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# Scleroderma

## New Zealand support group

## AUTUMN 2023

Greetings to you all...

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



We hope everyone is well and looking after themselves.

We hope our members, your families and friends were not too effected by Cyclone Gabrielle and for those who have been effected, that you are safe and well.

We also hope everyone has had some time to relax and take a break over the Christmas / New year holiday period.

The months are flying by, I can't believe that we are now into Autumn and it's time to think about getting the flu jab in readiness for the winter colds.

We hear first from Jenny Andrews with the Presidents report. Jenny gives us good advice and keeps us up to date with what's going on in our Scleroderma community around New Zealand.

We have a Memorial page for Carolyn Barkhausen. We will miss you for your kindness, positiveness and friendship.

We have stories to share from our members including an article from Dianne on why it is a good idea to join a Scleroderma support group. A story about Kimberley and her diamond art, Perry Bray-The life and times, and a piece from Richard Jehan on Helminthic therapy. We have some interesting articles from SclerodermaNews.com regarding approved Treatments for Scleroderma.

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

Be safe and take care everyone.

Warmest regards,

**Tina and Jenny**



# Presidents Report:

## Autumn 2023



My thoughts go out to all those people who have been affected by Cyclone Gabrielle. I'm sure I, and everyone else in the country have broken hearts just thinking about what you are all going through. What a huge impact it will be having on so many lives. We all feel so useless being so far away with little we can do to help. Great though, to see so many businesses and individuals around the country who are sending up supplies and taking in monetary gifts to help the many, many, people in trouble. Please support these efforts from your local areas.

My condolences go out to anyone who has lost loved ones in the past couple of months. Please know that you are on our minds and in our hearts as you navigate through such an unbearably sad time.

A big welcome to all our new members. I wish you all the very best in your journey with Scleroderma. Near the end of the newsletter are our support group contacts, and the dates of each groups meetings. It is a great idea to join a group if you are able to, as the support you will receive from others going through a similar journey can be very beneficial.

2023 has started for some with major disruption but hopefully the worst has happened and we can carry on through the year in a much more stable environment.

As always a big thank you to our committee members. Thank you so much to the support group leaders, Facebook coordinators, website administrator. And a very big thank you to all you who read this newsletter. It is nice to know the hours that go into it are appreciated by many. Thank you ☺

New Year's Resolutions!!! Do you make one? I have been making the same ones for about 30 years now..... Lose weight, exercise more, stop eating so much junk food.... Does it work, NO. Normally by January 5<sup>th</sup> I have failed. Well this year I have tweaked it to make it more doable. My main one was:

*To move more.* I have an apple watch which in the fitness ap has 3 circles. One for exercise, one for

movement and one for stand. Each day I try to close all three rings. Even if it means running up and down the hallway at 9pm as I only need 1 more minute of exercise to close it.

*To eat slightly healthier.* Meaning I don't freak out and think I aren't allowed **any** sugar, or yummy treats, so I do the opposite and eat everything in the pantry. This means I have drastically limited my intake of these things. Although I am prone to the odd easter egg now and then. Instead of having biscuits after every meal I now pick up my knitting and keep my hands busy. Which brings me to my next new thing. I am back knitting. I hadn't knitted since I was a teenager and decided it was time. Boy I am loving it. I am making kitty's in overalls at the moment. Below is a photo of my first ever one. Don't look too closely but she is pretty cute. It is so nice to have found that thing I am enjoying doing again. I do love to garden, but limit myself quite a bit. So to come in and sit down and knit is the break I need from gardening.

Look for that thing that you have a passion for that you like to do that keeps you active and makes you smile. Anything that makes you smile and lifts your mood, has got to be good for you.

Take care everyone.

Jenny ☺





# Memorial for Carolyn Barkhausen

*“To the world you are one person,  
to one person you are the world”*

*Quote from Carolyn's 'Fijian Family' at the service*

On the 21<sup>st</sup> February 2023 we lost a beautiful soul. Carolyn Barkhausen was one of the good ones. She was such a generous, kind, fun and hardworking person. Carolyn was a big supporter of Scleroderma New Zealand and through her position at BNS Design and Print she worked hard on our marketing. She had awesome ideas for our fundraising and it was such a joy to work with her and I always enjoyed a chat along the way. She and the Christchurch group took the sunflower to a whole new level with their lovely shirts, head bands etc. Our condolences go out to Dathan her son, Carl her partner and her family. They sent her off with a beautiful service that Carolyn had done most of the organising for herself. I doubt there was a dry eye in the hall and all over with it being live streamed. Carolyn you will be very sadly missed by all those whose lives you have touched.

