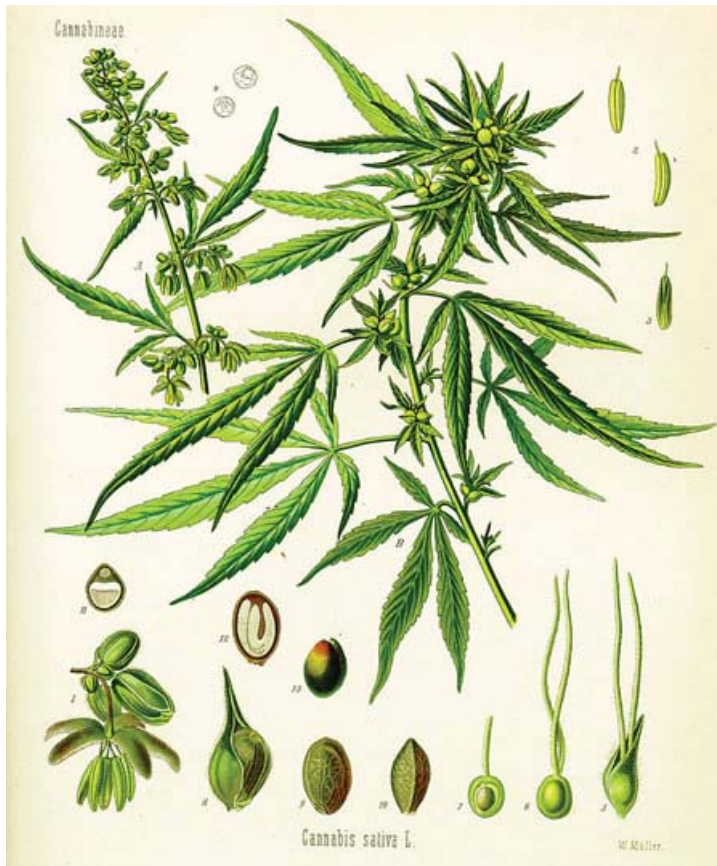
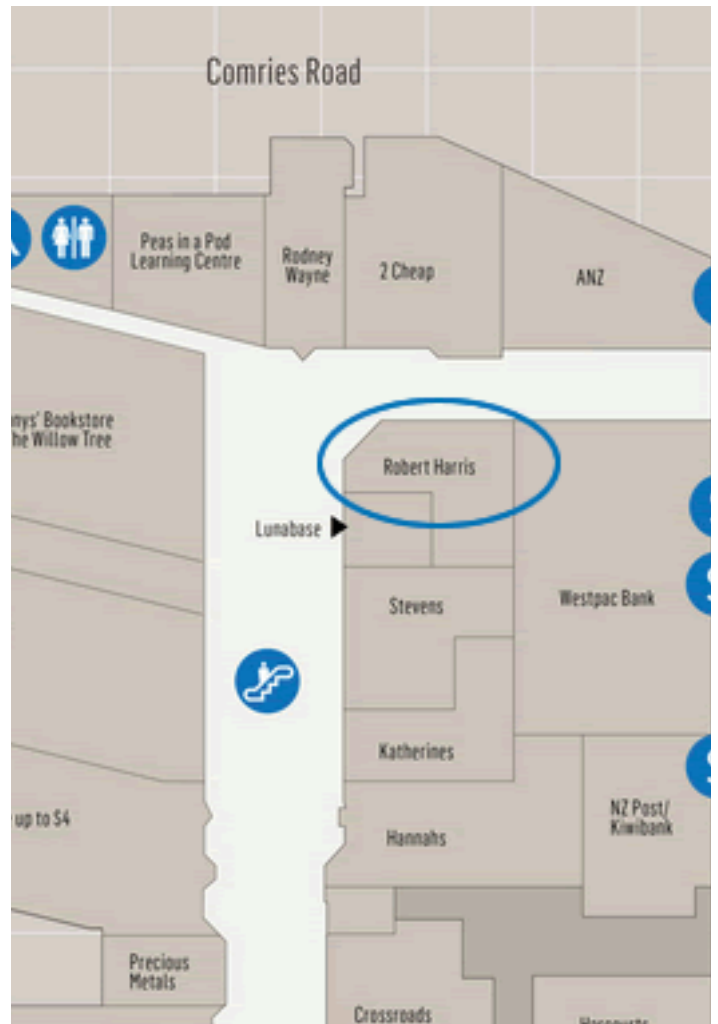
Our all-day, seminar this year will be on Saturday, 5th November. We're holding it at the same venue: St Johns Methodist Church Hall Hamilton East.

We'll provide more information and details of presenters in a couple months.

Please also help support Scleroderma NZ by either calling into Target Furniture, Hamilton, which is selling Entertainment Books either in store at Te Rapa Road, Hamilton or online please click on your area.

