

Welcome ..... 1  
President's Report ..... 2  
Members Stories –  
- Dianne Minehan – Stem Cell Transplant ..... 3,4  
- Heather Milligan – Experiencing Calcinosis ..... 5  
- Life & Times of Perry ..... 6-9  
- Janine Brierley – Her break away.....10  
Dianne Purdie –Dressing your digital Ulcers ..,11-13  
Events Happening..... 14  
- International Scleroderma Day  
- Zoom Meetings  
- Information Wanted  
- Situations Vacant  
Scleroderma NZ Conference ..... 15,16  
CanBead.....17  
Members Update:  
- Podiatrists and Finger Nail cutting ..... 18  
- Give a little ..... 18  
Members News .....19-21  
Group Meetings Dates 2026: Regional: ..... 22  
Welcome to Scleroderma NZ Inc & Contacts ..... 23

# Scleroderma

## New Zealand support group

# Winter 2026

NUMBER: 68 JUNE 2026

## Greetings to you all...

### Welcome to the Winter edition of our Scleroderma Newsletter

Kia ora koutou, we hope everyone is keeping well and taking care of themselves.

We have a jam-packed quarterly newsletter for you! First up, we feature our President's report.

Next, Dianne Minehan shares her personal journey through a stem cell transplant, while Heather opens up about her experience with calcinosis. We also take a look at the life and times of Perry—complete with some amazing leaf art—and explore an informative piece on how scleroderma affects the lungs.

Additionally, Janine Brierley writes about her recent trip to Christchurch, and Dianne Purdie provides practical guidance on how to manage and dress digital ulcers.

On the community front, we have a "Situations Vacant" notice. Tina and I will be stepping down from producing this newsletter if we can find someone to take over the reins. We will offer full support during the transition period and beyond. We have thoroughly enjoyed this role and loved staying in touch with all our group leaders and members, but we feel it is time for fresh eyes to give the publication a creative revamp!

Organisation for our 2027 Conference is well underway. You can find full details alongside a registration form on page 15.

We also spotlight CanBead, highlighting the wonderful work they do to support Scleroderma NZ members.

Please feel free to send us your news, stories, jokes, tips, or anything else you would like to share. Our contact details are listed on the final page.

Remember, this newsletter belongs to you. Sharing your personal experiences and activities can bring immense comfort and connection to other members walking a similar path. Take care everyone.

Tina and Jenny



# Presidents Report:

---



## Hi from the Deep South

As I sit here watching the rain, I am incredibly grateful to have finished my walk without getting wet this morning! I am currently aiming to walk 100km this June. We are just past the halfway mark of the month, and I have hit 67km so far. I am also reminiscing about my time in Europe this time last year. Oh well—Southland and the Netherlands are much of a muchness anyway! 😊

Our deepest condolences go out to everyone who has lost a loved one over the past three months. We are holding you all closely in our thoughts.

We held our AGM on June 6th, and it was wonderful to catch up with so many of you. We are thrilled to welcome two new committee members: Sandra McAuley from Lake Hawea and Di Minehan from Hawke's Bay. We look forward to working alongside you both. We are incredibly fortunate to have such a dedicated committee advocating for our Scleroderma NZ members.

A huge thank you to everyone who completed our recent survey. We had a fantastic turnout, with nearly 50% of our members participating! We will share the insights and results in our upcoming Spring Newsletter.

In other news, the reprint of our *Understanding and Managing Scleroderma* booklet is moving closer to production. Updating this resource every few years ensures we stay aligned with the latest developments in the health sector.

June is Scleroderma Awareness Month. If there is a prominent landmark in your town that can be illuminated in our official colours, that would be amazing—especially on June 29th for International Scleroderma Day! Behind the scenes, our dedicated team is also working hard on the website to improve our online space for everyone.

Looking ahead, our 2027 Conference is officially booked for Wellington next April! Registrations are now open, and you can find full details further along in this newsletter. The event will take place at The Dowse Art Museum in Central Hutt on April 17th. A special thank you to Dianne for her incredible work in organising and finalising these details.

As the winter chill sets in, it is definitely time to rug up. Please remember to wear a warm hat and gloves when heading outside. Sudden changes in temperature—like walking into a cold supermarket—can trigger symptoms, so keep your gloves handy while running errands.

If you haven't already, please consider getting your winter flu vaccination sorted at your local pharmacy. Finally, we know the colder months can make it harder to find the motivation to go out and socialise. However, staying connected is vital for our well-being. If the weather keeps you indoors, try to reach out to someone via a phone call or FaceTime. A quick chat can make a world of difference on a dismal winter day. Keep warm, keep in touch, and keep smiling!

Take care all. **Jenny**



# Members Stories:

## Di Minehan....On her Stem Cell Transplant

Hi all, this is my story about having a Stem Cell Transplant in Sydney, Australia.

I was diagnosed with aggressive Systemic Sclerosis Scleroderma in April 2024. After trying every medication available to no avail, my only option was to have a transplant in Australia. Unfortunately they cannot be done in NZ. It is around a 3 month procedure and you need a support person all the way.

Obviously to have this procedure done was going to be very costly. We battled with Health NZ for over 12 months. Luckily for me I have a husband that wouldn't give up. He spent hours writing emails, meeting with our local MP, who took my case to the Minister of Health, Simeon Brown. We also wrote to Simeon. As time really wasn't on my side, my arms and hands deteriorated. If I had the transplant sooner, my hands might not be so curled! We got to the stage that we offered to fund it ourselves, but were turned down, as they said it has to go through the right hospital channels. Our last resort was to go to Seven Sharp on TV, which got them sitting up in their seats! So long story short, they decided to pay. And after so much drama, it has now been accepted to fund Stem Cell Transplants through Health NZ. So hopefully when our next New Zealander needs this treatment, funding should finally be straight forward.

We set off to Australia in October 2025, to get started. Prior to starting you need to have Lung function tests, Cardiac MRI, Echocardiogram and a Right Heart Catheter. Then after lots of blood taken I had my first round of Chemotherapy, and they gave me a good dose of anti-nausea medication which helped a lot. I then had a daily injection put in my stomach, which my sister had the pleasure of doing for 10 days. These injections are to help stimulate production of white blood cells. I then had a Vas-Cath inserted into my neck, this is a type of central line which enables them to collect my stem cells. This was done the following morning which took 4 hours. They need around 5 million stem cells to work with, I produced 15 million, so I was doing something right!

