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NUMBER: 66 JUNE 2025

# Scleroderma

## New Zealand support group

## Summer 2025

### Greetings to you all...

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



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

Well, this year has flown by so quickly, we hope everyone is well and looking after themselves.

If you have recently been diagnosed with Scleroderma or have just joined our community, Welcome. We have quite a few new members so we wish you well on your Scleroderma Journey. Not the journey you had planned for but hopefully we can be of some support to you and we hope that you find some useful information in our newlsetter.

We hear first, from Jenny Andrews with the Presidents report. Jenny keeps us up to date with what's going on around New Zealand.

We have news from the Waikato Team about the Scleroderma Seminar 2025 held in Te Awamutu on 18<sup>th</sup> October. Thank you to all the speakers listed below who generously donated their time to share their expertise:

- Scott Wilson and Chagi Mannakkari
- Karen Moratti
- Delwyn Mckenzie
- Melissa Haines
- Brittany Vincent
- Alison Storey

We wish everyone a **Merry Christmas**, a safe and restful time over the holiday period and a **Happy New Year** for 2026.

We hope everyone takes the time to relax and take a break to look after yourselves and recharge.

Take care everyone.

Nga mihi,

Tina and Jenny



# Presidents Report:



## Merry Christmas to you all,

I hope this finds you all well enough to enjoy some family/friend relaxation time. The Christmas Trees will be up and the decorations put all around. I did mine back

in the middle of November as I have no children at home judging me and telling me it is not December 1<sup>st</sup> yet. I came up the drive the other night in the dark and the curtains were open and I was greeted with my beautiful lights on my Christmas Tree. It certainly brings a smile to my face.

Wow, I was blown away by the success of the Waikato Scleroderma Seminar in October. Erena and her team did such an amazing job, the decorations around the venue were amazing and were done by a group of young ladies who volunteered their time to decorate and help in the kitchen. Such a lovely group of ladies. The other volunteers in the kitchen kept us feed and watered with a fabulous choice of food and everyone else just made it a very smooth running day. Thank you team Waikato/Waipā. We had an array of wonderful speakers who kept the crowd enthralled during the day. It was also the 10<sup>th</sup> anniversary year of Scleroderma New Zealand Incorporated which was pretty special, having been founded in 2015. There will be a report on the seminar further on through the newsletter. People came from all over the North Island and Perry and myself from the South. I was fortunate enough to be invited to stay with Lea and had the most delightful stay for a couple of nights. It felt wonderful to be looked after. Thank you Lea, your kindness will not be forgotten.

During the summer months, it is very important to look after your skin. Please make sure you wear a sunhat and have sunblock on every day. The last

thing we want is to irritate our skin more with sunburn. And remember the strip on your back when you bend over in the garden and your top doesn't quite cover you all. That is such a sore spot to have sunburnt. Speaking from experience:)

I want to thank the Committee for another year of commitment to Scleroderma New Zealand. You are all very much appreciated. We will be calling for new members during next year if anyone is interested in coming on board. We are a great group of like-minded people who are busy with our own lives but can find that time for the very odd meeting where we get to see each other on line and have a wee chat. It is always great to have some fresh ideas from new members too.

Thanks heaps to all the support group leaders who keep our support groups running. You are amazing and I love the empathy you show to your groups. It is a very important part of Scleroderma New Zealand and helps our members in such a variety of ways.

Finally, wishing you all a very safe and healthy Christmas and New year period. Remember to ask for help rather than doing everything yourself and wearing yourself out. Once the craziness is over take time for yourself and enjoy the sunshine.

Take care all. **Jenny**





# Members Stories:

## Tina McLean's overseas family holiday ...

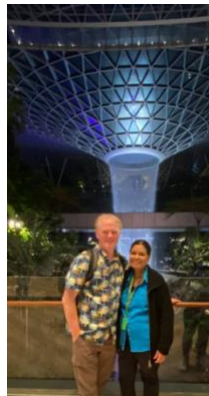
Sharing photos of our holiday to Singapore, London, Edinburgh, Dubai and Abu Dhabi....

Early in September this year, our family took a holiday to Scotland so that our son Ian could meet my husband, Alastair's Scottish relatives, as Ian had not met them yet. A couple of years before, we had taken Ian to Indonesia to meet my Indonesian relatives, so we decided it was fair that he also got to meet with the Scottish half of the family.

The trip was just over 4 weeks, but we wanted to see and do as many things that we could in the 4 weeks, as well as spend time with Alastair's relatives in Edinburgh. We made sure to take stop overs in Singapore and London, spending several days in each city before making our way to Edinburgh and then returning via Dubai and spending several days there too. While in Dubai, we took the opportunity to do a guided day tour to Abu Dhabi.

One of the things I was nervous about during our travel was how I was going to cope with the long walks at the airports, and all the transfers, but I was wearing my "Hidden Disability" sunflower lanyard and had informed the airlines before each trip that I would need wheelchair assistance, especially if there were stairs involved, so this really helped me during our travel. We had an awesome time, very tired but well worth it. It was also lovely to be able to meet up again with Alastair's cousins and uncle and Ian had the opportunity to meet his uncles and aunt.

### Singapore:



### London:



### Edinburgh:



Edinburgh Castle





# Members Stories:

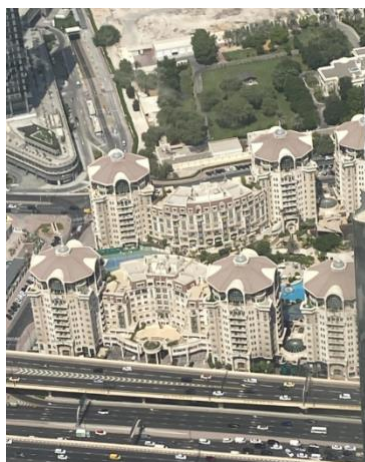
## Tina McLean's holiday photos continued ...

### Dubai:

Our trip to Dubai was very surreal, a city sprawling with lots of new buildings being built with desert surrounding the outskirts of the city. All the buildings in the newer part of Dubai were bigger, taller and awesome. The most fun activity we had in Dubai was when we spent a day out travelling to the desert in 4x4 vehicles on the sand dunes. We did some sight seeing, fun activities in the desert and had a buffet dinner with traditional entertainment in the evening before being driven back to our hotel at night. We also took the opportunity to visit Abu Dhabi on a guided day tour and visited the white mosque.



