

Welcome.....	1
President's Report.....	2
Scleroderma Members News.....	3
<u>Members Stories –</u>	
Chris Carlyon – Lake Dunstan Cycling Trail.....	7
Scleroderma Diagnosis.....	8
Scleroderma Causes / Symptoms.....	9
Types of Scleroderma .....	10
Podiatrists and Fingernail cutting .....	10
Scleroderma-Related Conditions .....	11
Invercargill Seminar .....	12
Seminar Registration & Funnies .....	13
Members News.....	14-17
Badges/Sunflower.....	18
Breathework Video, Patient View.....	19
Group Meeting Dates Wellington/Christchurch.....	20
Give a Little to Scleroderma New Zealand Inc .....	21
Scleroderma NZ Inc. – Rewardhub.....	21
Group Meetings: .....	22
Welcome to Scleroderma NZ Inc & Contacts.....	23

# Scleroderma

## New Zealand support group

## SUMMER 2023

Greetings to you all...

Welcome to the Summer edition of our Scleroderma Newsletter...



We hope everyone is well and looking after themselves. As we move towards the end of the year and get ready for Christmas and New Year celebrations, we hope everyone takes the time to relax and take a break to look after themselves and recharge.

We wish everyone a wonderful Christmas and Happy New Year for 2024. Have a safe and restful holiday season.

Summer is here and we hope the weather improves and everyone is able to get out and enjoy the warmer days.

We hear first from Jenny Andrews with the Presidents report. Jenny keeps us up to date with what's happening in our Scleroderma community around New Zealand. We have some interesting articles and some useful information about Scleroderma related issues.

We have some stories from our members and information about our upcoming seminar in Invercargill on 6<sup>th</sup> April 2024.

We have our regular Members News from our different support groups, information on our Scleroderma NZ Inc. Fundraising cards, Give a Little page and the Rewardhub retail site.

Be safe and take care everyone.  
Warmest regards,  
**Tina and Jenny**



# Presidents Report:

## Summer 2023

*Merry Christmas and Happy Holidays to you all. ☺*



*This is me and my Grand Daughter. There is someone cropped out. Who do you think it might be?*

*Oh my goodness where did 2023 disappear to. I don't know about all of you but as each year comes by life gets busier and busier. I thought when the kids left home I would be cruising all day. But alas that is not the case. Certainly keeps me out of trouble though. I hope you have all been having some festive time moving into the fun season... Recently I was on a trailer in our local Santa Parade with our 2 grandchildren and three of their friends. It don't know who was more excited, me or them. It was amazing seeing how happy they were and how smiley the crowd was. It really was magical.*

*With the warmer weather and the friends and family around us, life can seem a little bit easier at this time. Sometimes it's good to not have time to think about our health and just focus on the good stuff. If that is not the case for you, then please find the time to do something just for you. Something you really enjoy doing, whether it is sitting outside under an umbrella watching the clouds, doing a craft project outside, or just people watching. I love going to the beach and seeing different lots of people doing their thing and laughing and playing.*

*Of course though with the warmer weather we get the flies coming into the house. I am using them as my new exercise regime as I look like a crazy woman swatting like mad to take no prisoners. I'm sure my arms will be well toned by the end of summer.*

*As a society this year we have been working away in the background looking at different research options, looking into media screens in GP's etc. We got the badges made so if anyone wants one, these are free to all members. We are getting things ready for the Seminar in April and we have new stationary being printed at the moment. If any one comes up with a bright idea of something we can do to bring Scleroderma to the attention of the wider community please feel free to contact one of the committee and share your ideas. We are always looking at new ways to get awareness out there.*

*A huge thank you to the committee for their continued work. It is so nice to have such a variety of committee*

*members from all over the country. You are awesome and so appreciated. ☺*

*Thank you to all those Support Group leaders, who keep things happening in the different areas. Whether you have 2 people or 20 people in your group you are making a difference in someone's life, so thank you.*

*So as I finish up for 2023 I, and the committee would like to wish you all a very safe, healthy, fun and happy Christmas and New year. I wish 2024 will bring great things to you all. Take care*

*Jenny ☺*



*It's the big man himself! We found him at a Market day and I was very privileged to be asked by Willow to join her in the photo. Thank you Santa for making our day☺*



# Scleroderma Members News:

## Dianne Purdie on: Our recent Scleroderma Zoom meeting with Dr Will Taylor – 4 Nov 2023:

Scleroderma – symptoms and treatments  
Professor Will Taylor from the Wellington Regional Rheumatology Unit Hutt Hospital

On the 4<sup>th</sup> of November Professor Will Taylor gave a talk to about an overview of Scleroderma via a zoom meeting. We had a good turn out from around the country and at the end of the talk there was a very good Q&A session. Thank you to all, who attended, it was lovely to see you all and we look forward to seeing you again for a catch up next time.

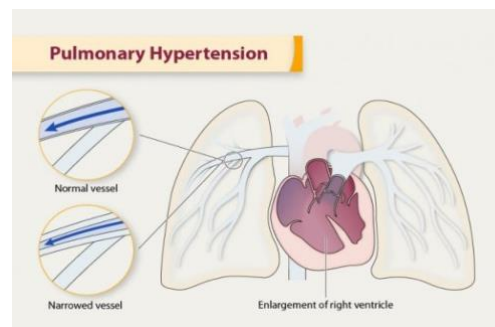
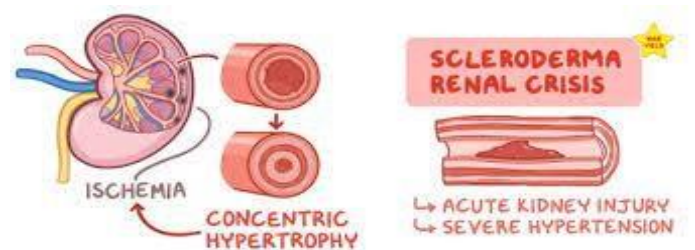
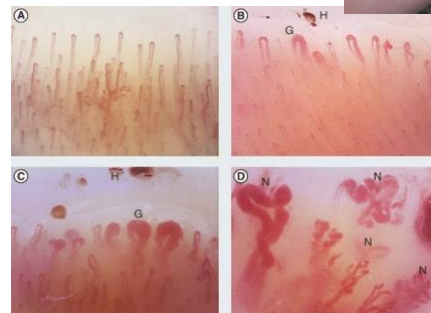
The following information is from Professor Taylor's presentation.

## WHAT IS SCLERODERMA (SYSTEMIC SCLEROSIS, SSC)?

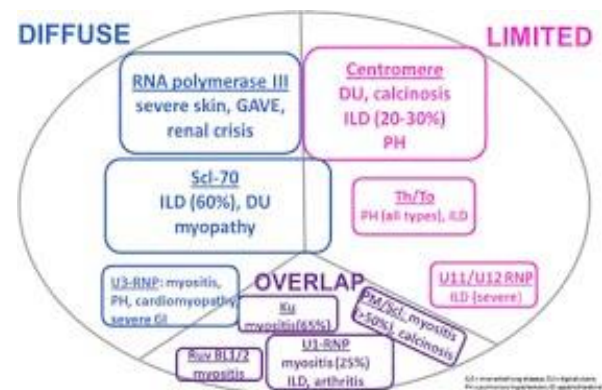
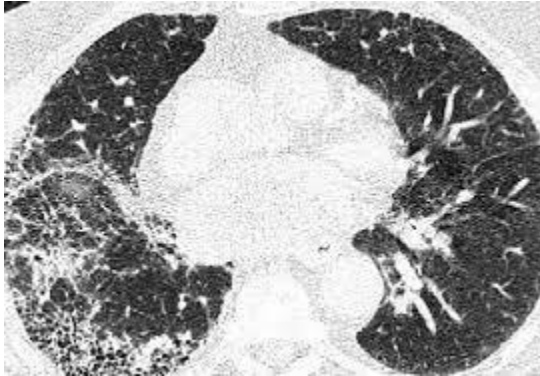
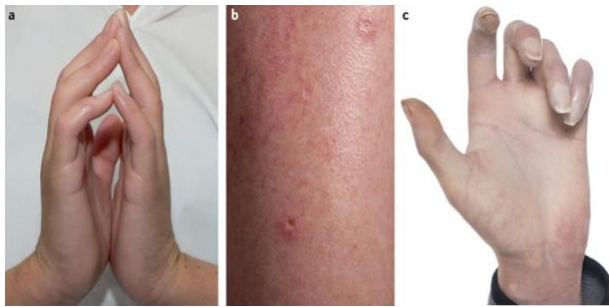
- \*Unknown cause, wide range of manifestations.
- \*Marked variation in how it affects different people with SSc.
- \*Somewhat genetic (only 5% of twins both have SSc); 1 in 60 first-degree relatives also have SSc (compared with 1 in 8000 of the general population).
- \*Some environmental toxins have been associated with SSc like disorders (rarely).