I was having major trouble with ulcers on my knuckles, that had become very infected, So I spent a few days in hospital on IV antibiotics, and was booked to have an MRI to check the infection

hadn't hit the bone. They were just so infected and sore, at times the pain was unbearable.

There was then a 3 week break, before the transplant went ahead. Unfortunately in that time we had to rush back to home in NZ, as my Mum had had a heart attack, and was very unwell. We had 5 days with her, and she improved dramatically, so we headed back to Sydney. Only to test positive for covid!! I didn't even know I had it. So the transplant was put out to the following month. When the date arrived my pre blood tests showed I had Influenza B, much to my horror!! So I was sent home to NZ for Xmas and to return in the New Year. We were all so disappointed, as I had been so careful in public places, and always wore a mask. Let alone the cost of airfares, backwards and forwards. And the longer we stayed, our accommodation bill was getting pretty high!

We had a very quiet Xmas, and headed back for the 3rd time, to try again. Lucky the stem cell collection was fine, as they are on ice. This time the pre admission tests were nerve wracking, but thankfully I had no bugs. So I was eager to get started, and so were they. I arrived at St Vincent's hospital preparing for my 3 week stay. I had 5 rounds of chemotherapy, being 1, or sometimes 2 rounds a day. I survived them reasonably well besides the nausea was next level! I think it was worse than morning sickness!! Luckily for great nurses who looked after me extremely well, and would give me regular IV anti-nausea meds.

It was now time to have the transplant, as the chemo had killed everything off. So on the 19th January I had my stem cells put back after being on ice for nearly 3 months. It was actually the easiest part of the whole process. It was then rest time and I slowly gained a bit more energy. Day 3 I went to Intensive Care, as my blood pressure was too low, and I had fluid around my heart. I received a blood transfusion, which helped a lot. The next thing to deal with is losing your hair. As I was a Hairdresser for 20 years, I found this absolutely daunting! I had helped so many woman go through this over the years, and now it was happening to me!

After my 3 week stay, I had to stay close to the hospital for another 3 weeks. So back to the apartment with my sister, who was looking after me so well. She was just so calm and relaxed with me. As there was lots of tears and emotions over this time, to deal with. She was my rock,



and I don't think I could have done it without her. I did lots of resting and sleeping over this time. And we went for little walks, which were lovely.

Then off for a check-up, and some blood tests, before I got the all clear to come home to NZ. Going home was so exciting, but I knew the next 6 months would be very quiet, very few visitors, no socialising, and pretty much visits to the Rheumatologist or Doctors only. Thankfully we have online shopping, just so easy to order the groceries.

So it's now a wait and see game for the next 6-12 months. Apparently not a lot happens in the first 6 months. I still have good days and bad days. Or if I do a bit much, I pay for it, for the next few days. I now wait for my first appointment for Immunisations which start all over again, right from your first baby jabs. So I'm guessing I will be quite used to them all soon. I am just so thankful to finally have my Transplant, and hopefully it will improve my quality of life. I sure miss getting dressed up and off to work, and being around people. It wasn't a ride in the park, and at times, it was bloody tough, but we got there.

Best Wishes,  
Di Minehan



# Members Stories:

## Heather Milligan Her experience with Calcinosis....

My Experience with Calcinosis

On 6 June, I joined about 12 others in a Zoom meeting organised by Dianne Purdie.

We came together to talk about Raynaud's, digital ulcers and calcinosis—conditions that can have a much bigger impact on daily life than many people realise.

My own experience began around 15 years ago, when I started developing symptoms that were later diagnosed as systemic sclerosis. I was fortunate to have an astute GP who recognised that something more was going on and referred me to a rheumatologist. In October 2012, because I was developing digital ulcers—especially on my right thumb—I had an X-ray of my hands. (Picture 1)



For the next five years or so, digital ulcers and the calcinosis that followed became part of my life. I was constantly surprised that something as small as an 8mm ulcer could cause such intense pain. If I knocked it, the pain was so severe it almost made me faint. Because the ulcers were so painful, I eventually became quite skilled at removing small chips of calcinosis from them myself. My rheumatologist was horrified, and understandably so, because reopening the wounds put me at risk of infection. Thankfully, I was very lucky and did not develop one. (Pictures 2 and 3)



After about five years, the digital ulcers gradually became less frequent, even though my medication had not changed. I was still left with lumps on my fingers (Picture 4),



but over time my fingers became less “clawed”, which made a noticeable difference.

In October 2022, I had another X-ray to check the calcinosis. (Picture 5)



It showed how the calcinosis had developed over the previous 10 years. As I am right-handed, the calcinosis is much more noticeable in that hand.

Looking back, calcinosis has been one of the more painful and frustrating parts of living with systemic sclerosis. It has taught me how much these small physical changes can affect everyday life, and how important it is to share experiences, so others feel less alone.

Heather Milligan



# Members Stories:

## The life and times of Perry...

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

### Amazing Leaf Art

June 10, 2026 by [Perry](#)



Every now and again we come across stuff on social media such as; Facebook, Instagram, TikTok etc. that simply astounds us and leaves us with a sense of awe.

Recently, I was introduced to Lito, a leaf-cutting artist from Japan. His works of art are simply outstanding, the detail that he's able to put into a leaf are absolutely stunning, and one can only imagine the amount of precision required truly amazing to behold.

Lito was born in Tokyo and grew up in Kanagawa Prefecture, and in 2020 he set about starting to produce leaf cut-outs by learning the art himself to make positive use of his attention deficit and hyperactivity due to ADHD.

Almost every day, he posts his cut-outs on social networking sites, creating quite a buzz. A year after he started honing his skills a collection of his works was published in a book entitled "I'll always be by your side: A tiny, gentle world" and received a great deal of attention and feedback.

And within just 2 years his carved leaves, were published on social media and have aroused great

curiosity and attention around the world. His artwork has also featured on television programmes, and in newspapers and magazines in Japan and around the world.