Burj Khalifa behind

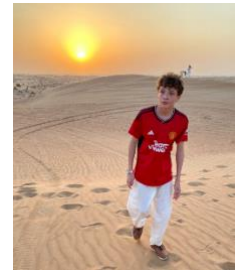


A view of our hotel from the 125<sup>th</sup> floor in the Burj Khalifa building.

### Dubai desert and traditional dancing:



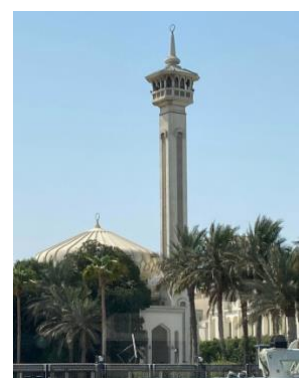
Day trip in convoy to the desert



### Abu Dhabi:



White Mosque



# Members Stories:

## Katie's Journey as young-ish Scleroderma patient

I was diagnosed in April 2024, at the age of 28, just a year after my son was born. I juggle life as a full-time mum, and a part-time relief teacher, all while helping my husband where I can on our dairy farm. When I was first diagnosed with scleroderma, I did have an adjustment period with many emotions, however I feel like I have taken it in my stride and it will just become one day at a time. My new motto became "do what I can, when I can, how I can, for as long as I can."

So that's what I do. I take my son to swimming lessons, I involve myself in playgroup, I go on adventures and I live life. I don't take anything for granted, and I have become so much braver than I ever thought I could be or would need to be. Whilst Scleroderma was not on my bingo card of life, I can't help but be grateful for the people I have met in this journey, who are all walking variations of the same path. The pictures I have shared are of myself on the SkySwing at Rotorua a couple of weeks ago, and my time swimming with turtles in May this year, which really reflect my new found motto above. I take my hat off to all of you, and wish you a very Merry Christmas and many blessings for the New Year.

Katie Scherer



## Christmas Poem

### 🌟 A Southern Christmas Poem for Those with Scleroderma 🌟

*When summer sun warms sky and sea,  
And Pohutukawa blooms – bright jubilee,  
We gather warmth in hearts and smiles,  
And walk life's road, through trials and miles.*

*Though days may bring fatigue and strain,  
And pain may test like summer rain,  
Your courage glows like summer light —  
Steadfast and true, so strong and bright.*

*No frosty winds or snowflakes fall,  
Instead we hear the waves' soft call,  
A barbecue, cool salads spread —  
Where laughter blooms and joy is fed.*

*May cricket games and ocean breeze  
Bring ease, and gentle moments, please;  
May sunlit skies and starry nights  
Surround you with soft, warm delights.*

*For in your heart a fire glows,  
More treasured than the summer rose,  
This Christmas may you feel and see  
You're cherished — loved, so tenderly.*

🌟 Merry Christmas — in sunshine, warmth,  
and peace this season and always





# Members Stories

## The life and times of Perry...

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

### Health Update #22: Nek Minnit

November 9, 2025 by Perry

I'm pretty sure that the majority of us have probably heard all, if not most of the following sayings; "You don't know what is around the corner." "If only I knew then what I know now." "It is only a matter of time." "It's amazing how quickly a person's life can change" "One minute everything is hunky dory, the next!"



Or how about the following; "Normal, what is normal?" "You never know when your time is up." "Stable? That's where horses live, aint it."

"Nek minnit\*" Now for those of you not familiar with Kiwi slang that last one you might want to look up on Google or something (or you can always skip to the end of this post for a bit of a low down on the phrase ).

The thing is, living with a dynamic disability or disease, let alone a rare disorder such as **Scleroderma**, can leave you thinking that life is a never-ending cycle of appointments and follow-ups, check-ins and questions, ups and downs, never knowing what's gonna happen next.

I've previously mentioned that life with this disease can be like a bit of a rollercoaster ride, or maybe more appropriately life can occasionally throw us a curveball, or at least leave us feeling as if we've been involved in a game that is literally end to end and your not quite sure what the outcome is going to be.

Only a few short weeks ago, we had a pleasant conversation with the rheumatologist at a follow-up appointment in which he mentioned, after taking stock of my recent echocardiogram results, CT Scan and general observations that things have settled down – mostly!



Apart from the need to have a separate IVU CT scan on my kidneys I appear to be 'stable!'

An irregularity was initially picked up earlier on in the year when I had my chest CT scan and I was put on a 32 week public system wait list to get another scan done lower down.

After waiting more than 32 weeks, we went private as the wait time had increased to over a year, and within a few days an appointment was confirmed for about two weeks later.

I'll no doubt fill you in on more about this in my next health update, as I'm currently waiting on a referral for a Urologist appointment. Stable for the most part – at least health wise that is

Now, unfortunately, that does not mean that my disease has gone into remission or anything! It is just that with the right dosage and timing of medications that I am on and how I've been approaching life dealing with this disease, maintaining healthy eating habits, exercise and stress, etc. that we seem to have been able to keep everything in check (ish).

However, there were obviously a few caveats in that observation – especially in the unfortunate event that I pick up a bug or something – "Nek minnit!"

Last year, I had the unfortunate experience of suffering from Neutropenia after catching a viral infection not long after having my Rituximab infusion. This saw my neutrophils and white blood cell count bottom out completely and I experienced a fall in the middle of the night, splitting my head open on the bathroom tile floor.



Let's just say that the mantra 'she'll be right' didn't come to fruition and Annette took me to hospital in the wee small hours of the morning. This necessitated about a week in hospital before being discharged

and us instituting a whole new health regime going forward to get some sense of equilibrium in our lives.

Anyhow this year, I get to experience the opposite of neutropenia – Neutrophilia (more on that shortly).

I've had a persistent dry cough for the past couple of months that hadn't cleared, so we finally went to the doctor to get on top of it. And after a couple of short stints on Prednisone to try and clear what was sitting in my chest it finally came to something – and with a vengeance.

My breathlessness started getting worse, especially after severe bouts of rasping coughs that brought up copious amounts of dirty looking phlegm, a raw throat, muscles in and around the chest and back that were severely affected by the constant bouts of hacking; along with the fatigue that came on string as the body tries to fight all the other things going on along with the occasional unsteadiness on my feet (moments that were hardly stable )

So I went to see the local GP again and I am now on a course of antibiotics to clear whatever infection has been causing me discomfort, and I'm awaiting another x-ray to get to the bottom of things that are going on for me at the moment.



# Members Stories

## The life and times of Perry... continued...

So, what is Neutrophilia? The body naturally produces extra neutrophils to help fight infections, inflammation, or stress – However, having too many (more than 7,500 neutrophils per microliter of blood in adults) can limit the ability of our immune system to fight the pathogens present and heal properly.