- Inflammation
- Autoimmunity
- Fibrosis
- Vasculopathy

## Vasculopathy



# Inflammation and Fibrosis



## Treatment

\*There is no known curative treatment.

\*Haemopoietic (from bone marrow) stem cell transplantation (HSCT) combined with chemotherapy is effective for highly selected patients with SSc but the treatment is complex (several variations) and the risks are significant, depending on the type of HSCT and the experience of the hospital team doing the treatment.

\*There are different treatments for different manifestations of SSc but none are universally effective.

\*General principle is an 'organ-based' strategy in the absence of a unified understanding or fundamental disease treatment targets for scleroderma.

### Raynaud's

Non-pharmacological – keep warm (including core and head), avoid changes in ambient temperature if possible, avoid certain medications (older beta-blockers, some nasal decongestants, methylphenidate, some migraine treatments, possibly oestrogen), stop smoking.

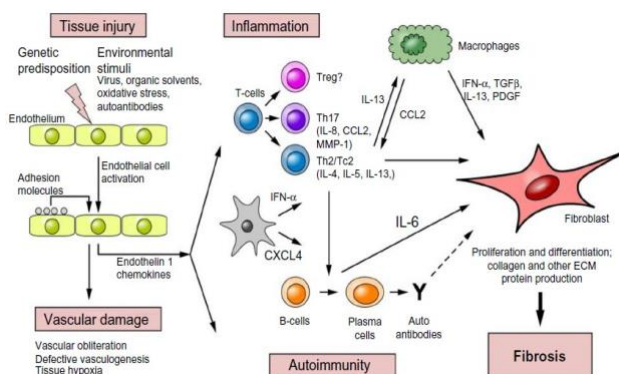
### Medications

\*Calcium channel blockers (e.g nifedipine, felodipine, amlodipine)

\*Sildenafil

\*Topical nitrate ointment (Nitro-Bid, not funded, Section 29) for individual fingers

## Autoimmunity



- \*Bosentan or Iloprost IV (especially for RP causing finger-tip ulcers)
- \*Losartan, fluoxetine have been tried with some evidence of effectiveness
- \*Complementary products (uncertain benefit)
- \*Antioxidants, ginkgo biloba, acupuncture, low-level laser

## Treatment – lung disease

### Interstitial lung disease

- \*Early detection might be helpful – typically screening with CT scan and pulmonary function tests every 1 to 2 years
- \*Rigorous treatment of reflux (high dose PPI, combination with other reflux treatments) to reduce aspiration
- \*Mycophenolate mofetil (MMF) 1.5 to 3 g daily

Other options

- \*cyclophosphamide (IV), azathioprine (oral), tocilizumab (unfunded for this indication in NZ)
- Progressive disease despite above
- \*nintedanib (unfunded for this indication in NZ), rituximab IV, lung transplantation may occasionally be appropriate
  - \*Palliative care may be appropriate for some people

## Treatment – lung disease

### Pulmonary hypertension

- \*Complex – usually requires cardiology and respiratory medicine involvement to confirm diagnosis (direct measurement of the pulmonary artery pressure needs a catheter study) and coordinate treatment (complex treatment eligibility rules)

- \*Vasodilating treatment – sildenafil, bosentan, ambrisentan, Iloprost IV or inhaled, selexipag (not funded in NZ)

- \*Lung transplantation may occasionally be an option

- \*Palliative care may be an option for some patients, including home oxygen and diuretics

## Treatment – skin thickening

Often improves (softens) without treatment

All treatment options are only modestly effective except maybe HSCT

Methotrexate and mycophenolate are most often used

Second line drugs include IVIG, rituximab, tocilizumab or cyclophosphamide (for severe, rapidly progressive disease where other options unavailable) and HSCT

Itching can be a significant problem (lanolin, counter-irritants, anti-histamines, short courses of low dose prednisone)

## Treatment – GI involvement

Reflux is very common, may require higher than usual doses of antacids; surgical treatment is not recommended because of high rate of postoperative swallowing problems and high rate of recurrence of reflux symptoms; motility/swallowing problems may respond to prokinetic medications such as domperidone, cisapride, metoclopramide; oesophageal stricture can respond to endoscopic dilation

Small bowel bacterial overgrowth causing diarrhoea – treated with rotating antibiotics; dietician involvement often necessary

Large bowel and anorectal disease – diarrhoea, constipation or faecal leakage – bulking agents (fibre), anti-diarrhoeal drugs, laxatives (depending on symptoms)

Involvement of gastroenterologist and/or colorectal surgeon may be necessary



## Treatment – renal crisis

Renal crisis is not common in SSc and will normally occur within the first 5 years if it occurs at all.

It is acute kidney injury due to vascular constriction within the kidney and presents with abrupt-onset of high blood pressure and impaired kidney function.

It needs to be identified and treated quickly in hospital (emergency situation) with drugs such as captopril or enalapril which reduce BP and promote an increase in blood flow through the kidney.

For people with risk factors for renal crisis (early-stage diffuse disease, rapidly progressive skin disease, or certain antibodies), daily home blood pressure monitoring may be prudent to identify renal crisis early.

## Treatment – heart

Cardiac involvement is common but symptoms are less common and mostly occur in later disease; screening with regular echocardiography and ECG is generally recommended.

Various effects – inflammation, fibrosis, rhythm disturbances, autonomic dysfunction, heart failure with preserved or reduced ejection fraction (HFpEF, HFrEF).

Cardiologist involvement is normally required for treatment – cardiac problems are treated in much the same way irrespective of the precise cause; more care required with beta-blockers. Myocarditis (inflammation of heart muscle) will require immune-suppressive treatment.

## Summary

SSc is a complex immune-mediated disease that is not very well understood.

It can affect many body systems – circulation, skin, gut, lungs and kidneys (and more).

The effects are a combination of INFLAMMATION, FIBROSIS, VASCULOPATHY, AUTOIMMUNITY.

SSc is not curable and there are no disease-specific treatments available, except maybe HSCT.

Management is generally directed towards how particular organs are affected, for which there is some more-or-less effective treatments available.

Involvement of respiratory medicine, cardiology, and gastroenterology as well as rheumatology is common; coordinating care can be complicated.

Cheers Dianne



# Members Stories:

## Chris Carlyon – Lake Dunstan Cycling Trail (14/11/2023)

Chris shares with us her adventures...

Want a stunning way to experience the Central Otago landscape? Bike the Cromwell to Clyde Trail around Lake Dunstan and be amazed by the scenery and the fabulous smell of wild thyme for the whole ride.