It was a pleasure having Carolyn as one of the initial committee members for Scleroderma NZ in 2015 when we became registered as a Incorporated Society and Registered Charity. Carolyn stayed on the committee until 2019 and then took over the role as the Christchurch group leader in 2019 until recently in 2022 when she became ill.

During those years Carolyn, liked to get involved with the marketing of our Society and very kindly donated Bumper stickers which were beautiful and stood out. Carolyn also developed Scleroderma NZ cards, book marks, shopping lists, pens and conference folders. Carolyn donated a lot of these very nice articles to our society. We kept asking for an invoice but they never came, it was very kind of her.

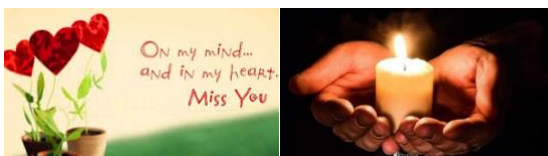
Carolyn also helped out with the organising of our Scleroderma NZ Understanding and Managing Scleroderma Booklets, she managed to get us a good competitive price for the printing.

All the times that I had communication with Carolyn, she was always pleasant, kind and eager to help, nothing was ever a problem. She worked hard on the day of the Christchurch Seminar alongside Kim Tocker. They made the seminar a great success.

We will miss Carolyn's positive attitude and kindness, she has worked hard, being a beautiful kind leader of the CHCH group, always vibrant with her sunflowers she will be greatly missed. Her wish is that the CHCH group will stay together and carry on supporting each other.

Scleroderma New Zealand Member

**Carolyn Barkhausen**



# Members Stories:

## Kimberley Small: Diamond Art

Crafters all around the world have fallen in love with Diamond Art Painting. This activity is easy to learn and incredibly rewarding and one of our Southland group, Kimberley Small has become one of these crafters. She gave Graham and I a master class on how she puts it all together with such tiny beads and precise placing of them on the canvas.

It is a delight to visit Kimberley in her home with her beautifully executed diamond art painting. From her specially commission canvass of The All Blacks logo and her favourite Super Rugby Pacific teams logos, to a colourful tiger in the hallway and a black cat and flowers in her bedroom, plus others.

Kimberley's hands are true Scleroderma hands with twists and ulcers, but this has not stopped her in the pursuit of her art.

*By Heather Milligan*





# Members Stories:

## The life and times of Perry...

Are you in the game or are you watching from the side-lines...

### Health Update #12 – Time out in Rivendell

March 6, 2023 by Perry



Last week, I had the opportunity to take some time out on my respite day to enjoy the sights and sounds of Rivendell (Kaitoke Regional Park).

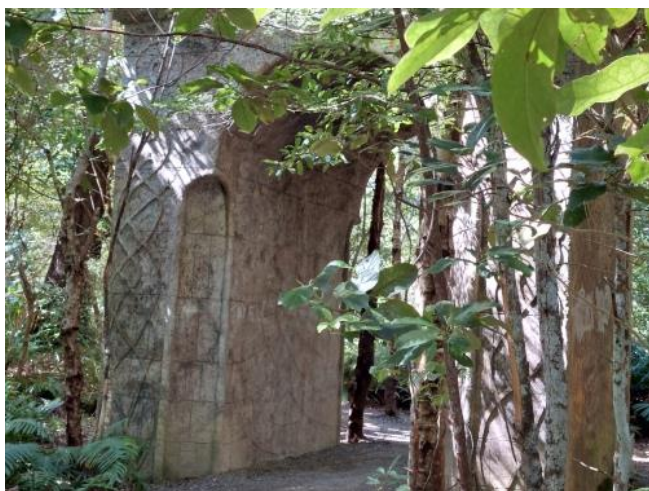
As the sound of the babbling river below flowed by and the cicadas echoed loudly in my ears, I paused to contemplate the past few months of my health journey and where things are at for me personally.

Meanwhile, the occasional tourist took photo opportunities under the stunning archway and amongst the beautiful backdrop of the beech forest, which of course was the film set for the Lord of the Rings.

(See image below)

To say that it has been an easy ride would be a gross exaggeration, as we've had quite an eventful couple of months. Firstly, due to Covid catching up with us (which I wrote about [here](#)) as well as various activities and outings that Annette & I have been a part of.