My latest blood test results show that I have almost 3 times the normal amount of neutrophils an adult should have in their system – 20,200 per microliter of blood

And the thing is, Neutrophilia can potentially lead to any underlying infection becoming severe, it can bring on sepsis and organ damage from chronic inflammation, and it increases the risk of blood clots in the body.

Nek minnit!

So, just when I thought everything was on the up and up and I was starting to get in my head that I can push myself just a tad more to get things done – I've spent pretty much the past two days mostly tucked up in bed. Quickly finding that I get exhausted doing just about anything.

Hopefully, by getting on top of this reasonably early, it won't turn into pneumonia and another hospital visit – although the remainder of the weekend I'm having to keep an eye on my temperature, heart rate and oxygen saturation more stringently than I have been of late.

Also, I need to keep a close eye out for any hot or cold chills / fever, as that will mean having to head into Christchurch Emergency Department immediately for a visit and possible extended stay – certainly not something I want to happen at this point.

Life with scleroderma keeps on giving and giving, and at times, I don't like it one bit especially as I often get told that I am looking good and don't look sick



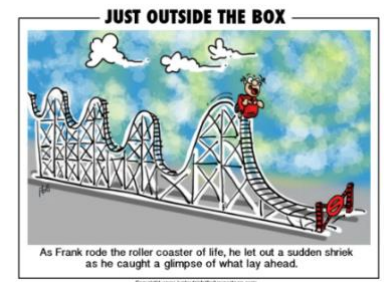
On the positive side (as there has always got to be a silver lining right!) It has enabled me to meet a lot of wonderful people and I've been blessed to journey alongside some along the way, as we each navigate new normals that come our way – And when I look around at others that are facing the many challenges that this rare dynamic disease exhibits I recognise that there is no such thing is normal. It is a setting on a washing machine (or at least it used to be)

In the meantime, be grateful for what you have – 'cause in a split second your life can be turned upside down – in essence, this is what the phrase 'nek minnit' is alluding to.

I'll carry on riding the rollercoaster of life with its many ups and downs, and enjoy it as much as possible while I can even with its many challenges along the way.

Blessings 'til next time 😊

\* FYI – Google AI says that the phrase 'nek minnit' became famous due to a viral 2011 YouTube video of New Zealand skateboarder Levi Hawken.



In the nine-second clip, he jokes about a hypothetical situation, saying: "Left my scooter outside the dairy; nek minnit..." before panning the camera to an already-broken scooter.

The phrase quickly entered everyday New Zealand language and became a popular internet meme, used to humorously punctuate a story where something unexpected happens in a short amount of time.



# Seminar news from the Waikato Team:

## *SEMINAR FEEDBACK* *2025*

### New Zealand Scleroderma Seminar – Focus on Wellness

The Waikato Scleroderma Group hosted the 2025 New Zealand Scleroderma Seminar on 18 October at the Te Awamutu Bible Chapel. The day brought together people living with scleroderma, their families and supporters for a time of learning, encouragement and connection.

This year's theme was "Wellness", a holistic view of Scleroderma and focusing on practical ways to improve quality of life for those affected by this rare auto immune condition.

All of the guest speakers generously donated their time to share their expertise.



From Waikato Hospital 2 Rheumatologists **Scott Wilson** and **Chagi Mannakkari**. Both work at the clinic with a solid foundation in what medications are being used both funded and non funded. Both treat clients with same care and humility with huge interest in new technology and how to attain it. Both interested in

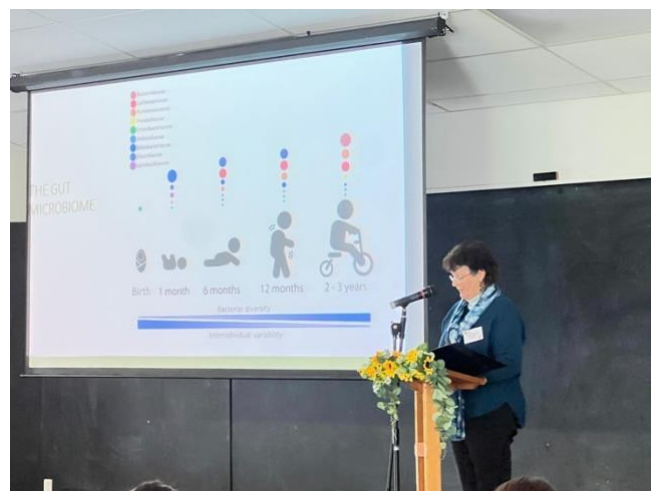
research around the globe and how NZ patients are able to access. The question of DHBs and Te Whatu Ora and the new initiatives where patients are able to be treated around NZ for their needs was raised. Not surprising it has turned out the political influence has disturbed once again those who work at grass roots, face to face with patients.



Via a video recording we heard from **Karen Moratti** living in New Plymouth. Due to intense

flooding travelling was not an option, however where there is a will there is a way, a 20-minute video gave insight in a non-intrusive Vibroacoustic cushion treatment that one experiences and supports the natural vibrations with organs and body internals to readjust to natural cycles. They become a little out of synch because of choices we make in everyday life. Very approachable and with a Reiki background always keen to chat [www.vibroacoustictherapy.nz](http://www.vibroacoustictherapy.nz).

After a break we heard truths and facts regarding best gut health. True nutrition is lifestyle, living with the land and the land being who you are as the biggest contributor to your best gut health. Good growing, nutrients to the plant before it gets to the plate is key. Knowing what nutrients and minerals are, is science. An invitation was there to be curious.



**Delwyn McKenzie** presented with printed Power point copies exactly what these are. No mincing facts or words. The reward is an appreciation for the best or the best nutrition, less inflammation, improved gut health and energy to do other activity learn or progress hobbies. Delwyn also gave us a short performance of her opera singing after our tidy up. If I knew she had this talent as well would had lunchtime entertainment.







Following lunch catered from Red Kitchen and pumpkin & kumara soup made by a group member, we drew raffle tickets. 17 donated items from around NZ and 8 dozen free range eggs from Delwyn McKenzie. Pleasing several people were able to choose their own raffle prize from the table. Then two gift basket draws. Half the merino gloves also sold at cost.

Post lunch we had the delightful **Melissa Haines** share her experiences with Scleroderma and food journey from mouth to oesophagus, to small digestive tract to big digestive tract and eventually leaving the body. Like we did with our babies observing and checking texture,



shape, size, colour of pooh is a real reality of keeping well. Melissa cross referenced with previous speaker and with a sense of humour and fixed information of how to recognize unwellness and how to keep well.

