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Scleroderma

New Zealand support group

Winter 2025

Greetings to you all...

Welcome to the Winter edition of our Scleroderma Newsletter

Kia ora koutou, nau mai haere mai, greetings to you all.

Winter is now officially here, we hope everyone is doing well. Now is the time to make sure that we are all looking after ourself and keeping our core body temperature warm, with warm layers of clothing, gloves, hats and scarfs when going outside. Its not too late to still get your flu jab if you haven't done so already before winter sets in.

We warmly welcome all our new members who have joined us. Getting diagnosed with scleroderma is not fun and can be scary but we hope you will find some of the articles in this newsletter useful and informative.

We hear first from Jenny Andrews with the Presidents report. Even though Jenny is out of the country on her overseas holiday, visiting other countries and doing exciting things, she is able to still keep in touch and send in her report to keep us up to date with what's happening within our community. Jenny has also sent us some of her holiday photos which we have shared in this issue.

We have a memorial for Tony Morriss, a member of our Wellington/Kapiti and Wairarapa sclerorderma group, who passed away in May.

We have an informative article written by Perry about Muscle Involvement in Systemic Sclerosis. We have interesting stories shared by our members Helen and Helene. We also have our regular members updates from our different support groups around New Zealand.

Don't forget **World Scleroderma Day** on the 29th **June** and check out the details on how to register for the **Scleroderma Seminar** to be held on the **18th October** in **Te Awamutu**. Thank you to the Waikato/Waipa group for organising this.

Please feel free to send us any news, stories, jokes or anything you would like to share with us at any time. Our contacts are listed on the last page of this newsletter.

Take care everyone.

Nga mihi,

Tina, Helene and **Jenny** (from her holiday overseas)

Presidents Report:

Hello Winter

Hi Everyone…

Welcome to winter. I hear it has been pretty harsh in some places at the moment so I hope you're staying nice and warm and inside beside your fire.

If you haven't already don't forget to get your flu jabs.

We had a great AGM meeting recently and were able to sign off the constitution so that's great that that's been done.

That was a lot of hard work by the committee members so thank you very much to the committee especially thank you to Dianne and Gordon who did most of the writing up of that.

We have Alumie and Gordon working on updating our website so thank you guys. I see what has been done is looking really good and so they will work away and just do little bits at a time so keep an eye out on the website.

The New Zealand Facebook page has lots of interesting things happening on it as well so thank you to all those who are putting up notices on there.

We will have some more information on the seminar through the newsletter so keep an eye on that and we should be able to take registrations for that very soon so get your flights booked or your accommodation and we look forward to catching up in Te Awamutu at the seminar.

A very big thank you to Erena and her team for doing the organising for this.

You are all doing a fantastic job thank you so much. wishing you all a happy Scleroderma day for the end of the month. Hopefully some different areas are lighting up for a day. If you have organised something and you want to share the photos please feel free to share them here for our next newsletter.

On a slightly different note I am out of the country at the moment. right now I am in Bratislava in Slovakia. We are into our 11th day already of our trip away. We enjoyed our first night in Auckland then Singapore then we had four nights in Dubai and did some really fun things.

I feel like I have become a bit of a height junkie now. With going up to the 148th floor of the Burj Khalifa then walking across the glass floor of The Dubai Frame. I'm feeling very brave these days.

Had a very interesting trip around the museum of the future also in Dubai and did lots of walking around the mall which was pretty awesome. We then flew onto Budapest and had three nights there staying in a beautiful old hotel with lots of character. We did some relaxing in the thermal baths and lots of walking.

We are now on the river cruise and have had just two nights so far. The food is fabulous , the staff are amazing, The happy hour is lots of fun and the excursions are really interesting so it's proving to be pretty cool. We walked around the old city of Bratislava today and then up to the UFO and I'll put a couple of photos to show you so take care everyone and stay warm.

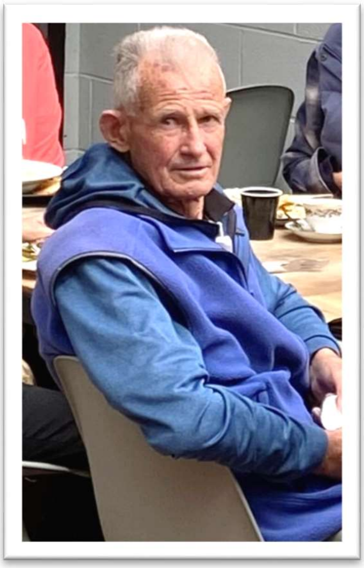
10 minutes until Happy hour so time to sign off.

Regards Jenny

Memorial for Tony Morriss

Scleroderma New Zealand Member

In Memory of Anthony (Tony) John Morriss



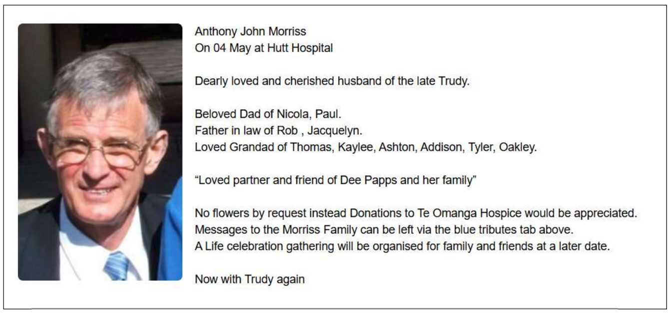
On 4th May 2025 at Hutt Hospital

The Wellington / Kapiti / Wairarapa Scleroderma Support group is sad to announce that their fellow supporter passed away on the 4th of May.
Tony became ill and his condition worsened quickly.
Tony had been with our group for 4 years and he often attended the quarterly lunch gatherings.
Tony will be sadly missed by our members that knew him well.
Our sincere condolences go out to his family and friends.
Warm regards, Dianne

Tony was indeed a very lovely and kind gentleman. I found Tony was always very cheerful and positive, and gave good advice. I was lucky to get to know Tony and chat with him when he came to our group lunches. At our last group lunch at Chocolate fish cafe, Tony and Dee were there, even though Tony was not very well, he was happy to be with everyone. I will miss seeing your smiling face and caring nature and the way you loved to listen to everyone talk Tony.
Our deepest condolence go to Tony's family and Tony's partner Dee.
Warm regards, Tina

I first met Tony 4 years ago I said to Karin I have finally met someone who has very similar symptoms to me, considering all the various trials and tribulations we all go through. Over the years Tony would participate in the discussions, but mostly listen, and our chats were usefull for all of us, and we could see each time we met a deterioration in his health that he bore with quiet stoicism. We were all quite shocked at his state of health the last time we saw him on that lovely day out at the Chocolate fish and now his suffering is over, go well my friend.