Many of which have been encouraging and enjoyable, some (only a few thankfully) – not so much! However, even the enjoyable ones have highlighted the overall deterioration of my physical capabilities to a degree, especially when it comes to going on walks.



One recent example is a recent trip to Mangamaire to see New Zealand's Premium Sunflower Field near Pahiatua. It appealed to me obviously because of the connection to the sunflower being the international symbol of *Scleroderma*.

Also because as a family unit (just the three of us) we hadn't really done anything for quite some time as our social calendars hadn't exactly lined up

So we took a drive up to Levin stopping off for a late morning tea at the Salt and Pepper cafe, before heading over the hill to the other side of the Tararua Ranges.



Once at Mangamaire Sunflower Field we spent a good hour or so, along with heaps of other people exploring the field and taking heaps of photos of the surroundings.

Before resting up for a while enjoying the feel of the heat of the sun on our backs and eating our packed lunches.

Afterwards we stopped off to visit some friends on the way back down to Wellington which was just fabulous, and had some real fruit ice-cream

By the time I got home I was spent for the rest of the evening and I was feeling a tad lethargic for the whole of the next day too.

People with this rare autoimmune disease need to be careful that they don't overdo it and even small things, like taking a stroll around a field can take a huge toll on the body.

Below is a beautiful picture of the three of us enjoying the stunning day that we experienced at the field. The blooming season is over for now – but we will definitely put it on our must do list for next season.



Another example of overdoing it was our recent trip to Taupo to celebrate 30 years of marriage – Annette & I went for a couple of walks while we were there, one around part of the lake on the first night, followed by a lovely late morning stroll the following day around the Craters of the Moon.



# Members Stories:

Continued...

## The life and times of Perry...

Are you in the game or are you watching from the side-lines...

For the most part, both of these walks were on the flat – but by the second day, Annette could definitely tell that I wasn't able to do anymore walking, especially after our visit to Huka Falls – it was as if every part of me ached. She didn't even allow me to do any of the driving on our trip home as I'd simply overdone it.



Now, for someone who has been reasonably active most of my life, this can be a bit hard to fathom. It is not like either of these walks were overly long or anything.

But they obviously had an impact on me to some degree or another, as it took a few days to get over the weekend

This is one of the major drawbacks of having Scleroderma and Interstitial Lung Disease as the body just can't do what it used to do.

The mind may be willing and to a degree the body may agree with you, at least for a little while – but then the body simply says you're done, with very little warning.

Talk about frustrating – sufferers of this invisible disability are encouraged to keep their exercise up, but at times even going for an extended walk can be a drain on one's energy levels, that lasts for a few days.

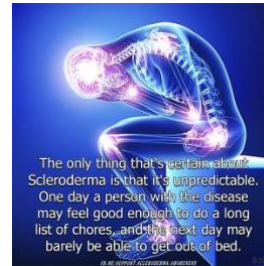
Below is a picture of the Craters of the Moon – we certainly live in one of the most beautiful countries in the world, if not arguably the most beautiful. I guess that's why Aotearoa used to have the colloquial name 'God's Zone'.



On a positive side our respiratory specialist is happy with the progress that I'm making after the last lot of Rituximab infusions. It would appear that we had achieved some kind of equilibrium and he reckons that the four monthly time frame between infusions should be ideal going forward.

Thankfully, I have almost finished being weaned off of Prednisone and all going well by the end of March I should be off it completely. However, it has been interesting how the body responds to even a 1mg drop.

I've experienced the odd mishap and at times feel quite lethargic for about the first week. It's as if the body is trying to encourage me to stay on it, but I've persevered and now we are almost done.



We have had to continually assess where I'm at with regard to my ability to do some other stuff throughout, as I'm finding some menial things are becoming increasingly difficult.

It's a bit of a worry when I have to hand over my drink bottle to someone else to take the twist top off of it, or ask my wife or daughter to take the tab off of the milk.

In the next little while we'll be looking at what aides I may need to acquire to help prolong my energy levels as much as we can.

This will include the likes of getting a mobility scooter in due course for longer outings and when I need to go up and down hills (which in the Wellington region there are plenty). This will enable me to take the dog out for longer walks in our area than a few circuits around the cul-de-sac.



There is a part of me that says that I'm not ready for that and live in a sense of denial that I need stuff to help my situation.