Then our lively **Brittany Vincent** presented a hand occupational therapist view on how to best maintain hand dexterity. With the tools of our everyday life, hands being affected by scleroderma is so real. Consistent exercise of fingers and hands daily, wearing splints at nights as best we can. Much of Brittany's presentation was on practical strategies and tips with hand and finger care. Brittany works out of Waikato hospital and specialises in making custom made splints for finger/s or hands. Brittany touched on chair exercising for legs, core and upperbody, hands naturally have a role to play.



Finally, spirited and get up and go **Alison Storey** from Storey Sports. Since retiring from Olympic rowing, a rhythmic gymnast, then putting her body on the line for beach volleyball Alison has always advocated that our bodies are designed to move. To do activity one enjoys is paramount. Music on have a bogey, use a hill for some cardio, jump on a stationary bike take the weight off. The BIGGEST change is to mindfully apply is High Interval Training. (HIT) Short periods on fast (maybe start with 30 seconds, slower 20 seconds, then fast, slower, fast. Slow up to 8 repetitions. Then to also use weights 8-12 repetitions (light to start with, maybe even an elastic resistance band) 30-45 minutes a week 3 times, every second day is ideal. Bodies use same muscle groups walking, sitting, standing, other muscle and tendons need to work sideways, backwards, it is just as important. Gee whizz we did it without thinking as kids, somewhere in our journey we forgot or stopped doing this.



#### SQUAT SAGITTAL ARM SWING

Reps : 10 to 15 Sets : 3 Intensity :  
Tempo : 1:1 Rest : 30 seconds

##### Preparation :

- Standing in upright position, raise DB to shoulder height in sagittal position

##### Movement :

- Let slightly bent arm "fall" while squatting down
- At completion of downward phase of swing, start to drive upwards with your squat
- The momentum of the squat will drive the arm back up and repeat
- Don't "control" the arm swing; let it become fluent



#### PUSH UP

Reps : 10 to 15 Sets : 3 Intensity :  
Tempo : 1:1 Rest : 30 seconds

##### Preparation :

- In a prone position, place hands at a width that will allow the forearms to be perpendicular to the floor when the elbows are flexed at 90 degrees.
- Come into plank position with elbows extended, make sure the entire body is in a neutral position.

##### Movement :

- Flexing at elbows, lower the body, maintaining neutral spine.
- Push back to starting position.
- Use desired REP TEMPO.



#### LUNGE - LATERAL (DB)

Reps : 10 to 15 Sets : 3 Intensity :  
Tempo : 1:1 Rest : 30 seconds

##### Preparation :

- Stand in proper alignment with hands on hips.
- Place feet straight ahead and shoulder width apart.

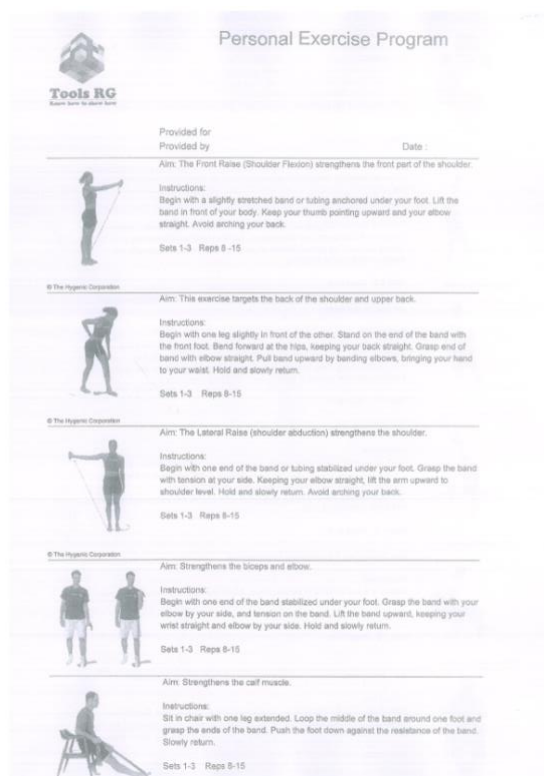
##### Movement :

- From optimal postural alignment, draw your lower abdomen inward toward your spine (activating the deep stabilizing mechanism).

To close off our day, we celebrated NZ Scleroderma 10 years as an Incorporated Body. Not to be confused with coffee groups that have had meets for 20 odd years. NZ Scleroderma has a purpose to bring more people around NZ together and connect them to reliable networks around the world.

I want to finish by thanking our Waikato Team for companionship, energy, resources, skills and for their compassion, honesty and harmony because that is how the Seminar was measured as a success.

Nga mihi Mahana Lea, Tom & Erena





# Spin online Seminar

Heather Milligan gives us a report on the online Seminar held in November...

## **Spin Scleroderma held an online seminar on 23rd November 2025**

Spin Scleroderma is a global research network. The headquarters are at the Jewish General Hospital in Montreal, with research sites and partners in Canada, the US and Australia.

There were 500 people attending via the internet from 22 countries.

The first researcher set the question why is it important to study joint inflammation in Scleroderma? – it does affect 30 – 50% of us, and it is a leading cause of pain, leading to disability.

It was important to find specific treatment for joint inflammation. At the moment those with scleroderma their joint inflammation is being treating as if it was Rheumatoid Arthritis, but her research shows that rheumatoid arthritis differs from Scleroderma on a cellular level. She hopes that her team will continue the research by introducing anti-interferon as a possibility for reducing the inflammation in Scleroderma.

The next researcher was discussing how Scleroderma may affect intimacy and sexuality. They had people complete a survey to understand how Scleroderma impacts intimacy. The survey showed pain, fatigue, loss of sexual desire and trouble with sexual function, mental health worries and body image issues and that it is important to talk openly about intimacy and there should be more research on this topic. Professionals to help would be your GP, sex therapists, medical specialist such as OBGYN or Rheumatologist.

The next speaker, who is an Australian rheumatologist. She talked about her research on carbon-fibre heating elements in gloves with small rechargeable batteries. She had been approached by one of her patients about heating gloves and would they be worth the expense of around \$300 plus needing a spare battery. She trialled the Zarkie gloves for motorcyclists (Australia) with 28 patients with Raynards due to

Scleroderma. They averaged wearing then for 4 hours per day.

The conclusion is that using heated gloves led to a meaningful improvement in Raynards and they are a safe, practical option.