Stay well everyone and remember you are the best advocate for your care.
Warm regards, Steve



Anthony John Morriss
On 04 May at Hutt Hospital

Dearly loved and cherished husband of the late Trudy.

Beloved Dad of Nicola, Paul.
Father in law of Rob , Jacquelyn.
Loved Grandad of Thomas, Kaylee, Ashton, Addison, Tyler, Oakley.

"Loved partner and friend of Dee Papps and her family"

No flowers by request instead Donations to Te Omanga Hospice would be appreciated.
Messages to the Morriss Family can be left via the blue tributes tab above.
A Life celebration gathering will be organised for family and friends at a later date.

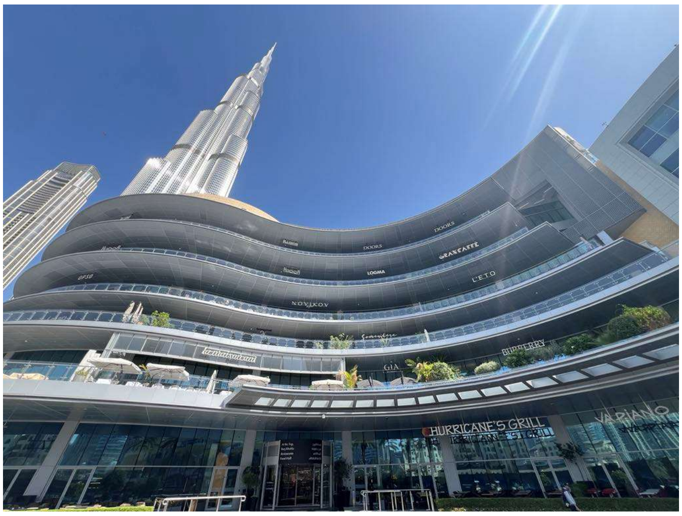
Now with Trudy again

Source: https://www.tributes.co.nz/

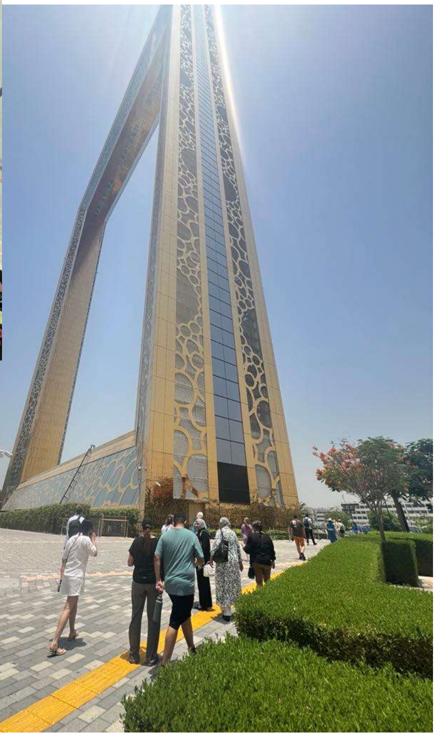
Members Stories:

Jenny Andrews shares her holiday photos…

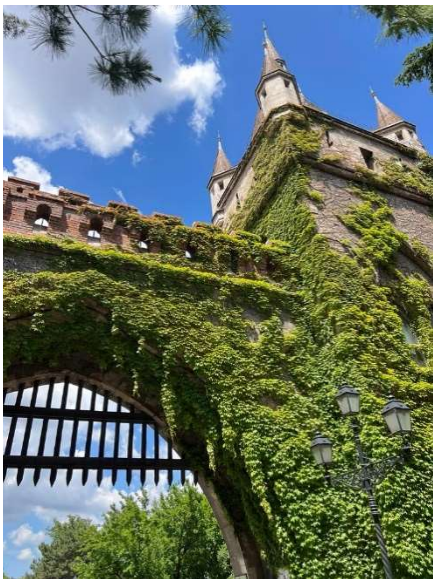
Jenny and Jeff are having a wonderful time on their overseas holiday at the moment. These photos are taken in Dubai, Budapest and at the old city of Bratislava.



The last photo on the next page, has Jane Sainsbury (secretary of Scleroderma NZ). Jenny says "*we met up with Jane and John for 10 minutes before our boats both sailed away in the opposite direction…*"




360°
UFO
SKYWALK



Members Stories:

Helene Sunitsch shares her story…

Helene tells us about her journey with Scleroderma and shares photos of the lovely knitting she makes ….

Scleroderma and me…

My journey started with the usual cold sensitivity affecting my fingers, raynauds had it all my life thought nothing of it. I had bigger fish to fry a life , marriage,children and a bi poplar diagnosis.

Then when I reached 50 years old. I noticed red dots on my face and hands.Thinking it was part of the ageing process thought nothing of them. They looked like freckles. [Telangiectasia]. I was working in a department store , one of my jobs was to put stock out. Heavy lifting was involved and while I was nursing my mother with cancer I noticed I was slowing down. I put it down to age and the need to lose some weight.

She passes and I carry on with my life. Though now I have my dad to watch out for.

I have no skin thickness that I noticed. My fingers were a bit puffy.

Then the dreaded Covid arrived and we were all in lockdown. Spending time with my husband in the backyard in the sun. Enjoying the peace and quiet.

Then when we went back to our jobs and restrictions my dad didn't understand the new world and gave up on his life.

Filled with grief for losing both parents in 3 years. I carried on till it happened.

I had a cough . Simple as that. I felt as though I had been punched in the ribs one day at work.

With Covid restrictions it was very hard to get a face to face appointments with my GP, let alone a specialist in the hospital. I had a Doctor in Timaru Hospital who was in my corner. Blood tests,X-rays,CT scans and Pulmonary Function tests.

I finally got to see a lovely specialist Dr Edwards in Christchurch hospital. Telling me . I have Interstitial lung disease associated limited scleroderma. My world took a different path. It was now filled with appointments. New words Th/To antibodies. Pulmonary hypertension, gastro-oesophageal dysmotility. To name a few.

My new one is Limited Scleroderma sine. Which is a rare form of scleroderma and hard to diagnose as there can be no or very little skin involvement. But are at increased risk of significant internal organ involvement.

Oh that's me.

Where am I today. I think I am lucky. I have a wonderful team. I am able to take part in a drug trial called MOONSCAPE. The study is looking at the effects of Vixarelimab for treatment of ILD associated scleroderma. Hopefully it will be another drug to add to the arsenal.

My husband just retired and we get to spend time together. I love to craft and able to crochet amigurumi and knitted hats,ear warmers and neck warmers. Which are made from New Zealand Yarn. I sell these at markets . I do have a Fb page under the label Sunitsch Style.

I am on Oxygen most of the time. I have a portable converter. For the times I am out and about.

Otherwise life is good. I am happy.