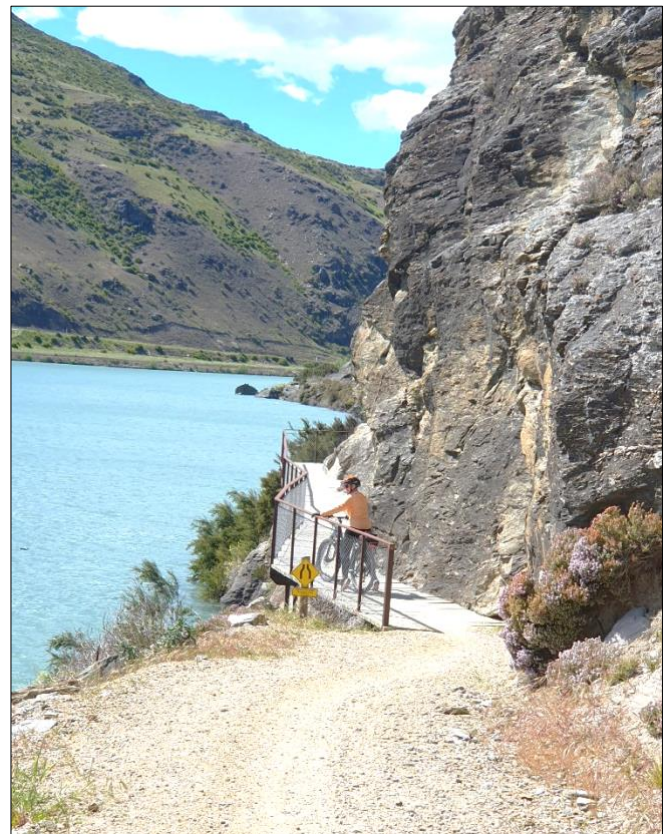
The path is well constructed. There is a narrow section and a couple of hill climbs, but I was impressed by the clip-on path hanging over the lake along the cliff of the Cromwell gorge, what a thrill.

We all spotted a few wild goats and loved cycling through the picturesque winery.

I rode to my ability and there was a section I needed to walk, but only for a few minutes, then it was back on the bike. The length of the trail was just right approx 44kms before riding into Clyde for a well deserved refreshment. Ice Cream being my treat.

I highly recommend this awesome day's adventure.

Note the wonderful blue sky and purples of the Thyme.



# Scleroderma Diagnosis

From Sclerodermanews.com

Scleroderma is a chronic autoimmune disease in which the immune system mistakenly attacks healthy tissues in the body. This induces an overproduction of collagen, a component of scar tissue, leading to the formation of patches of thick and hardened skin that characterize the disease. Excess collagen may also accumulate in different organs, causing damage.

Different types of scleroderma have different symptoms. The disease can be grouped broadly as localized scleroderma, which usually affects the skin only, or systemic scleroderma, when internal organs are also affected.

No single test is able to diagnose scleroderma, and several tests may be needed to exclude other conditions before a definitive diagnosis is reached. Tests also may be carried out as part of the diagnosis to see which organs the disease has affected.

## Physical examination

A physical examination will be done by a doctor to check for the common symptoms of scleroderma, such as skin changes. This includes the typical thick or tight patches of skin, sores on the fingers or toes, or calcium deposits under the skin (called calcinosis).

The doctor also may ask about other common symptoms, such as heartburn, difficulty swallowing, fatigue, breathlessness, joint pain, or Raynaud's phenomenon, when fingers and toes feel numb or prickly in response to cold temperatures or stress.

## Biopsy

A biopsy involves removing a small tissue sample to be examined under a microscope and tested in a laboratory. A skin biopsy may be taken from an altered patch of skin to help diagnose scleroderma. Clinicians will test the biopsy for characteristic signs of the disease, such as calcinosis or changes in blood vessels of the skin.

A skin biopsy alone, however, cannot differentiate between localized or systemic scleroderma, so further tests will be needed to determine whether internal organs are affected.

## Blood tests

Blood tests are commonly used to diagnose scleroderma, as they can identify the presence of autoantibodies. Antibodies are proteins normally produced by the immune system to help fight disease-causing invaders. Autoantibodies are antibodies that, rather than targeting a foreign invader like a virus, target the body's own healthy tissue.

The vast majority of scleroderma patients have detectable blood levels of antinuclear antibodies (ANA; against the cell nucleus). The presence of ANA alone does not confirm a diagnosis of scleroderma, as it can be present in other immune disorders such as lupus.

Blood tests can also reveal whether kidney function has been affected, which can occur in systemic disease.

## Tests for Raynaud's phenomenon

Raynaud's phenomenon is one of the most common symptoms of scleroderma. Tests for Raynaud's may include:

- Thermography on the hands, which uses an infrared camera to detect the level of heat generated in response to cold water.
- Nailfold capillaroscopy, which examines the small blood vessels under the fingernails.

## Lung function tests

The lungs, or the blood vessels of the lungs, are commonly affected in people with systemic scleroderma. The lungs need to be stretchy and flexible in order to inflate and deflate when breathing; in systemic scleroderma, excess scar tissue can make them stiff, and breathing more difficult. Tests may be done to assess how well the patient can breathe.

Imaging tests, such as a chest X-ray or a CT scan, may be needed, as this can reveal abnormalities such as a buildup of scar tissue in the lungs.

## Heart function tests

Systemic scleroderma often affects the heart, either through scarring of the heart tissue itself, or via conditions such as pulmonary arterial hypertension (PAH) putting strain on the heart. Two tests commonly used to assess the heart rhythm and function are:

- Electrocardiogram, which measures electrical signals across the heart, and can detect changes in heart muscle caused by the disease.
- Echocardiogram, which uses ultrasound to produce an image of the heart and can assess structural abnormalities.

## Gastrointestinal tests

The digestive system can be affected by systemic scleroderma, which can be detected through an endoscopy. This involves inserting a small flexible tube with a camera through the mouth or nose, to check for abnormalities in the esophagus (connects mouth with stomach) and intestines.

Manometry, a test that measures the strength of muscles in the esophagus, may also be used to assess swallowing difficulties.

*Last updated: May 6, 2021*

Source: <https://sclerodermanews.com/scleroderma-diagnosis>



# Scleroderma Causes

From Sclerodermanews.com

Scleroderma is a chronic autoimmune disease characterized by patches of scar-like thick skin. This rare connective tissue disorder is caused by the buildup of a protein called collagen, the main component of scar tissue.

Scleroderma, also known as systemic sclerosis, appears to develop spontaneously, and its underlying causes are largely unknown.

## Scleroderma development

Collagen is the most abundant protein in the body. A structural protein, collagen is deposited between cells to help keep tissues firm and flexible. It is produced by specialized cells called fibroblasts, which can also recognize and produce chemicals that allow them to communicate with the cells of the immune system.

After an injury, both the immune system and fibroblasts are activated as part of the wound healing process. The immune system protects the injured tissue by keeping disease-causing viruses and bacteria away, while fibroblasts secrete collagen, creating a scab to rapidly close the wound. Once the danger has passed and damage is repaired, the milieu of chemical signals shifts, which normally stops the inflammatory immune reaction and the excessive collagen production by the fibroblasts.

In people with scleroderma, the body keeps producing collagen as if there was a wound that constantly needs to be repaired. Scleroderma most often affects skin, but other organs can also be damaged as a result of collagen accumulating in tissues.

## Scleroderma and genetics

Scleroderma does not have a known genetic cause, and it is not classed as a hereditary disease — meaning that a person cannot pass the disease to their biological children. Still, those with scleroderma often have a family member with another autoimmune disease, like lupus or rheumatoid arthritis, implying that autoimmune diseases may have a heritable element.

More biological females — about four times as many — are affected by scleroderma than males, and the disease most commonly develops between ages 35 and 50. This distinction in age and sex may indicate an unidentified connection between the disease and a person's hormonal state.

In the U.S., Black and Native Americans are more often affected by scleroderma than whites. While socioeconomic factors likely play a role, these racial differences are also thought to reflect differences in genetic susceptibility to scleroderma between ethnic groups.

## Environmental factors

Some evidence points to possible environmental triggers of scleroderma. For example, infections by some viruses and long-term exposure to some chemicals, such as pesticides, silica dust, or polyvinyl chloride, are thought to be linked to the disease.

Variations in the type of exposure and disease symptoms, however, make it difficult to establish a clear cause-and-effect relationship between such triggers and scleroderma.