The last speaker spoke about their research which is ongoing into understanding fibrosis in Scleroderma and discovering new treatment targets. They collected small skin samples from 3 groups - healthy volunteers, people with early-stage scleroderma and people who had been diagnosed with scleroderma at least 10 years ago. They are analysing the parameters to evaluate skin fibrosis which they hope will help in the understanding of skin fibrosis and hope for earlier intervention and better protection of skin and organs.

The presentation had subtitles available finished right on time and was well organised. So pleased I was able to attend.

Hopefully the research results will be available in the future to New Zealand rheumatologists.

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A post on New Zealand Arthritis Facebook Page  
<https://www.facebook.com/photo?fbid=1477960344338890&set=a.519378800197054>

Kia ora everyone,

We've been contacted by Radio NZ, who are looking to speak with someone who has recently experienced delays accessing rheumatology services in Aotearoa.

If you're interested, please send us a private message on our Facebook Page.

There's absolutely no pressure; only volunteer if you feel safe and comfortable doing so. - Arthritis NZ



# Combination drug therapy boosts lung, skin health in SSc patients:

From: <https://sclerodermanews.com/news/combination-drug-therapy-boosts-skin-lung-health-ssc-patients>

## Study: Biggest benefits seem when drugs started simultaneously, after short gap

Written by Patricia Inácio, PhD | December 2, 2025



Combining rituximab and mycophenolate mofetil was significantly more effective than using either drug alone at reducing skin thickness and improving lung function after one year in people with [systemic sclerosis](#) (SSc), according to a large French study.

The safety profile of the combination therapy was similar to that of either drug alone. The greatest benefits were observed when both therapies were started simultaneously or after a short gap.

These findings support the need for additional studies assessing the combo therapy as a first-line treatment in SSc, researchers said.

The study, "[Evaluation of the mycophenolate mofetil–rituximab combination in systemic sclerosis: a French retrospective multicenter study \(MycRiSSc\)](#)," was published in the Journal of Autoimmunity.

### Evidence for combined use of two drugs in SSc limited

SSc, or scleroderma, is a chronic autoimmune disease that causes hardening and scarring (fibrosis) of the skin and internal organs. Many patients develop interstitial lung disease (ILD), a group of conditions that cause inflammation and scarring in the lungs.

Rituximab and mycophenolate mofetil are two immunosuppressants recommended for managing systemic sclerosis-associated interstitial lung disease (SSc-ILD). However, evidence for their combined use has been limited.

"Due to the challenges of conducting combination trials in SSc, high-quality real-world data comparing the [rituximab and mycophenolate mofetil] combination to [rituximab] or [mycophenolate mofetil] monotherapy are essential to inform clinical practice and strengthen

the evidence base for this strategy," the scientists wrote.

The team from France studied 127 adults with SSc, following them across 17 centers. Patients received either of the two drugs alone or a combination of both for at least 12 months.

A total of 47 patients, 61.7% of whom were women and whose median age at [SSc diagnosis](#) was 45, received the combo therapy. They were compared with 30 participants who were treated with rituximab and 50 who were given mycophenolate mofetil.

Within the combination group, most had [diffuse cutaneous SSc](#) (68.1%), and a vast majority had ILD (85.1%). Nearly 28% had overlapping autoimmune conditions, such as [Sjögren's disease](#).

### Skin thickness decreased significantly with combo therapy

Patients in the mycophenolate mofetil-only group began treatment earlier after having been diagnosed. These patients also had better lung function than those in the combination group, as assessed by a higher forced vital capacity (FVC) — a key measure of lung function — at the start of treatment (baseline).

After one year, skin thickness, measured by the modified Rodnan skin score (mRSS), decreased significantly with the combination therapy, from 14 to 7 points. The mycophenolate mofetil group also showed a modest but significant improvement, while the rituximab group experienced no meaningful change.

Lung function, measured by FVC, also improved significantly in the combination group, from a median of 63.1% to 67%, while remaining stable with either rituximab or mycophenolate mofetil alone. The diffusing capacity for carbon monoxide — the ability of the lungs to transfer oxygen from the air to blood — did not change significantly in any group.

Compared with rituximab alone, combination therapy was more effective in reducing skin thickness and in improving skin and/or lung involvement.

Combination therapy eased ILD in almost two-thirds (63%) of patients, compared to 27.8% with rituximab or 28.6% with mycophenolate mofetil alone. Similarly, 70.4% of patients on combination therapy showed improvements in skin and/or lung complications, versus 27.8% of those given rituximab and 52.4% of those who received mycophenolate mofetil.





## Combination drug therapy boosts lung, skin health in SSc patients:

[Continued from previous page...](#)

### Upfront combination therapy linked to higher likelihood of ILD easing

Among the 47 patients on the combo approach, 20 (42.6%) received upfront combination therapy, while 27 (57.4%) received sequential combination therapy, when the second drug is added later.

In the upfront group, the median delay between the two medications was 3.5 months. In contrast, in the sequential group, mycophenolate mofetil was started first in nearly all cases (88.9%), and rituximab was added after a median of 31 months.

In the upfront treatment group, mRSS dropped from 18 to 7, and FVC increased from 67% to 80% after 12 months, while minimal changes occurred in the sequential group.

Overall, 73.7% of patients in the upfront group experienced improvement in ILD, compared with 25% in the sequential group. Likewise, 80% of upfront combination-treated patients improved in skin and/or lung measures, compared with 33.3% of those in the sequential therapy group.

Safety analyses showed that the higher frequency of adverse events in the combo therapy group was not statistically significant. Only one patient in the combination group had a severe drop in antibody levels, known as hypogammaglobulinemia.

A multivariate analysis — based on the relationship between several variables — confirmed that baseline mRSS was an independent predictor of skin improvement after 12 months, while upfront combination therapy was independently linked to a higher likelihood of ILD easing and skin and/or lung improvement.

Overall, these findings show that the combination of rituximab and mycophenolate mofetil “reduces skin fibrosis [scarring], improves lung function, and is well tolerated in SSc, with no significant safety difference compared to monotherapy,” the researchers wrote.



#### About the Author

**Patricia Inácio, PhD** Patricia holds her PhD in cell biology from the University Nova de Lisboa, Portugal, and has served as an author on several research projects and fellowships, as well as major grant applications for European agencies. She also served as a PhD student research assistant in the Department of Microbiology & Immunology, Columbia University, New York, for which she was awarded a Luso-American Development Foundation (FLAD) fellowship.