Helene S

Some beautiful crafts that Helene makes…

Members Stories:

Helen Parsons shares her story…

Helen tells us about travelling with her medicines and the pre-peparation that goes with it….

I thought I'd record my experience of packing my drugs for travel. Most of us will have had to do this.

I fly to UK in a week or so. I always have detailed lists for all my packing. What goes into my checked-in baggage, what goes into my cabin bag.

I also have a small, pretty backpack with my technology in it, and a dark brown leather handbag with my travel meds. One of these can fit into the cabin bag so that I comply with the pieces and weight requirement.

But it's the counting of the pills that flummoxes me. 1 tab in early morning, each day of the week for 3 weeks, that's easy. That adds up to 21 tabs.

But what about 4 tabs, 3 times daily, for 3 weeks (which is 21 days I think), equals . . . . what?????

And I do this sort of arithmetic for six different medications.

Then I need some separately for the travel days. Again counted out in detail, and deposited into other tiny bags that I'll keep in that brown leather handbag near me.

One of my big things is that I also want emergency supplies of all my meds.

Roger went off to the pharmacy to pick up my new lot of drugs. He came home with a truckload full.

I mentioned to him that I was travelling with a duplicate three weeks of meds. He was appalled. However, he said he understood when I pointed out that I could take just one spare week of drugs, but that mightn't be helpful if one of us had a medical emergency.

I read all the stories of people from Aotearoa who were held up overseas during covid without medications. I'd be horrified to be in that situation.

But oh dear, as I write this I am uncertain if I have calculated the meds that I'll put into my dinky weekly dispensers. Four of them. I'm still using those while I'm at home.

I can't for the life of me work out if I counted them in. I feel I'm going nutty. Do I really have to do all that arithmetic again?

Helen P

These lovely photos were taken by Helen's grandson: Sebastien Kwan-Parsons

Members Stories:

The life and times of Perry…

Are you in the game or are you watching from the sidelines…

Muscle Involvement in Systemic Sclerosis: A Simple Explanation

June 4, 2025 by Perry

Muscle involvement is one of the most serious symptoms of scleroderma, or systemic sclerosis (SSc), with about one-third of all patients reporting some muscle weakness.

It can have a significant impact on patients quality of life and prognosis, and it can be associated with reduced muscle strength, pain, and difficulty with daily activities.

In some cases, severe muscle involvement can lead to complications like respiratory problems, cardiac involvement, and impaired mobility.

Muscle involvement in scleroderma can be quite varied, with different presentations and degrees of severity making it difficult to not only diagnose properly so that treatments can be provided – but also measuring the activity of muscle involvement is complicated.

Since being diagnosed with Scleroderma back in November 2018 I have constantly had muscle aches and pain which come on in fits and starts ☹

The following article entitled 'Muscle Involvement in Systemic Sclerosis: A Simple Explanation' was written by Professor Susanna Proudman for Scleroderma Australia, and I felt it was quite pertinent, being Scleroderma Awareness Month to highlight this issue here on my blog.

She writes; Systemic sclerosis (SSc, a.k.a. scleroderma), is an autoimmune disease that affects the skin, blood vessels, and various organs including the muscles. Muscle problems in scleroderma can range from mild discomfort to severe weakness that affects daily activities. Understanding how and why muscles are affected can help people manage their symptoms and improve their quality of life.

Muscle problems are more common in people with diffuse systemic sclerosis (dcSSc) than in those with limited systemic sclerosis (lcSSc).

How Does Scleroderma Affect the Muscles?

The overactive immune system in people with scleroderma mistakenly attacks the body's own tissues. This leads to inflammation and excessive production of collagen, a protein that normally helps keep the skin and organs firm and elastic. In scleroderma, too much collagen builds up, causing thickening and stiffness in various parts of the body, including the muscles.

There are two main ways that scleroderma affects the muscles – Inflammation and Fibrosis.

Inflammation of the Muscles (Myositis):

Some people with scleroderma develop a condition called myositis, which means "muscle inflammation." This can cause pain, tenderness, and weakness, especially in the shoulders, upper arms, hips, and thighs.

Myositis makes it difficult to climb stairs, lift objects, or even stand up from a seated position. Over time, if the inflammation is not controlled, the muscles can become weaker and smaller.

This form improves with immunosuppressive medications.

Fibrosis (Scarring) of the Muscles: In addition to inflammation, scleroderma can cause fibrosis, or scarring, in the muscles. This happens when excess collagen replaces healthy muscle tissue, making the muscles stiff and less flexible.

Fibrosis can make movement difficult and lead to a gradual loss of strength. Unfortunately this form does not respond to immunosuppressive medications.

Symptoms of Muscle Involvement in Scleroderma

People with scleroderma-related muscle problems may experience:

- Muscle weakness, especially in the arms and legs
- Muscle pain or tenderness
- Fatigue, even with mild activity
- Stiffness, particularly in the morning or after rest
- Difficulty with everyday tasks like walking, lifting objects, or getting out of a chair

Members Stories:

The life and times of Perry…

continued…

Muscle Involvement in Systemic Sclerosis: A Simple Explanation

June 4, 2025 by Perry

These symptoms can vary from person to person. Some individuals may have only mild muscle issues, while others may experience severe weakness that affects their independence.

Diagnosing Muscle Involvement in Scleroderma

Doctors use several tests to determine if scleroderma is affecting the muscles. These may include:

- Blood tests to check for muscle damage or inflammation (e.g., creatine kinase levels)
- Electromyography (EMG) to measure the electrical activity of muscles
- MRI scans to detect muscle inflammation or fibrosis
- Muscle biopsy to examine muscle tissue under a microscope which is the most reliable way to confirm the diagnosis.

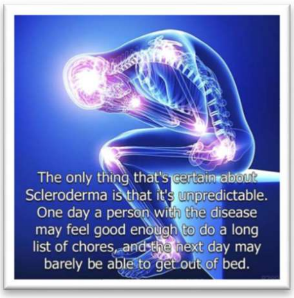
However, these tests are not perfect. For example, a person can still have muscle problems even if their CK levels are normal. As there is no standard classification system for muscle disease in scleroderma, estimates of how common muscle involvement is in scleroderma vary widely, from 6% to 96% of patients. The proportion of patients enrolled in the Australian Scleroderma Cohort Study with biopsy-proven myositis ranges from 2-10%

Why Is Muscle Involvement Often Missed?

Doctors may not always recognize muscle problems in people with scleroderma. This is because muscle weakness can have other causes, such as

- Lack of physical activity due to pain or stiffness
- Poor nutrition
- Side effects of medications like steroids or cholesterol-lowering drugs
- Skin thickening, joint stiffness, or internal scarring, which can also limit movement

Importance of Early Diagnosis & Screening


The only thing that's certain about Scleroderma is that it's unpredictable. One day a person with the disease may feel good enough to do a long list of chores, and the next day may barely be able to get out of bed.