Lito has since held exhibitions of his works all over Japan with great commercial success attracting large numbers of visitors. In 2024, a private museum "Lito Leaf Art Museum Fukushima" opened in Fukushima, Japan to great acclaim. It is now into its third season 😊





Check out his [website here](#) and follow him on [instagram](#) for more examples of his amazing leaf art.



# Members Stories:

## The life and times of Perry...

### How Does Scleroderma Affect the Lungs?

June 9, 2026 by [Perry](#)

Below is a detailed explanation that I have adapted from a Facebook post created by [Scleroderma International](#).



Known formerly as Scleroderma International Organization, I've had the privilege to work with them over the past couple of years sharing aspects of my story.

Scleroderma International was created with a simple purpose: to help spread awareness, share stories, and bring people together through understanding and support. This month they celebrate their first anniversary surrounded by a growing global community that exceeds 11,000 followers.

For those of you who have been following [my health journey](#) over the past few years or so, you'll know that early on in the piece I was also diagnosed with Scleroderma related Interstitial Lung Disease (SSc-ILD).

But what exactly is Scleroderma related Interstitial Lung Disease? How does it affect those unfortunate enough to have been diagnosed with it? Let alone, what treatment options are available?

The thing is, lung involvement is one of the most serious complications of scleroderma (systemic sclerosis) and is considered one of the leading causes of illness and death among patients with the disease. Because of this, understanding how scleroderma affects the lungs is extremely important – not just for early detection, but also for proper treatment and better long-term outcomes.

Normally, the lungs are soft, flexible organs that allow oxygen to enter the bloodstream while removing carbon dioxide from the body. However, in people with scleroderma, the immune system becomes overactive and triggers inflammation and excessive collagen production.



As a result, scar tissue may gradually develop inside the lungs and blood vessels. Consequently, the lungs may become stiff, damaged, and less able to function properly.

The two main lung complications associated with scleroderma are interstitial lung disease (ILD) and pulmonary hypertension (PH).

Although both conditions affect the lungs, they involve different parts of the respiratory system.

Therefore, they may cause slightly different symptoms and complications.

#### Interstitial Lung Disease (ILD)

Interstitial lung disease occurs when inflammation and scarring develop in the interstitium, which is the tissue surrounding the air sacs of the lungs. Over time, the scarring may become permanent, making the lungs stiff and less elastic.

Because of this, the lungs cannot expand normally during breathing, and oxygen has more difficulty passing into the bloodstream. Therefore, patients may experience increasing shortness of breath and reduced physical endurance.



In the early stages, symptoms of interstitial lung disease may be mild or barely noticeable. For example, some patients may simply feel tired more easily or become short of breath during physical activity such as climbing stairs or walking long distances.

However, as lung scarring progresses, breathing difficulties may worsen even during simple daily activities or even while resting. In addition, patients may develop a persistent dry cough, chest discomfort, weakness, and fatigue. Doctors often use pulmonary function tests to evaluate how well the lungs are working. Specifically, these tests measure lung capacity and oxygen exchange.

Furthermore, a high-resolution CT scan is one of the most important tools used to detect inflammation and scarring in the lungs. In many cases, CT scans can reveal lung involvement even before severe symptoms appear.



## Pulmonary Hypertension (PH)

Pulmonary hypertension occurs when the blood vessels in the lungs become narrowed, damaged, or stiffened, thereby increasing pressure inside the pulmonary arteries. As a result, the heart must work harder to pump blood through the lungs. Eventually, this extra strain may weaken the heart and lead to heart failure if not treated properly.

Symptoms of pulmonary hypertension may include shortness of breath, dizziness, chest pain, fatigue, swelling of the legs or ankles, and fainting episodes.

Unfortunately, pulmonary hypertension may develop gradually and can sometimes be difficult to recognize in its early stages. Therefore, regular monitoring is extremely important for patients with systemic sclerosis.

In some cases, patients may experience both interstitial lung disease and pulmonary hypertension at the same time. When this happens, breathing problems and oxygen levels may become even more severe. Consequently, early diagnosis and treatment are critical in preventing further complications and improving survival.

The exact reason why scleroderma affects the lungs is not fully understood.

Nevertheless, researchers believe that immune system dysfunction, inflammation, blood vessel damage, and abnormal collagen production all contribute to lung injury and scarring.



Additionally, certain autoantibodies, such as anti-Scl-70 antibodies, are associated with a higher risk of interstitial lung disease in systemic sclerosis patients.

Because lung involvement can sometimes progress silently, doctors often recommend regular screening even if patients do not yet have noticeable breathing symptoms. Monitoring may include pulmonary function tests, echocardiograms, CT scans, oxygen level measurements, and exercise testing. Through regular evaluations, complications may be detected earlier and treated more effectively.

### Treatment Options

Although there is currently no cure for scleroderma-related lung disease, several treatments may help slow

progression, reduce inflammation, improve breathing, and enhance quality of life.

For instance, immunosuppressive medications such as mycophenolate mofetil, cyclophosphamide, rituximab, or azathioprine may help reduce immune system activity and limit lung damage. In addition, antifibrotic medications may sometimes be used to slow lung scarring.

Meanwhile, pulmonary hypertension may be treated with medications that help relax and widen blood vessels in the lungs. Oxygen therapy, pulmonary rehabilitation, breathing exercises, physical therapy, and regular medical follow-up may also help patients manage symptoms more effectively. In severe cases, lung transplantation may be considered for selected patients.

Living with lung involvement in scleroderma can be physically and emotionally challenging. Breathing difficulties, fatigue, reduced mobility, and fear of disease progression may affect mental health and daily activities.

Therefore, emotional support, counseling, patient organizations, healthy nutrition, regular exercise within safe limits, stress management, and avoiding smoking are all important aspects of overall care.



Because lung complications are among the most serious aspects of systemic sclerosis, raising awareness is extremely important.

Early recognition of symptoms, proper screening, continued medical research, improved treatments, and strong support systems may help patients receive earlier intervention and better long-term outcomes.

So, by spreading awareness about scleroderma and lung involvement, more people may better understand the challenges faced by patients living with this rare incurable autoimmune disease. Through education, advocacy, research, and community support, patients and families affected by scleroderma may gain greater hope, improved care, and a better quality of life.

I hope that you have found the above information not only informative, but also helpful in understanding aspects of this disease.