*Last updated: May 12, 2021*

# Symptoms of Scleroderma

## Overview

Scleroderma symptoms can vary dramatically, depending on which organs are affected and how severely. For some patients, symptoms can be mild; for others, they can be life-threatening. Symptoms also differ depending on the type of scleroderma.

Localized scleroderma primarily affects the skin, rarely damages internal organs, and runs a milder course. Systemic scleroderma is the more serious of the two. Patients may experience a broad range of symptoms due to damage to internal organs.

<b>Esophageal Dysfunction</b> Scleroderma patients with digestive tract involvement may experience symptoms such as heartburn, difficulty swallowing, a feeling of fullness, and intestinal complaints such as diarrhea, constipation, and gas. Gastroesophageal reflux disease is one of the most common symptoms that can develop into a chronic condition in scleroderma. <a href="#">LEARN MORE</a>	<b>Microstomia</b> Microstomia, one of the symptoms of scleroderma, is the narrowing of the tightening and hardening of the skin around the mouth. This tightening can ultimately cause difficulties in speaking, eating, brushing and flossing the teeth, as well as with dental procedures. It is not possible to prevent its development, but there are ways to delay or manage the difficulties associated with this condition. <a href="#">LEARN MORE</a>
<b>Muscle and Joint Involvement</b> If scleroderma affects the muscles, symptoms like muscular pain and muscle weakness are likely. If the joints are affected, patients may experience symptoms that are arthritis-like in their nature, including pain, stiffness, swelling, warmth, and tenderness. Joint involvement is relatively easy to diagnose, but muscle involvement is harder, because a person may experience no symptoms until muscular weakness is evident. <a href="#">LEARN MORE</a>	<b>Raynaud's Phenomenon</b> Almost all scleroderma patients develop what is called secondary Raynaud's phenomenon, a condition where the fingers and toes feel numb, prickly, and rigid in response to cold temperatures or stress. This is caused by the excess collagen that narrows small blood vessels in the fingers and toes. Raynaud's phenomenon is among the earliest symptoms of scleroderma. <a href="#">LEARN MORE</a>
<b>Sclerodactyly</b> Sclerodactyly is the thickening and hardening of the fingers, and sometimes toes, as a result of excessive collagen buildup in the skin. It is among the five symptoms that mark limited scleroderma, also known as CREST syndrome. (CREST stands for calcinosis, Raynaud's phenomenon, esophageal dysfunction, sclerodactyly, and telangiectasias). <a href="#">LEARN MORE</a>	<b>Telangiectasias</b> Telangiectasias are small blood vessels that become dilated, or widened, near the surface of the skin. They look like fine pink or red spots or lines that whiten briefly under pressure. Clusters of these blood vessels are called "matted telangiectasias" and form pink or red spots on the skin. They are common to both limited scleroderma and diffuse scleroderma. <a href="#">LEARN MORE</a>



# Types of Scleroderma

## Overview

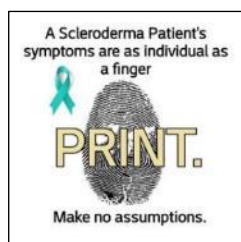
Scleroderma is a chronic autoimmune disease characterized mainly by hardening of the skin, although it can also affect internal organs. It is broadly separated into two major groups: localized scleroderma and systemic scleroderma.

In localized scleroderma, usually only the skin and/or underlying muscle tissue is affected, whereas in systemic scleroderma, the disease also affects internal organs. Patients can have different symptoms and different combinations of the disease. These are summarized below.

<b>Localized Scleroderma</b> The hallmarks of localized scleroderma are inflammation and thickening of the skin because of excessive levels of a structural protein called collagen. Localized scleroderma is relatively mild and commonly affects only a few areas of the body — usually the skin or muscles. Internal organs are typically not affected. <a href="#">LEARN MORE</a>	<b>Juvenile Scleroderma</b> Juvenile scleroderma is a rare type of scleroderma that occurs in children. It is generally localized and only affects the skin. In more severe cases, it can also affect the connective tissue, muscles, and bones, but unlike the more severe systemic scleroderma, it does not affect other organs such as the heart and the lungs. <a href="#">LEARN MORE</a>
<b>Linear Scleroderma</b> Linear scleroderma is a type of localized scleroderma that is most commonly diagnosed in children. Instead of patches of thickened skin commonly seen in the morphea type of localized scleroderma, patients with the linear type have thick streaks of skin usually affecting the limbs and torso. <a href="#">LEARN MORE</a>	<b>Morphea</b> Morphea is a term used to describe the skin symptoms of localized scleroderma, although the terms sometimes are used interchangeably. While it can occur in all age groups, it is more common among adults. Women develop morphea more frequently than men. <a href="#">LEARN MORE</a>
<b>Systemic Scleroderma</b> Systemic scleroderma, also called systemic sclerosis, is a multi-system autoimmune disease characterized by the accumulation of scar tissue in the skin and several internal organs such as the heart, kidney, lungs, and gastrointestinal tract. <a href="#">LEARN MORE</a>	<b>Limited Scleroderma</b> Limited scleroderma, also known as limited cutaneous systemic scleroderma, is a subtype of systemic scleroderma. It is marked by skin thickening accompanied by the accumulation of scar tissue in internal organs such as the heart, lungs, and intestinal tract. It is generally milder than diffuse scleroderma. <a href="#">LEARN MORE</a>
<b>Diffuse Scleroderma</b> Diffuse scleroderma is a subtype of systemic scleroderma. Patients with this type are more likely to have extensive skin fibrosis on the arms, legs, and trunk, with a higher risk of developing internal organ damage than those with limited scleroderma. Patients may also experience symptoms that worsen quickly and are more severe. <a href="#">LEARN MORE</a>	<b>Sine Sclerosis</b> Sine sclerosis is a rare autoimmune condition that affects only about 5% of people with systemic scleroderma. Patients with this type do not have the hard, thick skin that is characteristic of systemic scleroderma, but still experience an abnormal accumulation of scar tissue in their internal organs. <a href="#">LEARN MORE</a>

Source: <https://sclerodermanews.com/types-of-scleroderma/>

*Scleroderma News is strictly a news and information website about the disease. It does not provide medical advice, diagnosis or treatment. This content is not intended to be a substitute for professional medical advice, diagnosis, or treatment. Always seek the advice of your physician or other qualified health provider with any questions you may have regarding a medical condition. Never disregard professional medical advice or delay in seeking it because of something you have read on this website.*



## Podiatrists and Fingernail cutting

We have heard from Podiatrists throughout the country who are able to cut fingernails as well as toe nails. This is fantastic news as there has never been anyone specifically able to cut our fingernails.

Here is a list of Podiatrists. Please see below.

**Elaine Yelland** - Podiatrist & Business Owner  
is lovely Podiatrist on the Kapiti Coast who will be happy to cut finger nails. Her contact details as below:

**Foot Focus Podiatry Ltd**

Phone: 021 578 601

**Jessica Dobbs Podiatry** is a Hamilton based Podiatry clinic in Flagstaff, Hamilton and also specialize in mobile podiatry across the **Waikato**.

Our Podiatrist are trained in fingernail cutting and are happy to assist your members

<https://www.jessicadobbspodiatry.co.nz/>

**Dr Althea Carruth – Central Otago**

Dr Carruth does this only as part of general foot care.

To get in touch with her, her contact details are Mobile: 02041785262

**Simon Speight - \$45**

2nd Floor, 43 High Street,  
Auckland Central

Phone: 09 306 4006

Mobile: 021 535511

[www.speightspodiatry.co.nz](http://www.speightspodiatry.co.nz)

<https://www.facebook.com/Speights-Podiatry>

<https://www.instagram.com/speightspodiatry>

**Saf Kear**

Provides both clinic and home-based visits across Tauranga (BOP) region.