It is crucial to identify muscle inflammation, if it is present, early so that treatment with immunosuppressive medications can begin as soon as possible. Without treatment, muscle weakness may worsen over time. Since muscle problems are common in scleroderma and can have a major impact on daily life, some experts believe that all SSc patients should be screened for muscle involvement both at the time of diagnosis and during follow-up visits.

Treatment and Management

There is no cure for scleroderma, but muscle involvement can often be managed with a combination of treatments:

- Medications – Corticosteroids and immunosuppressive drugs can help reduce inflammation and slow muscle damage.
- Physical therapy – Stretching and strengthening exercises can help maintain mobility and prevent stiffness.
- Pain management – Over-the-counter pain relievers, heat therapy, and massage may provide relief.
- Nutrition – A balanced diet with enough protein helps support muscle health.

Muscle involvement in scleroderma can be challenging, but early diagnosis and treatment can help improve symptoms and maintain function. Staying active, following a treatment plan, and working with healthcare professionals can make a big difference in managing this aspect of the disease.

I hope that you've found this information helpful.

Blessings 'til next time ☺

Managing Raynauds

From: https://www.sruk.co.uk/about-raynauds/signs-symptoms-of-raynauds/

Although there is no cure for Raynaud's, it can be treated. The key to managing Raynaud's symptoms is to try to prevent an attack- planning ahead is vital. Here are some ways you can manage Raynaud's phenomenon symptoms and live as normal a life as possible.

Webinar on Raynaud's

Click https://www.youtube.com/watch?v=ebh8FD0RQxg

To watch our webinar on Understanding & Managing Raynaud's. Dr John Pauling shares key information, including who is at risk, symptoms, getting tested, prevention and treatments, as well as giving some practical tips and advice. We hope you find this useful.

There were lots more of your questions that were answered after the session - click here to download the comprehensive list. https://www.sruk.co.uk/media/filer_public/71/dc/71dc583a-5260-4085-9772-a77d3bc2554c/understanding_and_managing_raynauds_phenomenon_webinar_faq_gc_.pdf

General measures:

- Avoidance of repeated trauma to the fingertips and avoidance of vibrating tools.
- Control or limitation of emotional stress- stress plus cold exposure is an especially potent trigger for RP
- Avoidance of vasoconstricting drugs — avoid medications known to worsen vasospasm, when possible.

Several classes of drugs known to be associated with vasospasm include the following:

- Over-the-counter nasal decongestants(eg, phenylephrine, pseudoephedrine)
- Amphetamines, diet pills, and herbs with ephedra
    - Agents used to treat attention deficit hyperactivity disorder (ADHD) (methylphenidate and dextroamphetamine)
    - Some medications used for migraine headaches, including serotonin agonists (e.g, sumatriptan) or ergotamine

Keep warm

Do all you can to avoid cold environments, touching cold items or spending time in areas where temperatures fluctuate. Even a slight change in temperature can cause an attack. What you can do to keep warm:

- Wear warm clothes in cold temperatures
- Wear lots of thin layers and loose clothing in order to remain as warm as possible.
- Use hand warmers, feet warmers, gloves and thick socks to keep cold fingers and toes comfortable on chilly days.
- There are some more products to help keep warm in our online shop such as thermal shoe insoles and fleece blanket.

Relax and pace yourself

Try to steer clear of stressful situations as stress and anxiety can trigger an attack. Take rests when you can to avoid getting too fatigued. The Pulmonary Hypertension Association (PHA UK) describes a good way of helping to focus on your breathing, called controlled breathing, (also known as diaphragmatic breathing) which uses your diaphragm and lower chest muscles. To try this technique, follow the steps below:

- Get into a comfortable position where your neck, shoulders and back are well supported, such as in an upright chair with armrests or by leaning against a wall.
- Relax your shoulders, neck and arms.
- Place your hands on your tummy, just above your belly button.
- Give a little cough- the muscle you feel under your hand is your diaphragm.

From: https://www.sruk.co.uk/about-raynauds/signs-symptoms-of-raynauds/

- **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.
- **As you breathe out,** relax and let your tummy fall.

Complementary therapies

Complementary therapies can bring relief from symptoms for some. These are listed within our treatments section.

Speak to your doctor about treatments

One drug, Nifedipine, a calcium channel blocker, is licensed for Raynaud's, and there are drugs that are prescribed commonly for Raynaud's too. Nifedipine doesn't cure Raynaud's, but can help to relieve symptoms. Other medications have been used to treat Raynaud's, with mixed results, and more can be found on our treatments page.

- Iloprost is available for extreme cases.
- **Angiotensin II receptor blocker** — Angiotensin II receptor blockers (ARBs) may be used for patients with uncomplicated RP who may benefit from the use of an ARB for other indications (eg, hypertension, heart failure, proteinuric chronic kidney disease).
- **Selective serotonin reuptake inhibitor** — Fluoxetine may be used in patients with uncomplicated RP
- PDE5 inhibitors e.g sildenafil
- Topical GTN
- Endothelin-1 receptor antagonist e.g. Bosentan
- Botox is an experimental Raynaud's treatment, which 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 are at risk of ulcers. These can become infected and take some time to heal, so it's important to avoid them if possible. Here are some ways to keep ulcers at bay:

- Look after your skin and cover any broken areas with a clean plaster, Inadine or Mepilex.
- Keep an eye out 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

Always try to maintain a balanced, healthy diet and avoid caffeine and alcohol.

Some food supplements have helped Raynaud's sufferers, including evening primrose oil, gingko 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 quicker with recovering from surgery or suffering from digital ulcers.

If you smoke, try to quit

It is incredibly important to stop smoking, one cigarette can reduce the body's temperature by up to one degree for up to 20 minutes. There are real benefits to stopping. For example:

- Stopping smoking your treatment is safer for you.
- You can expect to respond better to your treatment.
- In the longer term, you will reduce your chances of your Raynaud’s worsening.

Stop Smoking Helplines (NZ Quitline number below)

- 0800 778 778

From: https://www.sruk.co.uk/about-raynauds/signs-symptoms-of-raynauds/

- Quitline provides a free telephone advice service (0800 778 778), text service (www.txt2quit.org.nz) and a Quitter Blog support group at www.quit.org.nz. The Quitline telephone service (0800 778 778) is available at the following times: Monday to Friday 08:00-21:30, Sun 10:00-17:30.

Take care during pregnancy and breastfeeding

Primary Raynaud's has little impact on pregnancy. Most patients find that the Raynaud's symptoms are less severe during pregnancy, probably due to the hormonal changes that occur. However, Raynaud's symptoms may worsen three or four months after delivery, and will usually then return to the previous severity. The effect of any Raynaud's medication you are taking should be considered, as some commonly used drugs are not safe during pregnancy.
Practical aspects to avoid attacks should be taken during delivery, such as warming infusion fluids. Raynaud's can affect the nipples when a mother is breastfeeding.