## New skin markers help doctors refine dcSSc treatment prognosis

### Analysis: Protein markers and disease duration strongly predict MMF response

Written by [Margarida Maia, PhD](#) | October 14, 2025



In people with [diffuse cutaneous systemic sclerosis](#) (dcSSc), certain skin features, including levels of specific molecules and cells, depend on disease duration, a study finds.

These features, combined with disease duration, allowed researchers to predict patients’ response to mycophenolate mofetil (MMF), an immunosuppressive therapy commonly used for dcSSc.

These findings suggest “skin biopsies may be useful for refining prognosis and guiding patient management decisions,” the researchers wrote.

The study, “[Skin biopsies enhance prediction of clinical trajectory in diffuse cutaneous systemic sclerosis](#),” was published in *Arthritis & Rheumatology*.

### Defining scleroderma and the problem

In [scleroderma](#), the immune system mistakenly attacks skin and connective tissue, causing excessive inflammation and scarring (fibrosis). As scar tissue builds up, the skin thickens and hardens, resulting in [symptoms](#) that can vary widely in severity.

People with the diffuse form of scleroderma (dcSSc) are more likely to develop extensive fibrosis on the arms, legs, and trunk. They are also more likely to have damage to the body’s internal organs, and symptoms may worsen rapidly.

“Estimating individual disease trajectories in dcSSc remains a major unmet need with direct implications for patient care decisions and clinical trial design,” the researchers wrote. “Previous observational studies have shown that disease duration and [initial] modified Rodnan skin score (mRSS) are associated with disease progression.”

The mRSS is a measure of how thick the skin is in 17 areas of the body, with higher scores indicating thicker skin and more severe skin involvement.



# New skin markers help doctors refine dcSSc treatment prognosis:

From: <https://sclerodermanews.com/news/combination-drug-therapy-boosts-skin-lung-health-ssc-patients>

[Continued from previous page...](#)

Here, a team of U.S. researchers investigated whether changes in the skin are associated with disease duration and whether some of these skin features can help predict treatment responses.

They analyzed skin biopsies — small samples of skin examined under a microscope — from 105 adults with dcSSc. All had participated in previous clinical trials of experimental therapies for dcSSc: 79 in the [Phase 3 RESOLVE-1 trial \(NCT03398837\)](#) of lenabasum, 18 in a [Phase 2 study \(NCT01670565\)](#) of belimumab, and eight in a [Phase 2 trial \(NCT01166139\)](#) of nilotinib.

A total of 49 people had early-stage disease (duration of less than 1.5 years) and 56 had late-stage disease (lasting 1.5 years or more).

## Skin biopsies reveal cell markers and scores

The researchers focused on fibroblasts — the cells that produce collagen, the main component of scar tissue — by looking at the levels of two proteins: alpha-SMA and CD34. Alpha-SMA is a marker of activated fibroblasts, called myofibroblast, that are more active in producing collagen. Higher levels of alpha-SMA are linked to worse mRSS. In contrast, CD34 is produced by fibroblasts in healthy skin, but found at reduced levels in scleroderma.

They also counted immune cells, including B-cells and T-cells, in skin samples.

Results showed people with early-stage dcSSc had significantly fewer fibroblasts producing high levels of CD34, significantly higher levels of alpha-SMA in fibroblasts, and significantly more B-cells in the skin compared with the late-stage disease group.

This suggests early dcSSc is more active, with more scar-forming fibroblasts and immune cells.

To measure treatment response, the researchers analyzed mRSS data from 68 people treated with MMF, which “was the most common medication used” in this group, and has had a “prominent role in dcSSc skin treatment in recently published guidelines,” the team wrote.

A decrease of more than 5 points in the mRSS after one year was considered a meaningful improvement.

Statistical analyses showed the strongest predictors of treatment response were sex and disease duration, as well as CD34 and alpha-SMA levels in skin fibroblasts at treatment start. Notably, “the effect of fibroblast

scores on clinical outcomes varied by disease duration at the time of biopsy,” the researchers wrote.

Among people with early-stage disease, high levels of both CD34 and alpha-SMA predicted better chances of clinical improvement. High alpha-SMA levels, in contrast, predicted worse outcomes in the late-stage disease group.

The lowest response rates occurred in early disease patients with low levels of both CD34 and alpha-SMA (14%), and in late-disease patients with high alpha-SMA, regardless of CD34 levels (40%-50%).

While immune cells did not differ by alpha-SMA status in early-stage disease, B-cells were much more frequent in late disease patients with high SMA levels.

“These findings demonstrate that mRSS alone does not capture key differences in [fibroblast-related profile] between early and later stages of SSc that were shown to influence disease trajectory,” the researchers wrote. “Skin fibroblast and immune profiles may offer more precise insights into disease subsets, beyond clinical measures, and may be used to inform patient management decisions.”

“Skin biopsies have a role, along with disease duration, in identifying periods of time during which patients may be more or less likely to improve with MMF,” the team concluded.



### About the Author

**Margarida Maia, PhD** Margarida is a biochemist (University of Porto, Portugal) with a PhD in biomedical sciences (VIB and KU Leuven, Belgium). Her main interest is science communication. She is also passionate about design and the dialogue between art and science.





# 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**

### **Greig Price, Home Visits from Takaka to Blenheim**

Email [info@mobilepod.nz](mailto: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

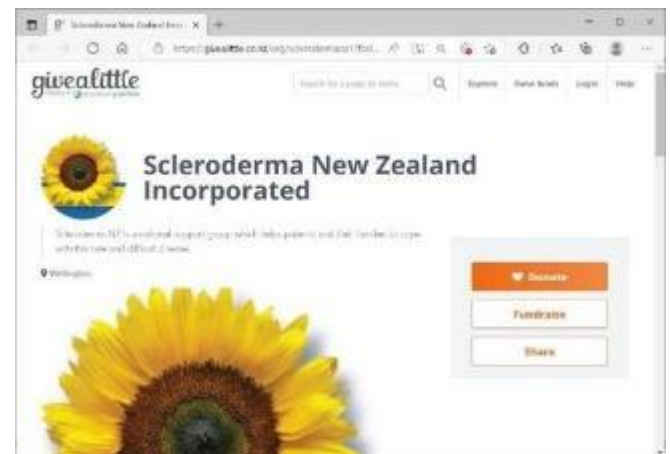


**Scleroderma New Zealand Incorporated**

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**



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

<https://givealittle.co.nz/org/sclerodermanz1?fbclid=IwAR29Znk701JSOwf9n0Ew-063nj0FrySOCpV44mBCpIPhtXV7UFF9KIAAnAzM>

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 **31st of January** at **1.30pm**