Phone: 07 219 7811

Mobile: 021 121 0435

Email: [hello@thegoodpodiatrist.co.nz](mailto:hello@thegoodpodiatrist.co.nz)



# Scleroderma-Related Conditions:

From Sclerodermanews.com

[Scleroderma](#) is a rare and chronic condition caused by the immune system mistakenly attacking healthy connective tissue. The body responds by overproducing a protein called collagen, resulting in the connective tissue tightening and hardening. The connective tissue provides structural integrity and strengthens tissues. It is mainly found under the skin, but is also an important component of different organs and blood vessels.

In [localized scleroderma](#), the skin is usually the only tissue affected, but in the more serious [systemic scleroderma](#), a variety of organs can be damaged. This can lead to a scleroderma patient developing a range of other conditions.

## Pulmonary arterial hypertension (PAH)

[Pulmonary arterial hypertension](#) (PAH), or high pressure in the blood vessels of the lungs, is a common complication of systemic scleroderma, occurring in about [40 percent of patients](#). It is more common in patients with limited cutaneous scleroderma.

Scleroderma can also cause inflammation and scarring in the blood vessels of the lungs. The damage can trigger vasoconstriction, or the narrowing of the blood vessels, which makes it more difficult for blood to flow and increases blood pressure in the arteries.

PAH can be difficult to diagnose initially as common early symptoms, such as shortness of breath leading to an increasing inability to exercise, are often overlooked. Although there is no cure for PAH, there is a [range of therapies](#) approved to help manage the symptoms of the condition.

## Kidney problems

Systemic scleroderma can often [affect the kidneys](#) and, in severe cases, may lead to renal crisis, which can result in kidney failure if left untreated.

Renal crisis may be difficult to identify as the early symptoms, such as an increase in blood pressure or the abnormal presence of protein in the urine, may be seen in all scleroderma patients. Renal crisis can come on suddenly and is normally associated with a rapid increase in blood pressure that can cause headaches, blurred vision, or even seizures.

[Other symptoms](#) of kidney involvement include nausea, vomiting, shortness of breath, a fast heartbeat, and chest pains.

Kidney involvement is usually associated with [diffuse systemic scleroderma](#) and is only rarely seen in [limited scleroderma](#).

## Muscle and joint problems

Muscle weakness, especially in the [upper arms and thighs](#), can occur in scleroderma patients due to [different causes](#), including damage from inflammation or muscle fibrosis

(scarring), or wasting from malnutrition due to gastrointestinal problems. Muscle weakness can also occur due to other conditions, such as [hyperthyroidism](#), or due to medications, such as corticosteroids.

Scleroderma can also cause [arthritis-like symptoms](#) from inflammation in the joints. This can cause pain, stiffness, swelling, warmth, and tenderness in the joints.

A common characteristic of systemic scleroderma is [sclerodactyly](#). When fibrotic tissue builds up in the skin of the hands, the joints can stiffen, leading to an inability to bend or straighten the fingers.

## Interstitial lung disease (ILD)

All types of systemic sclerosis can result in inflammation and scarring of the lung tissue causing [interstitial lung disease](#) (ILD). The scarring results in the lung tissue becoming stiffer and thicker, which restricts lung function and reduces the volume of air that can enter and leave the lungs. As a result, patients with scleroderma and ILD can be short of breath, and as the disease progresses, find simple daily tasks difficult to complete.

Scar tissue in the lungs may also restrict and damage the blood vessels of the lungs, [leading to pulmonary hypertension](#).

## Sjögren's syndrome

[Sjögren's syndrome](#) is another type of autoimmune condition that commonly occurs alongside systemic sclerosis. It affects fluid-producing glands, causing inflammation and impairing their function. Sjögren's syndrome commonly [leads to](#) dry eyes and mouth as the saliva- and tear-producing glands are affected. Several treatments are available to manage the symptoms, including eye drops, saliva substitutes, or saliva stimulants.

## Other conditions

There are potential associations between scleroderma and [several other conditions](#), including:

- [Erythromelalgia](#), where patients experience flare-ups of redness, heat, and a burning sensation in the hands, arms, legs, and face.
- [Fibromyalgia](#), where patients experience a continuous pain throughout the body.
- Increased risk of [pulmonary embolism](#), where blood clots block the blood vessels of the lungs.
- Other [autoimmune conditions](#), such as [lupus](#) and [rheumatoid arthritis](#).
- [Vasculitis](#), which causes inflammation and damage to blood vessels, resulting in restricted blood flow to the affected tissues

Source: <https://sclerodermanews.com/scleroderma-related-conditions/>





Scleroderma New Zealand and the  
Southland Scleroderma Support group presents

## Scleroderma Seminar 2024

Experts and friends come  
together for a day of education,  
discussion and support

**Saturday April 6<sup>th</sup>, 2024**

The Kelvin Hotel  
20 Kelvin Street, Invercargill  
Opens 8.30am – Presentations from 9.00am  
\$25 per person – registration  
To be paid direct to Scleroderma NZ account  
38-9017-0107454-00  
*Please use your name and seminar as reference*



This seminar is open to anyone interested in learning more about  
all types of Scleroderma including health workers, patients, carers,  
family and friends. Morning tea, lunch and afternoon tea provided.

### INCLUDES PRESENTATIONS FROM:

- Prof. Simon Stebbings, Rheumatologist Dunedin: Blood vessel problems in Scleroderma
- Dr. Sarah Jordan, Rheumatologist Dunedin: Lung issues in Scleroderma and treatment
- Dr. Katey Jenks, Rheumatologist Dunedin: Skin problems and treatment
- Dr. Paddy O'Connor, Southland Hospital: Gut Problems and treatment
- Dr. Miranda Buhler, Hand Therapist: Hand Therapy



**Scleroderma  
New Zealand Inc**

For more info or to register before  
March 22<sup>nd</sup> please contact Jenny:  
jennyred@xtra.co.nz or 027 3166 124



# Invercargill Seminar:

## Invercargill Seminar: Registration is open

To register for the Invercargill Seminar email/phone with the following details to [jennyred@xtra.co.nz](mailto:jennyred@xtra.co.nz) or 0273 166124:

NAME:

ADDRESS:

PHONE NUMBER:

EMAIL:

DIETARY REQUIREMENTS:



Thank you to all those who have registered for the seminar on 6th April 2024.

If you wish to attend please email me with your information as above.

It is \$25 per head and Scleroderma New Zealand will be subsidising the rest. Morning tea, Afternoon tea and lunch will all be provided. If you wish to book accommodation at the *Kelvin Hotel* where the seminar is to be held then give them a call on 03 218 2829 and let them know you will be attending the seminar.

### FUNNIES

What does Santa suffer from if he gets stuck in a chimney? Claus-trophobia!

What happened to the man who stole an Advent Calendar? He got 25 days!

Who delivers presents to baby sharks at Christmas? Santa Jaws!

What do they sing at a snowman's birthday party? Freeze a jolly good fellow!

What do Santa's little helpers learn at school? The elf-abet!

What kind of motorbike does Santa ride? A Holly Davidson

Why was the snowman looking through the carrots? He was picking his nose!

Why was the turkey in the pop group? Because he was the only one with drumsticks!

What do you get if you cross Santa with a duck? A Christmas Quacker!

What goes "Oh, Oh, Oh"? Santa walking backwards!

### The Optimist

*Little Susie had been born with a sunny disposition, and was the most optimistic kid anybody had ever seen.*

*She loved people and animals, and no matter what happened, she always saw the bright side.*

*She was also an artistic girl. So one Christmas, her parents got her a big bag of clay for making pottery. They put it on the back porch next to a bag of horse manure for the garden.*

*On Christmas Eve, dad wrapped the presents. It was a little dark on the porch, and as you may have guessed, he wrapped the manure by mistake, instead of the pottery clay.*

*On Christmas morning, Susie was so excited to see what Santa had brought her. When she finally got to unwrap her big present, her parents watched with anticipation to see how much she liked her clay.*

*When Susie opened the package, and then the bag inside containing several pounds of stinky horse manure, the parents were aghast.*

*But before they could apologize, Susie said, "Oh boy! I got a pony!"*



# Members News...



## Bay of Plenty Scleroderma Group

The Bay of Plenty group haven't met recently but will again in the new year. We look forward to hearing their news.