Take gentle exercise

Exercise, within your own limits, can boost circulation and may improve Raynaud's. Even very gentle exercise can help to get the blood flowing – if you are feeling cold, for example, try swinging your arms as you walk.

Occasionally, exercise can trigger Raynaud's attacks. Look out for signs of this happening and change your fitness plan if needs be. Many find swimming can help their Raynaud's, but please check the temperature of the water before swimming as a cold pool could trigger an attack.

Try one of these low impact exercises to see if it helps your Raynaud's. Exercise is a great way to lift your mood and ensure that you stay fit and healthy:

- Walking is by far the most popular low-impact exercise. It works the cardiovascular system and burns calories. To get your heart rate up, walk faster than a stroll. Picking up the pace can increase the intensity of your workouts. Add short bursts of speed or walk up an occasional steep hill.
- Swimming works the whole body. It's a great way to tone up and get trim. Swimming a few lengths involves most of the muscle groups, and you'll get a good aerobic workout if you increase the pace. Swimming can also help you lose weight if you swim at a steady and continuous pace throughout your session.
- Cycling is a low-impact activity. But you can still injure yourself if you have the wrong size bike, or if the saddle and handlebars are at the wrong height. Cycling is an aerobic exercise that works your lower body and cardiovascular system. Start slowly and increase the length of your cycling sessions gradually.
- Yoga can improve both your physical fitness and your general wellbeing through a series of postures and breathing exercises. Regular yoga practice helps develop strength, balance, and flexibility. It can also lift your mood.
- Pilates focuses on rebalancing the body and improving posture through slow, controlled movements and exercises. Regular practise can help you improve muscle strength and your overall sense of wellbeing. It can be helpful for people who can't or must not jump around too much.
- Dancing is one of the best things about dancing is that while you're having fun moving to music and meeting new people, you're getting all the health benefits of a good workout. From Ceroc to the foxtrot, there's a dance style to suit all tastes.

Please consult your GP before making any major lifestyle changes.

Get help with work place issues

If you struggle in the workplace, make sure you talk to your employer about it. The NHS has more [information on health in the workplace here]

Scleroderma Seminar 2025 A holistic View

Date: 18 October 2025
Venue: Te Awamutu Bible Chapel Seminar room
110 Chapel Drive, Te Awamutu

Waikato Scleroderma warmly invites one and all to 2025 Annual Seminar.

$30 registration
Payable to :
38-9017-0107454-00
Scleroderma new Zealand Incorported
please include your name and the reference 'seminar'
Email Janine at: jobrearley12gmail.com to let her know you have paid.

Seminar news from the Waikato Team:

Kia ora tatou,

Event: Scleroderma Seminar 2025 – A holistic View.
Date: 18th October 2025
Venue: Te Awamutu Bible Chapel, Chapel Drive Te Awamutu

Registration: $30.00
Start Time: 9am registrations
End Time: 3.30pm

Firstly, we would like to acknowledge the support of one of our guest speakers above, Delwyn. Gratefully, clarity in communication has resulted in Delwyn with her husband being able to attend to share her passion and interest in helping with Nutritional knowledge. While many of us may share food issues specific nutrition to is individualised and Delwyn is one that has gone the extra mile with clients.

A Holistic View

Our group of Waikato ladies have been pacing ourselves to the finish line of Saturday October 18th. Not only have we been able to enjoy each other's company our journey with Scleroderma but also a range of skills. It is a collaborative effort with lovely energy.
Our venue the Te Awamutu Bible Chapel in Te Awamutu has a rural outlook, it has a number of suitable rooms depending on numbers that can cater for our Seminar. Rooms are well lit, comfortable and warm, plenty of car parking, Campers or RV overnight stay welcome.

Accommodation

For those who are undertaking the hikoi (travel) and looking to stay, there are a few options. Te Awamutu has 3 motels in various places Around Te Awamutu, less than a kilometre away is Matariki Motor Lodge. If your preference is Hamilton or Cambridge time frames of travel are 25 minutes to Te Awamutu. Jetpark Hamilton Hotel is walking distance from the terminal.
Our ladies (whanau) are able to provide transport if needed to and from accommodation sites, Hamilton, Cambridge or Te Awamutu. We are also able to billet a handful of attendees, flick me an email let's see how we can manaakitia kia koutou (accommodate you).

If you have questions or queries, please email and our ladies will discuss.

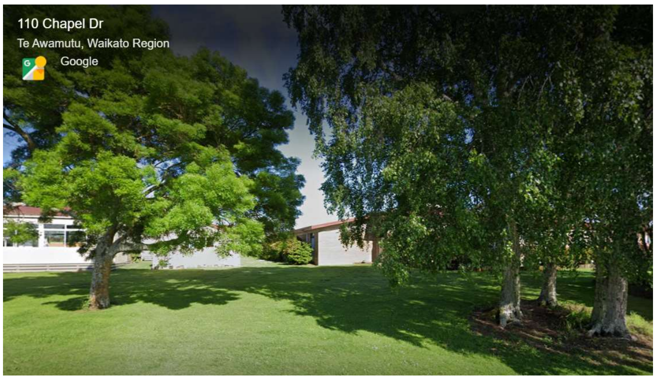
Ngaa mihi maioha thank you with sincere regards,
Linda, Erena, Jill, Lea, Maree, Susil, Rachel Janine, Katie, Paula

Scleroderma Seminar 2025 A holistic View

Date: 18 October 2025
Venue: Te Awamutu Bible Chapel Seminar room
110 Chapel Drive, Te Awamutu

Waikato Scleroderma warmly invites one and all to 2025 Annual Seminar.

$30 registration
Payable to :
38-9017-0107454-00
Scleroderma new Zealand Incorported
please include your name and the reference 'seminar'
Email Janine at: jobrearley12gmail.com to let her know you have paid.

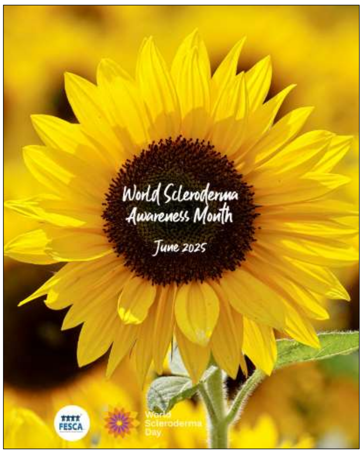


World Scleroderma Day

29th June 2025

World Scleroderma Day is observed annually on the 29th of June. This year, it falls on a Sunday, but for the entire month of June, we dedicate it to raising awareness about scleroderma…

What is World Scleroderma Day ?