Blessings 'til next time 😊



# Members Stories:

## Janine Brierley.... A break away.

I am always a bit hesitant to head to cold climates but armed with my winter woollies I headed off albeit with trepidation that Raynaud's and fatigue were going to be my companions .

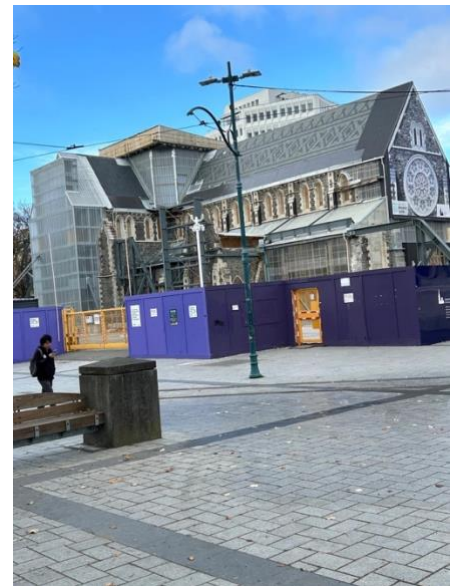
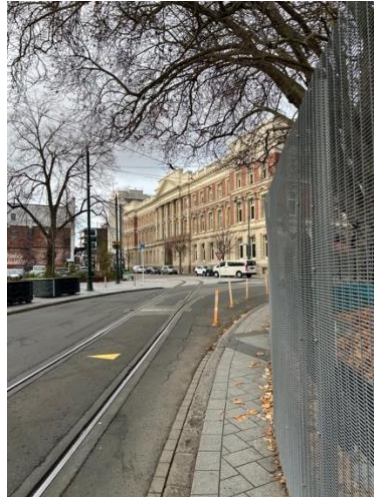
We stayed at the Crowne Plaza hotel, very nice . Hubby conferenced his heart out and I caught up with a friend for a bit of a tour in the car and the next day I braved the elements on foot. Wonderful to see the city being reconstructed and my slow pace (thanks scleroderma!) was an advantage as I got to see details I would've missed.

The cold wasn't so bad, I've no doubt my 'toasty touch' gloves helped.

The following day was my last and I have to admit I was a bit pooped so hot chocolate and reading were called for.

It was a really fabulous mini break. Thanks Christchurch. Winter mini break in Christchurch. Hot chocolate by the fire and hand warming gloves saved the day, keeping Raynaud's at bay.

toasty touch gloves: <https://toastytouch.com/>



# Self Help:

## Dianne Purdie – Talks about how to Dress Digital Ulcers

How to Dress Digital Ulcers, Royal Free London NHS.

### What are digital ulcers?

DU are ulcers or wounds on toes or fingers commonly caused by conditions like Scleroderma. The nurse might give you some wound dressings or other items for changing the wound dressings or your local healthcare professional might prescribe you some wound dressings to apply to DU.

Items and wound dressings provided will vary according to the nurse's or healthcare professional's discretion on what will be helpful for you. It is important you are shown how to apply the wound dressing by the DU specialist nurse. You may find it helpful to bring your carer or family member with you when you are shown how to change the dressing, so they are best prepared to help you.

If you need to change a dressing before you are shown, just remember the dressing will need to be covered, this could be by an adhesive dry dressing with padding in the middle, or finger bandage, mepore, gauze, mifix or micropore tape. Take care to make sure it is comfortable and does not restrict your movement.

### Wound dressing items that may be provided or prescribed



- Some of the items may include normal saline, scissors, dressing pack, white bag, micropore tape, mifix, gauze and various wound dressings.
- Please keep the empty packets of the dressings so that if you need some more, you may be able to request a prescription from your GP Practice.
- 
- 

- You may also be given information on skincare, hand exercises, natural therapies, paraffin hand waxing, and a digital ulcer leaflet.

### A step-by-step guide to changing a dressing

#### 1. Wash your hands

Count to 20 as you rub your hands together with water and soap substitute or soap. Wash your hands thoroughly with soap substitute or soap especially between your fingers and palms.



Dry your hands with a clean towel or kitchen towel.

#### 2. Set Up your items



- Set up all the items you or your carer will need for the wound dressing application on a clean surface and with clean hands.
- Avoid setting up items on, such as a closed toilet lid, near pet food, baby changing mats, and others.
- It is important to minimise the introduction of infection to the DU.

#### 3. How often to change your dressing

Wound dressing changes vary according to the dressing for example it is recommended that the anti-microbial dressings such as:



- Inadine or Aquacel Ag are changed between two to seven days to give them maximum time to work.
- We recommend all dressings to be changed every two to three days to avoid maceration and excessive moisture, which can delay healing.
- The outer cover dressings are white they usually get dirty quickly. If the outer dressing gets dirty and needs to be changed before the recommended changing date, the inner dressing eg. inadine can be left on the ulcer without touching and the outer cover changed.

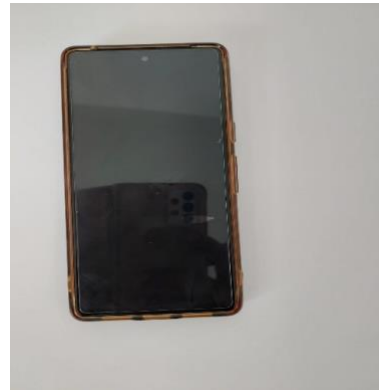
Nonetheless, if the DU is not infected or its autoamputating (a condition where the affected tissue naturally separates from the body), the intention will be to keep the dressing dry, it can be kept on for more than 3 days. But your nurse may advise you differently according to how your DU looks.

#### 4. Keep it clean

- When a DU is open, or broken it is important to keep it clean.
- If you or your carer are changing the dressing, while taking it off the dressing may be stuck to the ulcer, please do not pull it off but wet it with tap water or soak in water, for Aquacel dressing soak until it becomes gel-like or easy to remove, to avoid further skin damage or pain.
- Ensure that the previous wound dressing is completely removed.
- For instance, if the dressing contains honey, clean and make sure all the honey is removed, avoid filling up or adding onto old wound dressings, which are no longer effective.
- For alginate dressings (dressings made from seaweed fibres that help manage wound drainage and promote healing) e.g. sorbasan or silvercel remove any fibres and ensure the surrounding area is dry before applying the next dressing.