## Hawkes Bay Scleroderma Group

Francis and I had a great catch up yesterday. We met at a cafe in Taradale and a bit of time in the craft shops. Very enjoyable - we have set our next date for 3 weeks. We are both feeling quite well of late which makes life easier. Hope it lasts. Xmas just round the corner, time flies Cheers Gail 🌻🌻🌻



## New Plymouth Scleroderma Group

The New Plymouth group met up in October and had a lovely catch up. We had four join in, which was lovely to see everyone.



## Christchurch Scleroderma Group

The Christchurch group have been meeting regularly, thank you to Dianne for organising this. We will have more from them in the New year.



## Southland Scleroderma Group

Thank you again to Jenny for organising us for a get-together on Sunday 19th November in Winton. It was great to see familiar faces plus a couple of new people, one included Helen's grandson, Torben. Helen was visiting Dunedin from Auckland and we got the impression that she had all but kidnapped Torben from Dunedin where he lives, so they would have a catch up driving to Winton and back.

As we were waiting for our meals to arrive, Helen and I talked about the Zoom meeting that Diane had organized on the 4 November with Associate Professor Will Taylor. I did ask if he being a Rheumatologist covered not only the medical complications of Scleroderma, but also our mental health difficulties. He commented he had every concern with our mental health struggles and makes sure that his patients know they can approach his nurses for help with this.

I was delighted that one of our New Zealand members I keep in touch with was at the meeting. She spoke eloquently about hopefully having a stem cell transplant in Australia, but at the moment she is fighting roadblocks with medication. Good luck Jen and we hope things get sorted for you.

Helen commented that there appears to be about 1,000 people with Scleroderma in New Zealand, Prof. Taylor agreed with this figure, so please feel rather special.....or not that you are 1 in 50,000.

I joined Scleroderma Australia's online meeting discussing Oral health later in the month with Dr Tami Yap an Oral Medicine Specialist. She covered many topics and questions about Scleroderma and our oral health. The takeaway message for me was that if you cared for teeth before being diagnosed with Scleroderma and now your teeth are a mess, there is nothing you could have done to prevent this happening, it is a result of Scleroderma.

We are all looking forward to the Seminar next year and look forward to seeing you there. Heather Milligan





## Waipa and Waikato Scleroderma Group

### *Mere Kirihimete kīa koutou katoa,*

After a long Hayasis we finally got to put new faces to names. Our two small groups from Waipa and Waikato met in Matamata for our end of year Luncheon. The luncheon provided a wonderful opportunity for members to meet. The objective was to enable fun, learning and community. Absolutely smashed it. We held a quiz with a mix of Scleroderma questions and true/false fun facts. What a clever and fun group we have. The quiz provided a platform to get to know each other and wow, what an awesome, clever group, can't wait for the next gathering. Everybody contributed their wealth of knowledge and experience. A special focus was to inform our members of updated facts of NZ Scleroderma through the quiz and our role. We had 9 attendees. 4 Wapa members, 3 Waikato members and a wonderful support person with Waikato group. We were also fortunate enough to have Alumie come especially, who travelled over the Kaimai Ranges from Tauranga to spend time with us. We were mindful many of our members are at different places and stages. Also mindful of the fact that their work and continued support to us is the reason we were able to come together under the one common factor.

The idea from for the luncheon was to have a little fun and share a little about ourselves. Attendees could bring an item that showed what they did in their spare time, like a hobby, two of our members are crochet hobbyists. Alumie showed us her Sunflower with colours of happiness, and Susil a shawl with wonderful tension, both definitely skilled and I was able to observe a sense of pride with their work.

Rachel although was not able to show due to the size, works with recycled Rimu. I was lucky enough to see pictures, impressed to see confidence and yet feminine features to her pieces.

Rachel and I also supported the challenge set for summer gardening. Each of our members were given a card, a pack of sunflower seeds and NZ Scleroderma pins. Members were also asked to contribute ideas for our next fun gathering. All welcome, come and share in the wonderful company. Any members that couldn't attend luncheon would like direct notifications of upcoming events via email please get in touch so we can add you. If transportation is limiting your ability to attend, let us know early and we can look at carpool options. Together we are stronger, come and enjoy. Support people are always welcome.



A huge Thank You to Jenny and Team for our beautiful Scleroderma pins, our koha is on the way.

Otira e hoa ma, safe travels, sunblock, sunhats

Erena & Rachel



Paula Hansen, Jill Davies, Lea Hunt, Rachel Burgoyne, Erena Bruce, Susil Pereira, Alumie Nguyen, Maree Meredith, taking photo Dwayne Hansen



Some more photos from the Waipa/Waikato Group



Rachel Burgoyne shares a photo of her wood work art. Rachel thought perhaps she could make a mirror specifically to represent Scleroderma NZ....illusions. She saw sunflowers that could be fitted around the frame. She begins with very rubbish looking timber and with lots of time and love can bring out the beauty beneath; just like us all.

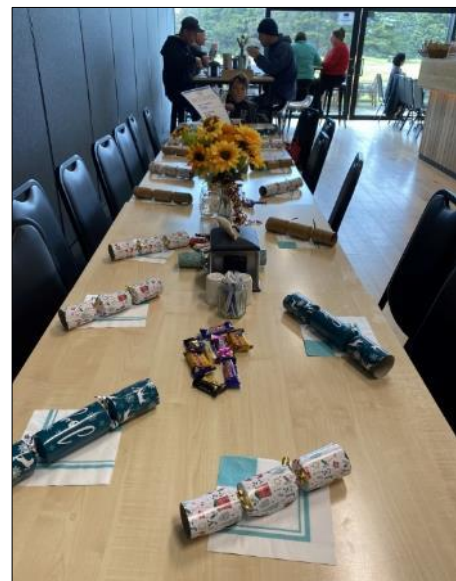


## Wellington / Kapiti and Wairarapa Scleroderma Group

A huge thank you to Dianne for organising another wonderful get together for the Wellington / Kapiti and Wairarapa Scleroderma Group who met on Saturday 25 November for a special Christmas lunch. We all met at The Farm Cafe & Bar in Lower Hutt. Thank you to Erena's table setting idea, I decided to copy and got some sunflowers for our table so we can easily be identified for our new members. We warmly welcome new members Fiona, Dee and Sandy to our group and hope to see them more in future gatherings. We had a lovely Christmas lunch and happy to catch up with each other.

Take care and have a **Merry Christmas** and **Happy New Year** for 2024. Tina 😊

Photos from the Wellington/Kapiti/Wairarapa



# Members News continued...

Photos from the Wellington/Kapiti/Wairarapa



## Auckland Scleroderma Group

The Auckland Group met up on Monday the 27<sup>th</sup> November. It was a quieter group but we were able to have a wee catch up which was lovely. They will be meeting again in February. Members will be notified by email



# Events Happening:

## Scleroderma New Zealand Badges

Yes, the Scleroderma New Zealand badges are here ☺



Thank you to our wonderful president **Jenny** who has got our Scleroderma New Zealand badges completed and ordered. The badges have now been delivered and are all ready to be sent out to our group leaders who will

distribute to their members in their group catchups to any member who would like one.

These badges are free to all members, but if you would like more than 1 badge to give to your family, support person, friends or colleagues, a donation is greatly appreciated to cover costs.

If you are not able to go to a group catchup or there isn't a group in your region, please feel free to email Jenny and I am sure she will be happy to send you one.



Helen Parsons with her badge



## Planting Sunflower Seeds..



Thinking of doing something fun this year as part of our Scleroderma New Zealand group ?

**Why not plant sunflower seeds this summer.**

Take Photos of your sunflower growing and load them up on our Scleroderma New Zealand Facebook page:

<https://www.facebook.com/SclerodermaNewZealand/>

We will discuss and compare pictures, check who has the tallest sunflower, who has the largest flowers, who has the preetest, who has the fastest growing sunflower?