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

### Zoom meeting details:

Date: **Saturday January 31<sup>st</sup>, 2026**

Time: **01:30 PM** Auckland, Wellington

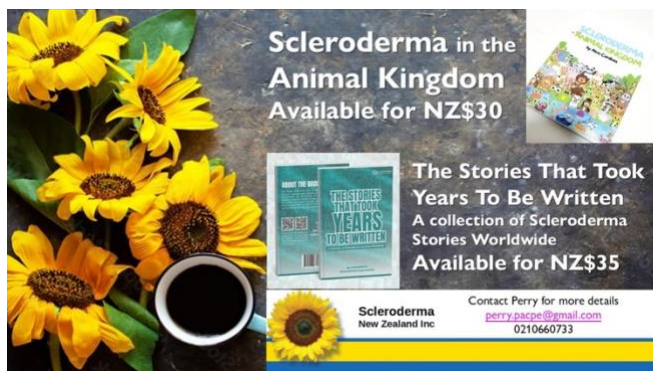
The link for this will be put up on the Facebook page or feel free to contact Perry in the new year on [perry.pacpe@gmail.com](mailto:perry.pacpe@gmail.com)

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. Perry is hoping to source some to have them available at the seminar in Te Awamutu in October.

*Thanks Perry, looking forward to having a read.*



### A Christmas Gift

***A guy bought his wife a beautiful diamond ring for Christmas.***

***After hearing about this extravagant gift, a friend of his said, "I thought she wanted one of those sporty four-wheel-drive vehicles."***

***"She did," he replied. "But where was I going to find a fake Jeep?"***

## How you can find the Auckland and Northland/Auckland Groups

Do come. Brings friends and family. We're a small friendly group. Contact: **Helen Parsons**

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

Mobile: **021 248 3869**

We always have our sunflowers on the table and I will always wear my badge. See photo's below.



## Digital Ulcers

For those of you who are suffering with digital ulcers and feel they hard to deal with. Do view this YouTube video and hear the stories of your fellow battlers.

'As part of her PhD research Tani Ngcozana, Senior Research Nurse at the Royal Free Hospital, interviewed several scleroderma patients dealing with digital ulcers, engaging with healthcare services and treatments'. Scleroderma & Raynaud's UK have put this video on their platform.

<https://www.youtube.com/watch?v=bAM-nZVDpSg&t=6s>

*(Scleroderma & Raynaud's UK (SRUK) is the only UK Charity dedicated to improving the lives of people with Scleroderma and Raynaud's. We are here to improve awareness and understanding of these conditions, to support those affected, fund ground breaking research and ultimately, to find a cure.)*

**Heather Milligan**





# Members News



## Wanaka Scleroderma Group

The Wanaka Group are up and running and meeting regularly. A small group at this stage but it only takes two people to make a Support Group. It is wonderful to see them meeting up and having coffee together and enjoying each other's company.



*Sue, Sandra  
& Julie*



## Hawkes Bay Scleroderma Group

We had a lovely meeting yesterday with seven of our nine members present and two support people. Jane joined us even though she had landed earlier in the day from the States. It was lovely to see her again. Everyone was in fine form and had plans for celebrating Christmas and the New Year.

Di wasn't able to be with us as she is in Sydney well into her transplant journey. She says all is going well and she is expecting the actual transplant to take place over Christmas. Hopefully she will be heading back in late January.

We were able to wish Natania all the best as she leaves for Sydney on 6 January to start her journey through the procedure.

I hope you all have a lovely Christmas and New Year planned.



*Regards,  
Frances*

*Hawkes Bay  
Group*



## Southland Scleroderma Group

Southland Group, Get together Gore 30th November. Thank you so much Jenny for your organising to get us together for lunch.

It was so good to catch up with those from Gore, Invercargill and central Southland

While we may not cure Scleroderma, we will support each other in managing it. Kindly Fleur made us all a lovely coaster to take home. Thank you Fleur they are so lovely. Looking forward to catching up at our next lunch next year.



## 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](mailto:alumie.uow@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)



## Waipa and Waikato Scleroderma Group

Christmas Potluck Lunch

On Friday, 28 November our Waipa Scleroderma Support Group held a Christmas lunch with a few of our members. It was a wonderful lunch hosted by the lovely Janine at her home in Hamilton. Unfortunately not all of our members could make it, as it's a busy time of year, however those who were there enjoyed sharing stories of their journeys and getting to know more about each other, and who they are, beyond the Scleroderma diagnosis. We are all looking forward to catching up for a coffee with the rest of our members in the new year. Please contact Erena Bruce if you wish to join them. [bruceerena@gmail.com](mailto:bruceerena@gmail.com)



# Members News continued.



## Wellington / Kapiti and Wairarapa Scleroderma Group

The Wellington / Kapiti and Wairarapa support group met at Boulcotts Farm café in Lower Hutt to celebrate and have an early christmas lunch. It was a great to see so many of us there, our regular members, including some members we hadn't seen in a while and getting to meet some new members too. There was 23 of us, so it was hard to get around the table to try and catch up with everyone but it was lovely to be able to catch up, share good food and have a good time.

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

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

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

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



## 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)



## Christchurch Scleroderma Group

If you would like to attend the Christchurch Support Group please get in contact with **Nicky Moore:** [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)



## Auckland Scleroderma Group

We meet up regularly and our small group is growing nicely. Feel free to join in with us.

**Helen Parsons**

[helenparsons@artcardsandposters.co.nz](mailto:helenparsons@artcardsandposters.co.nz)  
021 248 3869



## 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







## Scleroderma Zoom Meeting

[Scleroderma Zoom meeting 6th of December](#)

Thank you, Perry, for setting up this meeting. Sadly Perry was dealing with the death of his father-in-law and was unable to attend on the day.

There were 6 of us enjoying a catch up, when we had a lovely surprise in that Di was able to join us. Di is undergoing a stem cell transplant at the Haematology Department, St Vincent's Hospital, Sydney, she had her stem cells collected in mid-November which went so well, it's now just a waiting game, keeping healthy and well, until her transplant what was going to be early December. Di had been cautious in the extreme to keep herself safe from any infections, but alas she caught Covid and her transplant is now scheduled to start 10 days later than planned on the 17th of December, She is suffering terribly from finger ulcers which have arrived with vengeance and are being treating with antibiotics.

Di is covered for her treatment by Health New Zealand's 'High Cost Treatment Pool' This pays for her flights and hospital treatment, plus a small grant for living cost towards her stay in Sydney.