#### 5. Take a picture



- Take a picture of how it looks.
- Wash your hands again using step one with water and soap or soap substitute but not applying this on the broken skin.
- Dry your hands with a clean towel or kitchen roll.
- Changing a wound dressing or applying a dressing should be a clean process.

#### 6. Cleaning digital ulcers



- Normal saline, warm salty water, tap water, prontosan solution, octenisan, or octenillin are cleaning solutions that can be used to clean the ulcer before applying a new dressing.
- These cleaning solutions also reduce infection risk.
- The cleaning solution can be poured onto a clean gauze to clean the wound, avoid pouring the cleaning solution from its container or bottle directly to the ulcer.



## 7. Avoid touching DU



Once the DU has been cleaned avoid touching it directly otherwise it becomes unclean again and may introduce infection.

## 8. Apply appropriate wound dressing



Apply the appropriate dressing (refer to the Digital Ulcer leaflet or what the healthcare professionals have advised you to use) or your carer might help you with this. Please do not touch the area of the dressing that will be in contact with the open skin.

### Dressing on a knuckle or fingertip DU



- Cut just a small piece of the dressing sufficient for the broken area with clean scissors.
- When applying wound dressings in the form of paste e.g. manuka honey, please put the honey on a clean gauze first to prevent contamination and then apply it from the gauze to the ulcer, never apply the honey directly from the tube directly to the ulcer.

- Dressings such as duoderm extra thin do not need an outer cover.
- The outer dressing cover can be cut as shown above to enable folding to fit the area of the DU.

### Tips

- To avoid wetting the new dressing, the finger or hand with the ulcer can be wrapped with cling film. For washing up dishes, wrap the dressing in cling film and then wear slightly oversize latex/non latex gloves or cleaning gloves. For showering cling film can be applied and a plastic bag for the hand or plastic cast protection.
- To avoid repeatedly knocking the finger some people find finger Protector/Silicone or Rubber or Split Cowhide Finger Cots/Finger Guard Leather Working Essential, to remind themselves of the DU.
- Avoid making the wound dressing too tight that it is uncomfortable, make sure there is enough circulation, and make sure to apply a breathable wound dressing to avoid moist from sweats and other moisture that can cause bacteria growth.

### Please keep an eye on signs of infection

- Redness to skin surrounding the DU
- Increasing pain e.g. throbbing
- Skin surrounding the DU is warmer to touch
- Swelling and hardening of the skin surrounding the DU
- Yellow or green pus coming from the ulcer
- Offensive smell coming from the DU
- Increased wetness of the DU

### What to do when you suspect infection

- If you suspect infection contact your GP immediately and if possible, send them pictures showing the DU and request for antibiotics.
- If you already have prescribed rescue pack of antibiotics (prescribed standby antibiotics) in your cupboard, then you can start taking them.
- It might be useful for you to have a conversation with your GP, if you can have antibiotics on your regular prescription so that when you need them you can request them without being seen by the GP first.
- Only use antibiotics when there are obvious signs of infection.

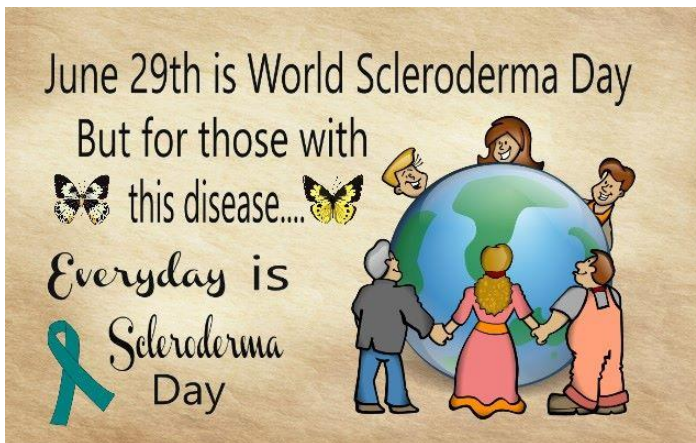


# Events Happening:

## Scleroderma Awareness Month: June

Observed annually throughout June, **Scleroderma Awareness Month** is a global campaign to educate the public about a rare, chronic autoimmune disease that causes the hardening and thickening of the skin and internal organs. The month-long initiative culminates on **World Scleroderma Day** on June 29.

- "Spread the word this Scleroderma Awareness Month. Each one, teach one—let's multiply our awareness together."
- "Let's talk about scleroderma. Share the facts with one person today to help us create a more informed world."



## INFORMATION WANTED:

Does anyone know of any Rheumatologists in the Whangarei area who specialise in Scleroderma. We have a new member needing some help. If you live near there and wish to get in touch with her, please contact me and I will put you in touch with each other. Thanks Jenny 0273166124

## Situations Vacant

### NEWSLETTER EDITOR WANTED:

After 8 wonderful years of editing the newsletter, we think it is time to hand over the reins. We have truly loved working on it, but we are ready to see someone else put their own creative spin on the project! If you are interested in taking over the editing role, we would love to chat with you.

Jenny 027 3166 124; Tina 021 040 7598

## Our next Scleroderma Zoom meeting:

Dear Members,

All welcome to the next online Scleroderma NZ support group meeting on the **15<sup>th</sup> of August**

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

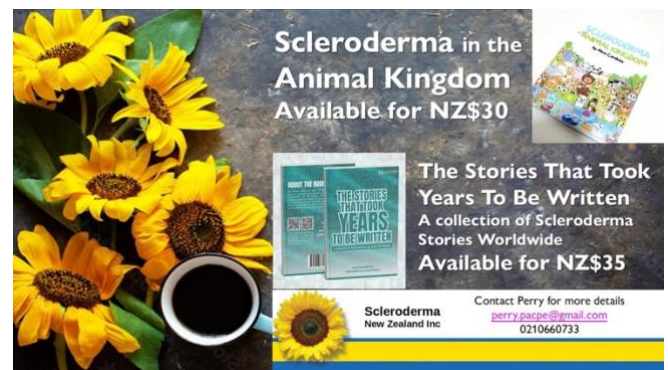
The link for this will be put up on the Facebook page or feel free to contact Perry at

[perry.pacpe@gmail.com](mailto:perry.pacpe@gmail.com)

Look forward to seeing you then. **Perry Bray**



Perry Bray has been in communication with Alvin Cardinez, a young man from the Philippines who wrote a children's book Scleroderma in the Animal Kingdom. If you would like to purchase one, get in touch with Perry.