The first European Scleroderma Day on the 29th June 2009 was celebrated in almost all of **FESCA's** member countries as it was decided by the FESCA at a meeting in 2008. Having a disease that nobody has heard of is a lonely business. When even the doctors cannot recognize it, or tell you what is going to happen, it is lonelier still. So Scleroderma Awareness Day was created to tell people, including the medical community, what it means to have this disabling disease. June 29 is a day to recognize the bravery of those who live with scleroderma, and to demand equal treatment and equal care for people with scleroderma across Europe and the rest of the world.

History of World Scleroderma Day

In February 2010 the **1st SYSTEMIC SCLEROSIS WORLD CONGRESS** was held in Florence, Italy, with participants from countries from all over the world. At the world congress it was agreed that June 29th would be celebrated all over the world.

Why 29 June ?

The gifted Swiss artist **Paul Klee** made painting his life's work, but it was strongly influenced by his illness, systemic scleroderma, as the painting chosen for Scleroderma Day demonstrates. He died June 29, 1940. The Swiss Paul Klee Zentrum in Bern boasts the world's most important collection of paintings, watercolours and drawings as well as archives and biographical material from all the creative periods of Paul Klee's life which also can be visited through their website: www.zpk.org

The First Poster for Scleroderma Day

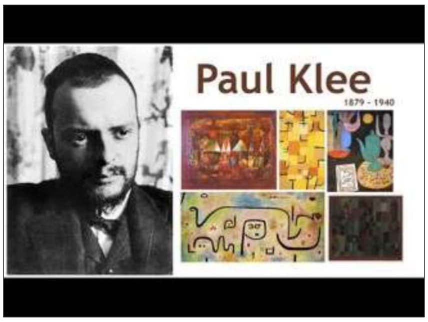
It was decided on the working meeting (Florance, 25-26 Jan, 2008) that launch of the EUROPEAN SCLERODERMA DAY will be on the 29th June, 2009.

Paul Klee, Kettledrummer 1940, 270 (coloured paste on paper on cardboard), 34.6 x 21.2 cm, Zentrum Paul Klee, Bern.

Text on the poster said:
June 29: European Scleroderma Day
More Than Skin Deep

Source:
https://fesca-scleroderma.eu/news-events/events/world-scleroderma-day/

On Sunday **29th of June** we celebrate Paul Klee's life.



Paul Klee (1879–1940)

One of the most influential artists of the 20th century, died at 60 years of age from complications of systemic sclerosis (scleroderma).

"Art does not reproduce what we see; rather, it makes us see. A drawing is simply a line going for a walk. A line is a dot that went for a walk" (A famous quote from Paul Klee).

Members Update:

Podiatrists and Fingernail cutting

Please see below a list of Podiatrists who also work with our finger nails.

Jessica Dobbs Podiatry, Hamilton
Clinic 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
2 Endeavour Avenue, Flagstaff, Hamilton 3210.
Mobile: 0274 242 442

Dr Althea Page-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: 020 41785262
Clinics are in Cromwell and Alexandra

Elaine Yelland, Kapiti Coast
Podiatrist & Business Owner
Foot Focus Podiatry Ltd, Kapiti Coast
Mobile: 021 578 601

Saf Kear, Tauranga
Write: hello@thegoodpodiatrist.co.nz
Phone: (07) 219 7811, Mobile: 021 121 0435

Simon Speight, Auckland
www.speightspodiatry.co.nz
https://www.facebook.com/Speights-Podiatry
https://www.instagram.com/speightspodiatry
2nd floor, 43 High Street, Auckland Central
Phone: (09) 306 4006, Mobile: 021-535511

Greig Price, Home Visits from Takaka to Blenheim
Email info@mobilepod.nz
Mobile: 022 419 0205

Catie Rowe Podiatry, Timaru
17 Dee St, Seaview, Timaru
Phone: (03) 683-1448, Mobile: 027 6882036

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

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.

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.

Events Happening:

Our next Scleroderma Zoom meeting:

Dear Members,

All welcome to the next online Scleroderma NZ support group meeting on the 14th of June at 1.30pm

A great opportunity to have a great catch up and to share with our Scleroderma friends.

Zoom meeting details:

Date: **Saturday June 14,** 2025
Time: **01:30 PM** Auckland, Wellington

Join from: PC, Mac, iOS or Android - https://otago.zoom.us/j/96865101860?pwd=7LiyTqHUGfOWmKGIfCoFezCuMXqMjt.1

Meeting ID: **968 6510 1860**
Password: **025901**
Look forward to seeing you then. **Perry Bray**

Auckland Scleroderma coffee group:

It's been suggested that I should explain how you can find our small coffee group at Daily Bread, the Kings Garden Café in Takapuna. We always try to sit at the first outdoor (but covered) long table. We spread these badges, booklets and crocheted sunflowers over the table. I've also popped in a photo of me – for recognition purpose.

Our next Auckland coffee group is:-

Date: **Monday, 16th June** at **10.00am**
Venue: **Daily Bread Cafe**, Kings Plant Barn, 11 Porana Road, Takapuna 0627, Auckland

Do come. Brings friends and family. We're a small friendly group. Contact: Helen Parsons
HelenParsons@artcardsandposters.co.nz
Mobile: 021 248 3869

Matariki 2025 – A Time to Reflect, Reconnect, and Look to the Stars

As the midwinter sky darkens over Aotearoa, a cluster of shimmering stars begins to rise in the early morning horizon — marking the arrival of Matariki 2025. Falling on Friday, 20 June, this special day is now recognised as a national public holiday, offering all New Zealanders a moment to pause, reflect, and reconnect with what truly matters.

But Matariki is more than just a date on the calendar. Rooted in the ancient traditions of Māori astronomy and storytelling, it heralds the Māori New Year — a time to honour those who have passed, celebrate the present with whānau (family), and plant seeds of hope for the future. It's a uniquely Kiwi celebration, rich in heritage and meaning, and increasingly embraced by people from all walks of life.

In 2025, Matariki takes on new depth. As it becomes more woven into the national consciousness, families across the motu (country) are finding creative, meaningful, and fun ways to bring it into their homes, schools, and communities. From stargazing adventures and traditional kai (food) to children's art projects and eco-friendly celebrations, Matariki is becoming a festival where the wisdom of the past meets the curiosity of the next generation.

In this article, we'll guide you through the origins and meaning of Matariki, share how it's celebrated across Aotearoa, and offer modern, kid-friendly ways to take part. Whether you're deeply connected to Māori culture or just starting your journey of understanding, Matariki 2025 is a moment for all of us — a chance to look up at the stars, remember where we've come from, and dream boldly about where we're going.