[www.entbook.co.nz/935q727](http://www.entbook.co.nz/935q727)

For any more information on the above please contact me on Ph 07 8535434 or email [linda.bell@hotmail.co.nz](mailto:linda.bell@hotmail.co.nz)



## Medical Marijuana

"It is apparent that medical marijuana is of great assistance to certain sufferers of various condition SD amongst them. Our government appear to be 'dragging their heels' compared with most other western societies."

"I move that: Scleroderma NZ Inc. contact Peter Dunne with a strong recommendation of medical marijuana being accepted for use in prescribed circumstances. Also that the members of said association are fully behind this move."

Rob Tomkies motion at the recent committee meeting was passed.

Committee member comments included: "I am very pleased to see Rob Tomkies proposal and am very supportive and accepting that this go ahead. The situation in NZ regarding the use of cannabis for medicinal purposes is quite frankly appalling, and there are many people who are unable to benefit from the benefits cannabis has to offer."; "Yes agree with medicinal marijuana, patients should be made fully aware of the psychological impact it can have on some people."

Carried.

# Managing Raynaud's

There have been a few enquiries lately about how to manage ulcers and how to control Raynauds, gathered by Dianne.

There is no cure for Raynaud's but it can be treated. Manage its symptoms by planning and live as normal a life as possible.

## Keep warm - Scleroderma & Raynauds UK

Avoid cold environments, touching cold items or spending time in fluctuating temperatures. Even a slight change in temperature can cause an attack.

Wear lots of thin layers and loose clothing to remain as warm as possible. Use hand warmers, gloves and thick socks to keep cold fingers and toes comfortable on chilly days.

## Pulmonary Hypertension Association (UK)

Try to avoid stress, which can trigger an attack. Rest when you can to avoid getting too fatigued.

The Pulmonary Hypertension Association (PHA UK) describes how to focus on your breathing, called controlled breathing (also known as diaphragmatic breathing), which uses your diaphragm and lower chest muscles:

1. Get comfortable so your neck, shoulders and back are well supported, such as in an upright chair with armrests or by leaning against a wall.
2. Relax your shoulders, neck and arms.
3. Place your hands on your tummy, just above your belly button.
4. Give a little cough - the muscle you feel under your hand is your diaphragm.
5. As you breathe in, allow your tummy to swell - you'll feel your hands rising and being pushed out by your diaphragm and tummy muscles.
6. As you breathe out, relax and let your tummy fall.

### Speak to your doctor about treatments

Nifedipine, a calcium channel-blocker, is licensed for Raynaud's. It doesn't cure Raynaud's, but can help to relieve symptoms. Never drink grapefruit juice when taking

Nifedipine: it can cause side effects.

Other medications have been used to treat Raynaud's, with mixed results:

- Iloprost is available for extreme cases.
- Botox, an experimental Raynaud's treatment, may reduce blood vessel spasm and block pain nerves. Increasing amounts of research is emerging for it, but it is only used in selected cases and usually only in specialist centres.
- Some Raynaud's sufferers have found acupuncture alleviates symptoms.

### Take action to prevent ulcers

People with secondary Raynaud's risk of ulcers, which can become infected and be slow to heal. It's important to avoid them if possible. Here are some ways to keep them at bay:

- Look after your skin and cover any broken areas with a clean plaster, Inadine or Mepilex.
- Be alert for signs of infection in broken skin – yellow discharge, redness, swelling, pain and failure to heal.
- If you see any of these signs, contact your GP or local rheumatology team immediately.
- Keep a diary of where your ulcers appear – this will help your doctor to monitor and treat the problem.

### Eat a healthy diet

Try to maintain a balanced, healthy diet. Avoid caffeine and alcohol. Some food supplements have helped Raynaud's sufferers, including evening primrose oil, ginkgo biloba and fish oils. Certain foods are also believed to help, like ginger, garlic and spicy food.

Eating protein can help the body to heal faster after surgery or to reduce suffering from digital ulcers.

If you smoke, it's very important to quit. Other than the obvious health reasons, one cigarette can reduce the body's temperature by up to one degree for up to 20 minutes.

*We'll bring more tips and advice next issue.*





# Noticeboard



Next Wgtn  
Meeting:  
Saturday, Aug 6

World  
Scleroderma  
Day  
June 29th

## 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:** Maureen Kirby-  
[Maureen.Kirby@southerndhb.govt.nz](mailto:Maureen.Kirby@southerndhb.govt.nz)

**Christchurch:** Kim Tocker-  
[akaroakim@gmail.com](mailto:akaroakim@gmail.com)

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

**Newsletter:** Barbara Spavin  
[barbara@netco.co.nz](mailto:barbara@netco.co.nz)

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

### Health contacts:

Southland Rheumatology Nurse:

Maureen Kirby

[maureen.kirby@southerndhb.govt.nz](mailto:maureen.kirby@southerndhb.govt.nz)