## Save the Date!

All Welcome

Scleroderma NZ Inc Conference

Warmly Hosted by the Wellington Regional Scleroderma Support Group

James Coe Center Dowse Art Museum  
45 Laings Road, Lower Hutt

17 April 2027

All Details Below



# Scleroderma New Zealand Inc Conference

---

## Scleroderma New Zealand Incorporated Conference 2027

You are invited to attend the 2027 Conference hosted by Wellington...

**A Warm Invitation to the  
2027 Scleroderma Inc Conference  
Held at the James Coe Center, Dowse Art Museum  
45 Laings Road Lower Hutt  
April Saturday 17 2027**

We will have a good line up of medical specialists in the areas of Rheumatology, Gastroenterology, Cardiology, Respiratory, Dental, Podiatry and Hand therapy.

There will be an opportunity to email Dianne Purdie with any questions you would like answered by any specialist prior to the conference. Your name will be kept confidential.

### **Conference Day Proceedings**

**Registration** 8.20am

**Main Conference** from 8.50am to 5pm

**Evening meal** at the Angus Hotel 6.30pm

**Registration** \$30.00 pp

Covers lunch and morning and afternoon teas

We want to make you feel as comfortable as possible, so please let Dianne know your Dietary requirements on the registration form, ie soft foods, GF , Dairy free and Allergies etc.

A Electronic Registration form is attached or post to Dianne Purdie  
19 Thatcher Cres Crofton Downs Wellington 6035.

**Registrations Now Open**

**Evening meal on Saturday night.**

Everyone is warmly invited to an Evening meal on Saturday night at the Angus Inn.

Mains range from \$25 to \$45 currently you can view the menu on line, but if we have enough people we arrange a menu.

<https://theangusrestaurantandbar.co.nz/menu/our-menu>

**James Coe Center at the Dowse**

The Dowse Art Museum is centrally located in Lower Hutt, we have three Hotels within walking distance, from 5 mins to 10 minutes.



You are warmly invited to the Scleroderma NZ Inc Conference  
James Coe Center Dowse Art Museum  
45 Laings Road Lower Hutt, 17 April 2027  
Registration Form  
**Registrations now open**

Name/s

Dietary Requirements, ie GF, Dairy Free, Soft Foods, Allergies etc.

Email

Phone

Which Region do you come from?

Payment (insert number of people attending)

\$30.00 (full day, including Lunch and Morning and Afternoon teas)

Will you be staying at the Angus Hotel for a group booking? Y/N

I/we, will be attending the Evening Meal at the Angus Hotel Y/N

Number attending  The evening meal is not covered by the registration fee.

Total\$

Please pay directly into the below Scleroderma NZ Inc Bank account

**Deadline by April 3<sup>rd</sup> 2027**

Please:- Reference your name/ Conference fee

Bank account SCLERODERMA NEW ZEALAND INCORPORATED 38-9017-0107454-00

Save this document and email this form, to Dianne Purdie [diannepurdie@xtra.co.nz](mailto:diannepurdie@xtra.co.nz)

Any questions please feel free to email or call Dianne on 04 479 5548

Or post to Dianne Purdie 19 Thatcher Cres Crofton Downs Wellington 6035



# CanBead supporting Scleroderma NZ:

CanBead (registered legally as the CanInspire Charitable Trust) is a New Zealand non-profit organisation that provides free creative art therapy workshops for individuals experiencing illness, trauma, disability, or personal loss.

Founded by Sarah Clifford after her own therapeutic experience making jewellery during melanoma treatment, the charity uses bead-crafting as a soothing, meditative tool to help participants find comfort and community.

Members of Scleroderma NZ are eligible to attend the free workshops offered by CanBead. These sessions are currently available in Southland, Christchurch, Wellington, and Hawke's Bay.

For more information see the link below:

<https://www.canbead.org/>



**To provide a supportive environment that distracts through creative activities, which build well-being for those experiencing illness trauma and loss.**



**Create - Inspired, personalised jewellery, connection, and treasured memories.**



**Support - In a nurturing and safe space.**  
**Inspire - Yourself and others with all you can achieve!**

**WHAT WE DO :**

CanBead was started to give people experiencing illness, trauma or loss a sense of purpose and fun. Our workshops are free of charge. Our incredible volunteers help break up donated jewellery, sew and assemble the kits and assist at the workshops. All of our Canbead Kits are funded from financial donations, grants and from thousands of donated beads.

**HOST AGENCIES :**

CanBead workshops are run through host agencies in our regions throughout New Zealand, Cancer Society, Daffodil House, Arowhenua Whanau Support Services, Dementia Group, Blood Cancer, Leukemia Group, Brain Injury New Zealand, House of Grace, Little Acorns, Mary Potter Hospice, Nurse Maude Hospice, Orange Tamariki, Child Cancer, Stroke Foundation New Zealand, and Sweet Louise. These host agencies vary within each region.

**TESTIMONIAL :**

"I would like to thank the CanBead team for patience, ideas and bubbly personalities of the CanBead instructors while they were teaching us to make our jewellery items. It was a fantastic night which we all got something out of and where we all left with a beaming smile. The people, the laughs and the stories made it one of the best CanTeen girl's nights yet."

Libby, participant at of CanTeen Christchurch

**ARE YOU INTERESTED IN DONATING OR VOLUNTEERING OR WANT TO SEE HOW YOU CAN SUPPORT CANINSPIRE? PLEASE CONTACT US!**  
office@caninspire.org.nz  
www.canbead.org.nz



# 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](mailto:hello@thegoodpodiatrist.co.nz)

Phone: **(07) 219 7811**, Mobile: **021 121 0435**

### **Simon Speight, Auckland**

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

### **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 looks like 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-O63nj0FrySOCpV44mBCpIPHTXV7Uf9KIAAnAzM>

And can also be shown like this (the URL address within):

[Scleroderma New Zealand Incorporated - Givealittle](https://givealittle.co.nz/org/sclerodermanz1?fbclid=IwAR29Znk701JSOwf9n0Ew-O63nj0FrySOCpV44mBCpIPHTXV7Uf9KIAAnAzM)

**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.



# Members News



## Wanaka Scleroderma Group

Our wee Wanaka group met for coffee catchup a few weeks ago. There were only four of us as one has already headed North to escape the winter.