Follow us on our Scleroderma New Zealand Facebook page:

<https://www.facebook.com/SclerodermaNewZealand/>



**FROM THE SCLERODERMA NZ COMMITTEE**



# Events Happening in November/December:

## Breathwork for pain and stress management

Nov 8, 2023

Natasha Godetz, health coach and breathwork practitioner, teaches breathing techniques that are gentle and safe for anyone to do. The breath is a powerful tool to manage pain and stress and is free for all of us! Event attendees ask questions and Natasha answers them and provides tailored examples of breathing techniques throughout the video.

Video link is on Ytube: <https://www.youtube.com/watch?v=-dT4YsGxhM>



Presented by:

**Arthritis New Zealand**

<https://www.youtube.com/@arthritisaotearoa>



**International Study on the Corporate Reputation of Pharma in 2023**

**Have your say!**

For weblink, see below

For the attention of: Scleroderma New Zealand Inc

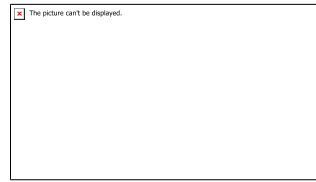
About this survey: This annual PatientView study is unique, in that it is conducted entirely independently. Patient groups participating in the study are given the study results for free (if they wish to receive them).

We would like to hear your opinions on the subject: whether, in 2023, pharma has met your expectations—and, if not, how might the industry, and individual pharma companies, improve at providing support and help to patients and patient groups?

Most of the major (and many of the smaller) pharma companies take the results of this annual survey very seriously. They rely on the insights they gain from the survey results to build strategies around patients. Your participation in this survey is therefore important.

**WEBLINK** to the survey on the 'Corporate Reputation of Pharma in 2023':

<https://www.surveymonkey.com/r/Corporate-Reputation-2023>



**Our Voice of Rare Disorders survey 2023 is now open – please share !**

Rare Disorders New Zealand is conducting its biennial survey on living with a rare disorder in Aotearoa New Zealand. The Voice of Rare Disorders Survey 2023 is open to anyone living with a rare disorder in New Zealand, as well as their carers and whānau. If you, or someone you care for, lives with a rare disorder you are strongly encouraged to participate. This is the only comprehensive data collected on rare disorders in New Zealand and will be used to inform policy makers on the challenges and systemic barriers facing those living with a rare disorder to encourage meaningful change.

**We have now extended the closing date to 30 November.**

The more responses we get, the stronger our collective voice will be. We currently have over 900 responses and are aiming for over 1,000, so we still have a way to go and greatly appreciate your support in spreading the word to all your networks.

We have a [page on our website](#) with easy ways to help share the survey, including blurbs for newsletters and social media posts, as well as a printable flyer.

We would also be really grateful if you could print the flyer and pin it on noticeboards in your community.

Thanks so much for your help!

To access the survey go to:

<https://www.raredisorders.org.nz/about-rare-disorders/voice-of-rare-disorders-survey-2023/>



# Group Meeting Dates for 2023/2024:

## Wellington Scleroderma Support Group

### Get Togethers:

November 2023 – November 2024

All Welcome

#### Co leaders contact details:

Tina Mclean: [altinamclean@xtra.co.nz](mailto:altinamclean@xtra.co.nz)

Cushla Marsters: [cushla.marsters@solnetsolutions.co.nz](mailto:cushla.marsters@solnetsolutions.co.nz)

Dianne Purdie: [diannepurdie@xtra.co.nz](mailto:diannepurdie@xtra.co.nz) Ph 04 479 5548

Date & Time	Venue	Address
Saturday 4 <sup>th</sup> November 2023 Time TBC	Zoom meeting Sharing experiences with managing Scleroderma People from other regions most welcome.	Zoom Link to be advertised closer to the time.
Saturday 25 <sup>th</sup> November 2023 11.30am	The Farm Cafe & Bar- Boulcott's Farm Heritage Golf Club	33 Military Road, Boulcott, Lower Hutt
Saturday 24 <sup>th</sup> February 2024 12.30pm	Chocolate Fish Cafe	100 Shelly Bay Road, Miramar
Saturday 27 <sup>th</sup> April 2024 12.30pm	The Farm Cafe & Bar- Boulcott's Farm Heritage Golf Club	33 Military Road, Boulcott, Lower Hutt
Saturday 25 <sup>th</sup> May 2024 1.30pm	Zoom meeting Sharing experiences with managing Scleroderma People from other regions most welcome.	Zoom Link to be advertised closer to the time.
Saturday 20 <sup>th</sup> July 2024 12.30pm	Mid Year Lunch Fisherman's Table	29 State Highway 59, Paekakariki
Saturday 21 <sup>st</sup> September 2024 12.30pm	Chocolate Fish Cafe	100 Shelly Bay Road, Miramar
Saturday 23 <sup>rd</sup> November 2024 12.30pm	The Farm Cafe & Bar- Boulcott's Farm Heritage Golf Club	33 Military Road, Boulcott, Lower Hutt



## Christchurch Scleroderma Support Group

### Get Togethers:

November 2023 – November 2024

All Welcome

We welcome any new members to come along too.

Please contact:

Dianne Purdie: [diannepurdie@xtra.co.nz](mailto:diannepurdie@xtra.co.nz) Ph 04 479 5548

Date	Venue and Time	Address
25 <sup>th</sup> November 2023	Burwood Hospital Travis Courtyard Café Saturday 2pm – 4pm	300 Burwood Road, Burwood, Christchurch
23rd March 2024,	Burwood Hospital Travis Courtyard Café Saturday 2pm – 4pm	300 Burwood Road, Burwood, Christchurch
25th May 2024	Burwood Hospital Travis Courtyard Café Saturday 2pm – 4pm	300 Burwood Road, Burwood, Christchurch
20th July 2024	Mid Year Lunch Venue to be Advised Saturday 12pm	TBA
21st September 2024	Burwood Hospital Travis Courtyard Café Saturday 2pm – 4pm	300 Burwood Road, Burwood, Christchurch
23rd November 2024	Burwood Hospital Travis Courtyard Café Saturday 2pm – 4pm	300 Burwood Road, Burwood, Christchurch



# givealittle **Give a little:** Scleroderma NZ Inc.

From [Scleroderma New Zealand Incorporated - Givealittle](#)

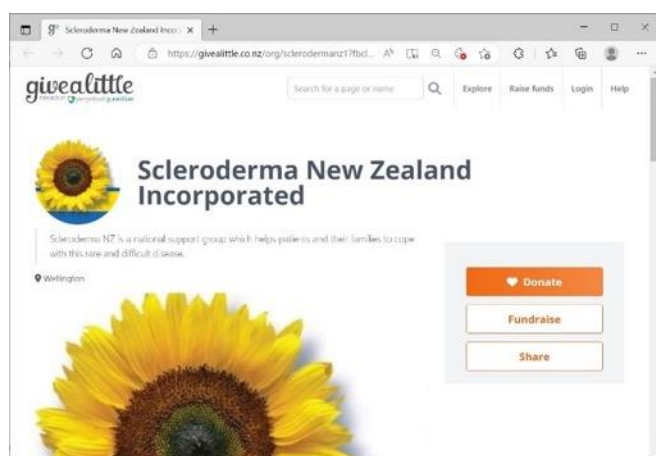


## Scleroderma New Zealand Incorporated

Scleroderma NZ is a national support group which helps patients and their families to cope with this rare and difficult disease.