[https://www.tewhatauora.govt.nz/for-health-providers/publicly-funded-health-and-disability-services/high-cost-treatment-pool?fbclid=IwY2xjawOr6rdleHRuA2FlbQIxMQBicmlkETE3VXVINnZ0VjBpaVN3WXdpC3J0YwZhchBfaWQQMjlyMDM5MTc4ODlwMDg5MgABHoSdHz9xHY0ZSgUM9vuHBOPyY5dJC5pDyATVIFnw4VVX2nc9fwqhjIP4p4y\\_aem\\_hZJBAn3xj7-MBQhigbrEyg](https://www.tewhatauora.govt.nz/for-health-providers/publicly-funded-health-and-disability-services/high-cost-treatment-pool?fbclid=IwY2xjawOr6rdleHRuA2FlbQIxMQBicmlkETE3VXVINnZ0VjBpaVN3WXdpC3J0YwZhchBfaWQQMjlyMDM5MTc4ODlwMDg5MgABHoSdHz9xHY0ZSgUM9vuHBOPyY5dJC5pDyATVIFnw4VVX2nc9fwqhjIP4p4y_aem_hZJBAn3xj7-MBQhigbrEyg)

Di and her family need help to cover accommodation, living expenses and flights for her family while she undergoes the extensive 3 month plus period of treatment. Her daughter Greta has set up a Give a Little Page to help with these expenses <https://givealittle.co.nz/cause/help-di-fight-a-rare-auto-immune-disease> Best wishes Di we do hope all goes well. **UPDATE:** Transplant cancelled again, as Di has tested positive for para influenza! So she flew home and will await a new

date some time in January. So disappointing for Di. We are all thinking of you.



### Entering Heaven

**Three men died on Christmas Eve and were met by Saint Peter at the pearly gates.**

**"In honour of this holy season," Saint Peter said, "You must each possess something that symbolizes Christmas to get into heaven."**

**The first man fumbled through his pockets and pulled out a lighter. He flicked it on. "It represents a candle," he said. "You may pass through the pearly gates," Saint Peter said.**

**The second man reached into his pocket and pulled out a set of keys. He shook them and said, "They're bells." Saint Peter said, "You may pass through the pearly gates."**

**The third man started searching desperately through his pockets and finally pulled out a pair of women's glasses.**

**St. Peter looked at the man with a raised eyebrow and asked, "And just what do those symbolize?"**

**The man replied, "They're Carol's."**



# Group Meetings Dates 2026: 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 Marsters:** [cushlam@outlook.com](mailto:cushlam@outlook.com)

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

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

Date and Time:	Venue:
Sat 21 <sup>st</sup> February @ 12:30pm	Chocolate Frog Café Palmer's Garden Centre 69/71 Miramar Avenue, Miramar, Wellington 6022
Sat 18 <sup>th</sup> April @ 12:30pm	The Farm Café & Bar 33 Military Road, Boulcott, Lower Hutt
Sat 18 <sup>th</sup> July @ 12:30pm	The Fisherman's Table TBC Mid-year winter lunch
Sat 19 <sup>th</sup> September @ 12:30pm	Chocolate Frog Café Palmer's Garden Centre 69/71 Miramar Avenue, Miramar, Wellington 6022
Sat 21 <sup>st</sup> 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

**Anne Allan:** [anneallan95@gmail.com](mailto:anneallan95@gmail.com)

## 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](mailto:nicky.moore@xtra.co.nz) Phone: 021 110 6123

## 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](mailto:hkjsunitsch@gmail.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](mailto:janepuckey99@gmail.com)

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

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

## Otago support group:

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

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

## New Plymouth support 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)

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

021 248 3869

Date and Time:	Venue:
Monday 19 <sup>th</sup> January @ 10.00am	Daily Bread, Kings Plant Barn 11 Porana Road, Takapuna, Auckland, 0627

## Northland/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](mailto:HelenParsons@artcardsandposters.co.nz)

021 248 3869

Date and Time:	Venue:
Wednesday 14 <sup>th</sup> January @ 10.30am	Columbus Café, 35 Colin Chester Drive, Silverdale, Auckland 0932 (in Mitre 10)

## Waikato/Waipā support group meets:

If you would like to join in with the Waikato/Waipā Group, please contact: -

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

## Hawkes Bay support group meets:

If you would like to join in with the Hawkes Bay Group, please get in touch with Gail.

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

Date and Time:	Venue:
Third Saturday of the month @ 11:30am	TBC

## Southland support group meets:

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

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

Date and Time	Venue
Sunday 15 <sup>th</sup> February @ 12:00pm	Invercargill venue TBC
Sunday 17 <sup>th</sup> May @ 12:00pm	Croydon Lodge, Gore







# 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](mailto:jennyred@xtra.co.nz)

**Vice President:**

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

**Secretary:**

**Jane Sainsbury**  
[jsainsbury@xtra.co.nz](mailto:jsainsbury@xtra.co.nz)

**Treasurer:**

**Gordon Purdie**  
[gordon.purdie@xtra.co.nz](mailto:gordon.purdie@xtra.co.nz)

**Newsletter:**

**Tina McLean**  
[tinaoaisamclean@outlook.com](mailto:tinaoaisamclean@outlook.com)  
**Jenny Andrews**  
[jennyred@xtra.co.nz](mailto:jennyred@xtra.co.nz)

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

**Bay of Plenty:**

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

**Waikato / Waipa:**

**Erena Bruce, Email:**  
[bruceerena@gmail.com](mailto:bruceerena@gmail.com)

**Hawkes Bay:**

**Frances Tod, Email:**  
[frantod47@gmail.com](mailto:frantod47@gmail.com)

**New Plymouth:**

**Kelsi Tidswell, Email:**  
[kelsitidswell@gmail.com](mailto:kelsitidswell@gmail.com)

**Wellington:**

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

**Christchurch:**

**Nicky Moore, Email:**  
[Nicky.moore@xtra.co.nz](mailto:Nicky.moore@xtra.co.nz)

**Palmerston North:**

**Anne Allan, Email:**  
[anneallan95@gmail.com](mailto:anneallan95@gmail.com)

**Waimate / Oamaru:**

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

**Otago:**

**Gaynor Meddings, Email:**  
[gaymeddings@gmail.com](mailto:gaymeddings@gmail.com)

**Southland:**

**Heather Milligan, Email:**  
[milliganseeds@xtra.co.nz](mailto:milliganseeds@xtra.co.nz)

**NZ Online Zoom Support:**

**Perry Bray, Email:**  
[perry.pacpe@gmail.com](mailto:perry.pacpe@gmail.com)

<http://scleroderma.org.nz/>