We shared our tricks on how to keep warm now winter is here - there's always something to learn!

A few more of us are heading away to warmer temps so we'll catch up again when we're all home again.



## Southland Scleroderma Group

The Southland Group had a very enjoyable lunch in Gore on Sunday, 17 May.

It was wonderful to catch up with everyone. While Scleroderma and its impact on our lives were naturally part of the conversation, we also talked about other health challenges that add another dimension to daily life.

Other topics included!!! We shared what happens behind the scenes at the recycling plant where he volunteers; Helen wore her sunglasses as she manages migraine aura, especially in low sunlight; Nigel showed us beautiful photos from his recent holiday in Rarotonga with Sarah and McKenzie; Barney and Graham reminisced about old Southland people and places; and Roger offered advice on what to look for if I decide to buy an electric bike. It was also lovely that Jenny's son, Quinn, could join us on his trip between Dunedin and Invercargill.





## Hawkes Bay Scleroderma Group

We had an enjoyable meeting. There were six of us there with lots of chatter and laughter as usual.  
Regards, Frances



## Christchurch Scleroderma Group

If you would like to attend the Christchurch Support Group please get in contact with **Perry Bray:**  
[nicky.moore@xtra.co.nz](mailto:nicky.moore@xtra.co.nz)



## Palmerston North Scleroderma Group

If you would like to join in with the Palmerston North group please get in contact with:  
**Anne Allan:** [anneallan95@gmail.com](mailto:anneallan95@gmail.com)



## Otago Scleroderma Group

If you would like to join in with the Otago group please contact **Gaynor:** [gaymeddings@gmail.com](mailto:gaymeddings@gmail.com)



## New Plymouth Scleroderma Group

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)



## Waipa and Waikato Scleroderma Group

The Waipa/Waikato group met recently. If you would like to join in with the group please get in touch with Erena.

Please contact **Erena Bruce** if you wish to join them.  
[brucearena@gmail.com](mailto:brucearena@gmail.com)



## Scleroderma Zoom Meeting

Perry organises these at different times throughout the year. The next dates at this stage are August 15<sup>th</sup> and December 15<sup>th</sup>. The Meeting details will be confirmed closer to the dates via our Facebook page.

### Winter and Scleroderma

Winter arrives with quiet hands,  
Brushing frost across the land,  
Silver mornings, crystal air,  
A fragile beauty everywhere.

Yet winter's touch can linger long  
In fingers where the cold feels strong,  
Where blood retreats, where warmth grows thin,  
And icy winds seep deep within.

The world is hushed beneath the snow,  
While hidden battles come and go.  
A coat, a scarf, a careful pace,  
Determination in each face.

The trees stand bare against the sky,  
Their branches stark, yet reaching high.  
They bend with storms, they brave the night,  
And wait in faith for springtime's light.

So too the heart that carries on,  
Through shortened days and later dawns.  
Though winter asks for strength and grace,  
It cannot dim the spirit's place.

For even in the coldest year,  
When pain and weariness draw near,  
There blooms a courage, calm and true,  
Like winter stars in midnight blue.

And when the thaw begins at last,  
No matter what the season passed,  
Hope rises gently, warm and clear—  
A promise held through every year.



# Members News continued.



## Wellington / Kapiti and Wairarapa Scleroderma Group

The Wellington / Kapiti and Wairarapa support group met at Boulcott's Farm café in Lower Hutt on the Saturday 18<sup>th</sup> April on a very wet rainy day.

The rain had been so bad overnight that there was flooding in the Hutt area, causing some of our members not able to drive out to the lunch due to the flooding on the roads. Despite all the rain, we had 6 of our members make it out to lunch. We had Steve, Karin, Richard, Sue, Jo, Dot and myself at lunch and had a good time chatting and catching up with each other. We discussed changing our mid-winter lunch gathering to a new venue, so please keep an eye out for upcoming email sent out with the new venue location.

If you would like to join in with our group, get in touch with:

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

Cushla Marsters: [cushlam@outlook.com](mailto:cushlam@outlook.com)

Tina McLean: [tinaoaisamclean@outlook.com](mailto:tinaoaisamclean@outlook.com)



## Bay of Plenty Scleroderma Group

Our autumn meetup saw a cosy group of six gather at Broom Tree Cafe. While a strong wind quickly forced us to abandon the outdoor tables, the warm atmosphere inside was perfect for a lunch of connection.

We were glad to meet with Dianne and her sister Christine for the first time. The smaller group size allowed for a natural, deep-dive conversation where everyone could share their recent experiences. We focused heavily on resource sharing - trading recommendations for local services, handy tools, and practical strategies that have helped us navigate recent challenges. From celebrating small wins to validating everyday hurdles, the collective wisdom in the room reminded us all of the power of a strong peer network.

A huge thank you to everyone who came and contributed to such an open, supportive space! We didn't go forward with our June meeting. The next 2 will be on August 1 and October 3.

If you would like to join the Bay of Plenty group get in touch with Alumie Nguyen: [alumie.uow@gmail.com](mailto:alumie.uow@gmail.com)



## Auckland Scleroderma Group

We're a friendly supportive group. Utterly casual. And we hope that people from wider Auckland can join us. But also, we're always available for a FB chat, or emails, or phone calls.

Helen Parsons

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

021 248 3869



From left

Cheryl Madsen, Mary Daniel, Daphne Hiett & her husband Tony Hiett, Helen Parsons, Lisa Cato, Kathy McEwan



## Northland/Auckland Scleroderma Group

This new group is to make it easier for the Northern Folks to join in with our group. It is a very warm, friendly, and informative catchup.