Source: https://matariki.co.nz/matariki-2025/

Events Happening:

World Scleroderma Day

29th June 2025

What will you and your group be doing to celebrate World Scelorderma Day ?

Scleroderma Awareness the of Month June

What will you do to mark the occasion ?

Group get together via zoom or in Person

Share Tips on how you manage Scleroderma

Show us your new warm woollies

Bring your Questions to our facebook

We welcome you too bring us your stories here on face book

We look forward to hearing from you, Keep warm :-)

For those in Wellington

Visit Carters Fountain in Oriental Bay

on **27th and 29th June**

for World Scleroderma Day
The Fountain will be lit in a yellow glow

Thank you to Dianne Purde for organising this with the Wellington City Council.

Shortest Day – Winter Solstice:

Sat, 21 Jun 2025, 2:41pm

New Zealand Time

This marks the shortest day and longest night of the year, as the southern hemisphere is farthest away from the sun at this point.

Wellington/Kapiti and Wairarapa Scleroderma Support Group:

Event: *Mid Winter Lunch*

Date: **Saturday 19th July 2025**

Venue: **Kokodeli Cafe,** located in The Hub, 74-76 Main Street, **Greytown**

Time: **12pm noon**

Do come. Brings friends and family, all welcome.

We would also like to invite members of the Palmerston North, Levin & Wanganui group.

The cafe has asked for numbers to be advised to them by **14 July**, so please let Fiona know if you would like to attend by that date.

Contact: Fiona Yaxley (Phone: 027-273-9399)

Email: fiona.gilloch@xtra.co.nz

Palmerston North/Levin & Wanganui Scleroderma Support Group:

Palmerston North, Levin & Wanganui

Support Group lunch

Saturday 9th of August

at 11.30am

Esplanade cafe

Venue: Esplanade Cafe, 1 Palm Drive, Victoria Esplanade
Palmerston North

Time: **11.30am**

Contact: Dianne Purdie (Phone: 04 4795548)

Email: diannepurdie@xtra.co.nz

Members News

Southland Scleroderma Group

Scleroderma get together Gore 4 May

Thank you, Jenny, for organising the get together. I am always astounded that Jenny also has us organised with name badges and booklets etc on the day if needed. We had 22 people attend. It was a bright sunny day, in fact Graham kept bobbing up and down closing and opening curtains to keep the glare of the sun out.

As well as the pleasure of meeting everyone, there was lots of chatting and keeping up with how we are all doing.

What was memorable to me on the day...

- One of our group has been prescribed 'high powered' painkillers by her rheumatologist for pain in her hands and feet. When she went phoned her GP's practice for her next three months prescription she was informed that she had a new doctor and he was not going to prescribe that medication, he had not consulted either her or the rheumatologist about the decision. She managed to get an emergency appointment with her rheumatologist, but had to cope without her medication for a week, hard work when she is employed in work that she uses her hands is on her feet all the time..
- I must admit I was one of those in a huddle with our phones and showing others photos of our ulcers, etc and physically inspecting fingers for ulcers. It was definitely a learning experience.
- Thanks Judy for agreeing for me to take a photo of your hands to send to a person in Timaru who is going through the same struggle.

Our groups openness and helpfulness is amazing.
Looking forward to seeing how everyone got through the winter at our next meeting in Invercargill on the 17th August.
Heather Milligan

A photo of Judy's hand with the Nitroderm patches, prescribed by her rheumatologist. Judy thinks her Nitroderm patches are so good for keeping the blood getting through to the extremities of her fingers.

Members News continued...

Southland Scleroderma Group

Impromptu Lunch with Perry in Invercargill:

Ian and Glenys Findlay, Graham and I were pleased to meet up with Perry and his two daughters Christina and Emily for an impromptu lunch in Invercargill on what was the coldest day of the year so far. Thank Perry I did enjoy the catch up. – **Heather Milligan**

Hawkes Bay Scleroderma Group

We had a get-together on Saturday and we enjoyed ourselves. Mamatha came for the first time and it was lovely getting to know her. We discussed the upcoming seminar and started organising who wants to go and travel and accommodation. Our next get-together will be the third Saturday in May.

Auckland Scleroderma Group

We're a small, very friendly group. We happily chat about life, work, family, friends, travel. And we do chat about scleroderma - the path we are travelling.

Helen Parsons
helenparsons@artcardsandposters.co.nz
021 248 3869

From left: Roger Parsons, Kelly Donnelly, Robyn Donnelly.

Bay of Plenty Scleroderma Group

The Bay of Plenty Group continue to meet up so if you would like to join them get in touch with Alumie Nguyen: alumie.uow@gmail.com

Waipa and Waikato Scleroderma Group

This wonderful group are in full on mood organising the seminar for us in October. Page 13 & 14 is where you would have found all their information regarding this.

Waipa, Hamilton, Putaruru, Morrinsville,
Please contact **Erena Bruce** if you wish to join them.
bruceerena@gmail.com

Members News continued...

Wellington / Kapiti and Wairarapa Scleroderma Group

The Wellington / Kapiti and Wairarapa support group gathered for our lunch on Saturday 17th May at Boulcott Farm on a lovely sunny day. We were sad for the passing of our member Tony, a very kind and caring gentleman who we will always remember. Our condolences to his family and partner Dee. We had a lovely lunch and took our time to catch up with each other and compare notes to see how we are all doing.

Warmest regards, Tina McLean

Photo above – from left to right: Myself, Karin & Steve, Fiona & Allen, Sandra, Dot, Michael & Jan, Sandra (Cushla's mum) & Cushla and Diana (on my right).

Photo above – from left to right:
Michael & Jan, Sandra (Cushla's mum) & Cushla and Diana, myself, Karin & Steve, Fiona & Allen, Sandra and Dot.

New Plymouth Scleroderma Group

The New Plymouth group met recently for a chat and friendship. If you would like to attend the New Plymouth Support Group please get in contact with **Kelsi Tidswell: kelsitidswell@gmail.com**

Christchurch Scleroderma Group

The Christchurch group met up in May at Travis Courtyard Café in Burwood Hospital. They will be having a mid winter lunch which they will be emailed about. If you would like to attend the Christchurch Support Group please get in contact with **Nicky Moore: nicky.moore@xtra.co.nz**

Otago Scleroderma Group

The Otago group met recently and shared their lovely photos in our last newsletter. If you would like to join in with the Otago group please contact Gaynor: gaymeddings@gmail.com

Palmerston North Scleroderma Group

The Palmerston North group will have their lunch on the 9th of August at 11.30am at the Esplanade café, 1 Palm Drive, Victoria Esplanade, Palmerston North. If you would like to join the Palmerston North group please get in contact with Dianne Purdie: diannepurdie@xtra.co.nz Phone: 04 4795548