An example of what our give a little website page is shown below:

[Scleroderma New Zealand Incorporated - Givealittle](#)



Our give a little URL link address is shown below: -

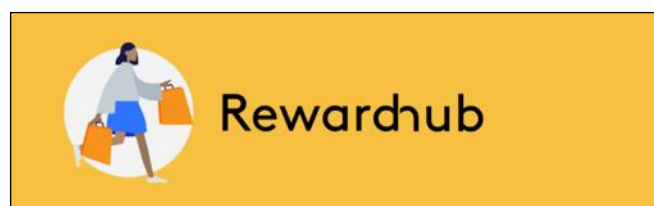
<https://givealittle.co.nz/org/sclerodermanz1?fbclid=IwAR29Znk701JSOwf9n0Ew-O63nj0FrySOCpV44mBCpIPHtXV7Uff9KIAnAzM>

If you are donating or you are circulating the givealittle link, please make sure you use the above address link, thank you.

Many General Practitioners have not had experience with this disease and Scleroderma NZ aims to help promote knowledge among our medical professionals and patients, by supplying them with educational booklets and hospital checklists for special requirements.

The purposes of Scleroderma NZ are to support, friendship, education, awareness, advocacy, lobbying, prevention, research and assistance with health care for people, their families and communities with Scleroderma (Systematic Sclerosis) and Undifferentiated Connective Tissue Disease.

# Scleroderma NZ Inc. Shopping



## REWARDHUB

Is it hard to leave the home when you aren't feeling the best. Why not do your shopping from the comfort of home. Rewardhub is a website where more than 100 leading brands will Reward us with free donations, at no extra cost to you, when you shop online and are signed up to support us.

It's an easy place to shop and includes special discount codes on big brands in fashion, beauty, entertainment, travel, utilities, money, homeware, food, drink and more.

To learn more and sign up to our page, please visit:  
<https://rewardhub.co.nz/scleroderma-new-zealand-incorporated?q=scleroderma>

*Below is a list of some of the brands available to shop with:*

Countdown	Vans
Life Pharmacy	Uggs.com.au
Paper Plus	Vistaprint
Ezibuy	Wotif
Mighty Ape	Booking.com
Cotton On	Forever New
Bargain Box	Converse
My Food Bag	Bedpost
Hello Fresh	Bedpost
Rodd & Gunn	Contiki
Lego	Airbnb
Bras N Things	Fishpond
Hallensteins	Specsavers
Skechers	Tarocash



This is a shopping website that rewards different causes with a percentage of a purchase made.

We have set Scleroderma NZ up and it is ready to go.

We're excited to share a way to raise funds that costs nothing and can even save you money.



# Group Meetings:

## Wellington support group meets:

**Venue:** *Chocolate Fish Cafe*

*100 Shelly Bay Road, Miramar*

**Time:** Saturday 24<sup>th</sup> February 2024 at 12.30pm

Wellington meeting dates and venues for the new year of 2024 are published above on page 20.

For any enquiries please contact Dianne:

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

## Christchurch support group meets:

**Venue:** *Burwood Hospital - Travis Courtyard Café*  
*300 Burwood Road, Burwood, Christchurch*

**Time :** Saturdays 2 - 4pm.

**Dates :** 23rd March 2024, 25th May 2024,  
21st September 2024, 23rd November 2024

**Mid Year Lunch:** 20th July 2024, Saturday 12pm  
Venue TBA

We welcome any new members to come along too.

Please contact **Dianne Purdie** if you would like to join in:

[diannepurdie@xtra.co.nz](mailto:diannepurdie@xtra.co.nz) Phone: 04 479 5548

## Southland support group meets:

Sunday February 11<sup>th</sup>, 12pm. Venue TBA

**Saturday April 6<sup>th</sup>, Seminar**, Kelvin Hotel, Invercargill

Sunday June 30<sup>th</sup>, 12pm

Sunday September 8<sup>th</sup> 12pm

Sunday November 24<sup>th</sup> 12pm

Please contact **Heather** if you wish to join us.

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

## Waikato/Waipia support group meets:

If you would like to join in with the Waikato/Waipia Group, please contact

**Erena Bruce**, Mobile: 021 186 9680

**Rachel Burgoyne**, Mobile: 027 3661881

## Palmerston North support group:

See Wellington Support group.

## Auckland support group:

Auckland's Group will be meeting in the new year:-

**Venue:** TBA

**Time:** An email will go out to Auckland Members. To be held monthly. And a reminder email to be sent out one week prior to each meeting.

For any enquires please contact either:-

**Helen Parsons:**

[HelenParsons@artcardsandposters.co.nz](mailto:HelenParsons@artcardsandposters.co.nz)

**Catherine Johnston:**

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

## New Plymouth support group meets:

**Venue:** TBA

**Time:** February.

So if you would like to attend the New Plymouth Support Group please get in contact with **Kelsi Tidswell:**

[kelsitidswell@gmail.com](mailto:kelsitidswell@gmail.com)

## Blenheim/Nelson support group:

**Jen Soane** is organising the Blenheim/Nelson support group so if you would like to attend please get in touch with Jen: [jennasoane@gmail.com](mailto:jennasoane@gmail.com)

## Hawkes Bay support group:

The Hawkes Bay group have regular catch ups. To be part of the Hawkes Bay Group please contact Gail.

**Gail Neilson:** [gail\\_neilson@hotmail.com](mailto:gail_neilson@hotmail.com)

## Bay of Plenty support group meets:

**Venue:** *Katikati Gold Club Cafe*

Meetings will be on the 1<sup>st</sup> Saturday bi-monthly.

These will start in February. So the 3<sup>rd</sup> February will be the first date. Then April 6<sup>th</sup>. More info will come out nearer the time.

Please contact one of us for information.

**Jane:** [janepuckey99@gmail.com](mailto:janepuckey99@gmail.com)

**Mary:** [marybestrd3@gmail.com](mailto:marybestrd3@gmail.com)

**Alumie:** [alumie.uow@gmail.com](mailto:alumie.uow@gmail.com)

## Otago support group:

Please contact **Gay** if you wish to join us.

[gaymeddings@gmail.com](mailto:gaymeddings@gmail.com)

## Waimate/Oamaru support group:

We have ladies meeting up in these areas so if you are interested in joining them please get in touch with

**Helene Sunitsch** at: [hkjsunitsch@gmail.com](mailto:hkjsunitsch@gmail.com)





# Welcome to Scleroderma New Zealand Inc.

To all our new members, who have recently joined us – Welcome....

Scleroderma New Zealand Inc. is for people with scleroderma and their families and friends. As there are not too many of us, we would like to be able to provide support, friendship, exchange of ideas & information.

Link to our Website address below: -  
<http://scleroderma.org.nz/>



Link to our Scleroderma NZ Facebook page: -  
<https://www.facebook.com/SclerodermaNewZealand/>



Link to our Auckland Facebook page: -  
<https://www.facebook.com/groups/sclero.ak/>



## Scleroderma New Zealand

President:	Jenny Andrews <a href="mailto:jennyred@xtra.co.nz">jennyred@xtra.co.nz</a>
Vice President:	Tina McLean <a href="mailto:altinamclean@xtra.co.nz">altinamclean@xtra.co.nz</a>
Secretary:	Jane Sainsbury <a href="mailto:jsainsbury@xtra.co.nz">jsainsbury@xtra.co.nz</a>
Treasurer:	Gordon Purdie <a href="mailto:gordon.purdie@xtra.co.nz">gordon.purdie@xtra.co.nz</a>
Newsletter:	Tina McLean <a href="mailto:altinamclean@xtra.co.nz">altinamclean@xtra.co.nz</a> Jenny Andrews <a href="mailto:jennyred@xtra.co.nz">jennyred@xtra.co.nz</a>
Committee Members:	Linda Bell Erena Bruce Cushla Marsters Dianne Purdie Heather Milligan Alumie Nguyen Frances Tod Rachel Burgoyne Helen Parsons

## Contacts:

### Find a Scleroderma Support Group near You:

Auckland:	Helen Parsons, Email: <a href="mailto:helenparsons@artcardsandposters.co.nz">helenparsons@artcardsandposters.co.nz</a> Catherine Johnston, Email: <a href="mailto:sassycat@xtra.co.nz">sassycat@xtra.co.nz</a>
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