Helen Parsons

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

021 248 3869



# Group Meetings Dates 2026: Regional

## Wellington/Kapiti/Wairarapa support group meets:

Date and Time:	Venue:
Sat 18 <sup>th</sup> July @ 12:30pm RSVP by 16 <sup>th</sup> to Dianne	Water Front Bar and Kitchen 3 Garden Road, Raumati Beach Mid-year winter lunch
Sat 19 <sup>th</sup> September @ 12:30pm	James Coe2, Dowse Art Centre 45 Laings Road, Lower Hutt
Sat 21 <sup>st</sup> November @ 12:30pm	The Farm Café & Bar 33 Military Road, Boulcott, Lower Hutt

## Palmerston North support group:

Date and Time:	Venue:
Wednesday 24 <sup>th</sup> June @ 10.15am	Manawatu Golf Club Cafe Centennial Drive, New Plymouth

## Christchurch support group meets:

Date and Time:	Venue:
Sat 18 <sup>th</sup> July @ 12.00pm	Koji Japanese Buffet Restaurant Mid-year winter lunch
Sat 19 <sup>th</sup> September @ 2.00pm – 4.00pm	Urban Eatery Barrington Oderings Garden Centre, Chch
Sat 21 <sup>st</sup> November @ 2.00pm – 4.00pm	Portstone Garden Cafe Ferry Road, Chch

## Bay of Plenty support group meets:

-The Next 3 Upcoming Meetup Dates (First Saturday Every Two Months): Location and Time to be confirmed depending on who can make it (minimum of 2 to go ahead) so that we can optimise our travelling time.

Date and Time	Venue
Saturday 1 <sup>st</sup> August @ TBC	TBC

## New Plymouth support group:

Date and Time:	Venue:
Saturday 27 <sup>th</sup> June @ 11.00am	Caffe Windsor, Inglewood New Plymouth

## Waikato/Waipaa support group meets:

Date and Time:	Venue:
Saturday 27 <sup>th</sup> June @ 10.30am for brunch	Café Fresco 78 Alison Street, Hamilton Lake

## Hawkes Bay support group meets:

Date and Time:	Venue:
Third Saturday of the month @ 11:30am	Serendipity Café 1412 Pakowhai Road, Hastings

## Southland support group meets:

Date and Time	Venue
Sunday 16 <sup>th</sup> August @ 12:00pm	Aged Care Southland, 50 Forth Street Invercargill
Sunday 22 <sup>nd</sup> November @ 12:00pm	Croydon Lodge, Gore

## Auckland support group meets:

Date and Time:	Venue:
Monday 6 <sup>th</sup> July @ 10.00am	Daily Bread, Kings Plant Barn 11 Porana Road, Takapuna, Auckland, 0627
Monday 3 <sup>rd</sup> August @ 10.00am	Daily Bread, Kings Plant Barn 11 Porana Road, Takapuna, Auckland, 0627
September	No Meetup-Helen's Overseas
Monday 5 <sup>th</sup> October @ 10.00am	Daily Bread, Kings Plant Barn 11 Porana Road, Takapuna, Auckland, 0627

## Northland/Auckland support group meets:

Date and Time:	Venue:
Wednesday 15 <sup>th</sup> July @ 10.30am	Columbus Café, 35 Colin Chester Drive, Silverdale, Auckland 0932 (in Mitre 10)
Wednesday 12 <sup>th</sup> August @ 10.30am	Columbus Café, 35 Colin Chester Drive, Silverdale, Auckland 0932 (in Mitre 10)
September	No meetup – Helen's Overseas
Wednesday 14 <sup>th</sup> October @ 10.30am	Columbus Café, 35 Colin Chester Drive, Silverdale, Auckland 0932 (in Mitre 10)

## Online Zoom Meeting with Perry

Date and Time:	Venue:
Saturday 15 <sup>th</sup> August Time TBC	Online link will come out nearer the time via email
Saturday 5 <sup>th</sup> December Time TBC	Online link will come out nearer the time via email

## 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: [hksunitsch@gmail.com](mailto:hksunitsch@gmail.com)

## Otago support group:

Please contact Gaynor if you wish to join us.  
[gaymeddings@gmail.com](mailto:gaymeddings@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.akl/>



## Scleroderma New Zealand

<b>President:</b>	<b>Jenny Andrews</b> sclerodermanz@gmail.com
<b>Vice President:</b>	<b>Tina McLean</b> tinaoaisamclean@outlook.com
<b>Secretary:</b>	<b>Jane Sainsbury</b> jsainsbury@xtra.co.nz
<b>Treasurer:</b>	<b>Gordon Purdie</b> gordon.purdie@xtra.co.nz
<b>Newsletter:</b>	<b>Tina McLean</b> tinaoaisamclean@outlook.com <b>Jenny Andrews</b> jennyred@xtra.co.nz

### Committee Members:

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

## Contacts:

### Find a Scleroderma a Support Group near You:

<b>Auckland/Northland:</b>	<b>Helen Parsons</b> , Email: helenparsons@artcardsandposters.co.nz
<b>Bay of Plenty:</b>	<b>Alumie Nguyen</b> , Email: alumie.uow@gmail.com
<b>Waikato / Waipa:</b>	<b>Erena Bruce</b> , Email: bruceerena@gmail.com
<b>Hawkes Bay:</b>	<b>Frances Tod</b> , Email: frantod47@gmail.com
<b>New Plymouth:</b>	<b>Kelsi Tidswell</b> , Email: kelsitidswell@gmail.com
<b>Wellington:</b>	<b>Cushla Marsters</b> , Email: cushlam@outlook.com
<b>Christchurch:</b>	<b>Perry Bray</b> , Email: perry.pacpe@gmail.com
<b>Palmerston North:</b>	<b>Anne Allan</b> , Email: anneallan95@gmail.com
<b>Waimate / Oamaru:</b>	<b>Helene Sunitsch</b> , Email: hkjsunitsch@gmail.com
<b>Otago:</b>	<b>Gaynor Meddings</b> , Email: gaymeddings@gmail.com
<b>Southland:</b>	<b>Heather Milligan</b> , Email: milliganseeds@xtra.co.nz
<b>Wanaka</b>	<b>Sue Neale</b> , Email: sueenealenz@gmail.com
<b>NZ Online Zoom Support:</b>	<b>Perry Bray</b> , Email: perry.pacpe@gmail.com