Group Meetings Dates 2025: Regional

Wellington / Kapiti / Wairarapa support group meets:

We welcome any new members to come along. If you would like to join us, please contact:

Cushla Masters: cushlam@outlook.com
Tina McLean: tinaoaisamclean@outlook.com
Fiona Yaxley: fiona.gilloch@xtra.co.nz

Date and Time:	Venue:
Saturday 19th July @ 12pm noon	**Kokodeli Cafe**, located in The Hub, 74-76 Main Street, **Greytown**
Sat 20th September @ 12:30pm	**Chocolate Fish Café** 100 Shelly Bay Road, **Miramar**
Sat 22nd November @ 12:30pm	**The Farm Café & Bar** 33 Military Road, Boulcott, **Lower Hutt**

Palmerston North support group:

We welcome any new members to come along. If you would like to join us, please contact Dianne Purdie:
diannepurdie@xtra.co.nz **Phone: 04 4795548**

Venue: *Esplanade Cafe*
1 Palm Drive, Victoria Esplanade
Palmerston North

Time: 11.30am

Date and Time:	Venue:
Saturday 9th August	**Esplanade Cafe e**
Saturday 8th November	**Esplanade Cafe**

Christchurch support group meets:

We welcome any new members to come along.
Please contact **Nicky Moore** if you would like to join in:
nicky.moore@xtra.co.nz **Phone:** 021 110 6123

Date and Time	Venue
Saturday 19th July - 12pm Midwinter Lunch	**Koji** **257 Lincoln Rd**
Saturday 20 September	**London Canteen** 92 Stourbridge, **Spreydon**
Tuesday 25 November	**Travis Courtyard Café** **Burwood Hospital**

Waimate/Oamaru support group:

We have members meeting up in these areas so if you are interested in joining them please get in touch with **Helene Sunitsch** at: hkjsunitsch@gmail.com

Otago support group:

Please contact **Gaynor** if you wish to join us.
gaymeddings@gmail.com

Auckland support group meets:

We welcome any new members to come along. Also, do contact me if you would us to meet at another time, day, or place. Please contact **Helen Parsons:**
HelenParsons@artcardsandposters.co.nz
021 248 3869

Venue: *Daily Bread, Kings Plant Barn*
11 Porana Road, Takapuna, Auckland
Time: **Monday 16th June** at **10am**

2025 Meeting Dates:
Mon, 14th July
Mon,18th August
Mon, 22nd September
Mon 27th October

Waikato/Waipa support group meets:

If you would like to join in with the Waikato/Waipa Group, please contact: -
Erena Bruce, Mobile: **021 186 9680**
Rachel Burgoyne, Mobile: **027 3661881**

New Plymouth support group:

Venue: *Locals Café, 11 Wallath Road, Westown, New Plymouth*
Time: **Saturday, 6th September at 11am**

If you would like to attend the New Plymouth Support Group please get in contact with **Kelsi Tidswell: -**
kelsitidswell@gmail.com

Hawkes Bay support group meets:

Venue: *Frances' Home, Villa 147, Willowbank, Retirement Village, Napier*
Time: **Third Saturday of the month**

If you would like to join in with the Hawkes Bay Group, please get in touch with Gail.
Gail Neilson: gail_neilson@hotmail.com

Bay of Plenty support group meets:

Come join us for more informative discussions and good company! Can't wait to see you there!
Please contact one of us for information.
Jane: janepuckey99@gmail.com
Mary: marybestrd3@gmail.com
Alumie: alumie.uow@gmail.com

Southland support group meets:

Venues: **To be confirmed**
Time: **12pm**
2025 Meeting Dates:
August 17th: In **Invercargill** at **12pm**
November 30th: In **Gore** at **12pm**

Please contact **Heather** if you wish to join us.
milliganseeds@xtra.co.nz

Welcome to Scleroderma New Zealand Inc.

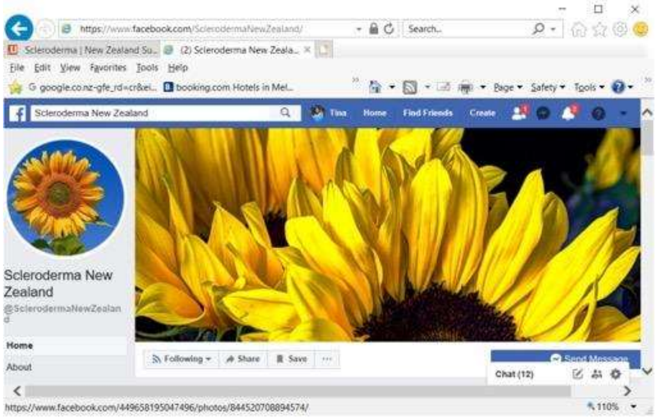
To all our new members, who have recently joined us – Welcome….

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.akl/**

Scleroderma New Zealand

President:	**Jenny Andrews** jennyred@xtra.co.nz
Vice President:	**Tina McLean** tinaoaisamclean@outlook.com
Secretary:	**Jane Sainsbury** jsainsbury@xtra.co.nz
Treasurer:	**Gordon Purdie** gordon.purdie@xtra.co.nz
Newsletter:	**Tina McLean** tinaoaisamclean@outlook.com **Jenny Andrews** jennyred@xtra.co.nz **Helene Sunitsch** hkjsunitsch@gmail.com

Committee Members:

Alumie Nguyen, Cushla Marsters, Dianne Purdie, Erena Bruce, Frances Tod, Heather Milligan, Helen Parsons, Helene Sunitsch, Perry Bray and Rachel Burgoyne.

Contacts:

Find a Scleroderma a Support Group near You:

Auckland:	**Helen Parsons,** Email: helenparsons@artcardsandposters.co.nz
Bay of Plenty:	**Alumie Nguyen**, Email: alumie.uow@gmail.com
Waikato / Waipa:	**Rachel Burgoyne,** Email: rachieb1981@gmail.com **Erena Bruce,** Email: bruceerena@gmail.com
Hawkes Bay:	**Gail Neilson,** Email: neilson_gail@hotmail.co.nz
New Plymouth:	**Kelsi Tidswell,** Email: kelsitidswell@gmail.com
Wellington:	**Cushla Marsters,** Email: cushlam@outlook.com
Christchurch:	**Nicky Moore,** Email: Nicky.moore@xtra.co.nz
Blenheim / Nelson:	**Jen Soane,** Email: jennasoane@gmail.com
Waimate / Oamaru:	**Helene Sunitsch,** Email hkjsunitsch@gmail.com
Otago:	**Gaynor Meddings,** Email: gaymeddings@gmail.com
Southland:	**Heather Milligan,** Email: milliganseeds@xtra.co.nz
NZ Online Zoom Support:	**Perry Bray,** Email: perry.pacpe@gmail.com