But the past few months have shown that even though I'm increasingly looking better on the outside – there is still a war going on in my insides that will never end and some days it is a struggle just to get out of bed.

But life goes on and I'll keep on fighting this and raising awareness, making sure that I'm able to contribute to the mission and ministry that God has called me to. Afterall they don't call us Scleroderma Warriors for nothing eh!

Blessings 'til next time

Perry





# Members Stories:

## Richard Jehan: My journey with Helminthic Therapy

Five years ago I was an extremely fit and healthy 57 year old. I was doing hill running and gym work daily. In early 2018 I noticed that my hands were stiff and swollen when I woke up every day. I went to the doctor and then to a rheumatologist and after a few blood tests was diagnosed with Mixed connective tissues disease, a crossover of rheumatoid arthritis and scleroderma. As the disease progressed my physical ability was very much affected and I had a lot of pain. We were living in a 2 story townhouse but had to sell this due to the fact that I was finding the stairs difficult, pain in joints and breathing stress.

Just over a 1 year ago I started on Helminthic therapy after seeing Jane Puckey and Lynn Jolley on the Sunday show. I have reinfected myself every 3 months. After about 9 months I noticed slight differences in my symptoms, less pain around my body and I seemed to be able to walk slightly faster. Now 14 months on from my 1<sup>st</sup> Helminthic treatment my health has greatly improved. I am now going for small runs, I can do a hill climb walk, and have been using Gym equipment at home. I have a lot less pain all over, my joints ache less and my recovery times after exercising are improving. I thought I'd share this news with you and the team at Scleroderma society as we really believe helminthic treatment can make a difference. Thanks for the work you do. Richard Jehan



*Richard with his motorbike*



# Why it's a good idea to join a Scleroderma Support Group

## Reference The Scleroderma Support Group Leader Education (SSLED) Program



After being involved with running support groups over the years you see how your group develops for the best, we make good friends and people come and go, as their situations change and their level of need for support. For me it has been a

positive experience and even better now that our Wellington group has changed its leadership protocol and we now have three Co-leaders. Tina Mclean, Cushla Marsters and myself. It is a good idea to share the load, and having more people will give different perspectives on what the people of the group might need. Like coming up with new ideas and be there to fill in for one another, like now as I'm unable to attend in person, all of which I appreciated the effort that Tina and Cushla are making to keep the group meeting in person.

The next best thing is running support meetings via zoom, which has become a large part of my life lately. I encourage everyone to join in if they can. It's a lot of fun, you are relaxed at home, no need to stress about what to wear, or we can have a theme like, hat day, which we all did one time a couple of years ago when we had the first lock down for covid. We are now learning through experience how to run these meetings well and those of you who have been through the SPIN leadership programme would have picked up a lot of helpful information.

The information below is from the module on Starting a Support Group, from *The Scleroderma Support Group Leader Education (SSLED) Program* I thought it was very good and summed up, understanding support groups and why it is a good idea to be part of one.

If anyone has the opportunity to attend the SSLED Leadership program, it is highly worthwhile.

**The goal of a support group** is to provide a safe environment where a group of people can come together to share knowledge and life experiences about a common challenge they're facing; in this case, the challenge of living with scleroderma. The unique relationships formed in support groups can be a positive influence in the lives of members, in both personal and practical ways.

### Peer support:

- Being able to openly talk about fears and feelings related to living with scleroderma
- Having a safe place to express emotions
- Knowing that you're not alone
- Spending time and developing relationships with people who understand what it's like to live with scleroderma
- Receiving and providing comfort and reassurance from others in the group
- Enjoying fun social activities

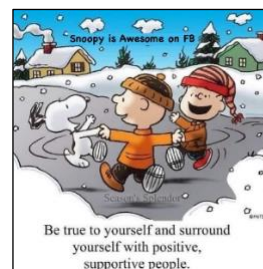
### Learning about scleroderma and healthcare options:

- Exchanging experiences and knowledge on common scleroderma tests and treatments, including treatment centres and scleroderma organizations
- Learning about current scleroderma research
- Learning how to be more involved in planning treatment with a health care provider
- Learning alternative strategies to complement medical treatment (e.g. meditation, yoga)

### Learning to live with scleroderma:

- Learning how other group members deal with issues related to scleroderma, such as, handling emotions and feelings
- Learning how to talk about scleroderma with others (e.g., family, friends, employers, work colleagues)
- How to handle financial issues associated with living with scleroderma (e.g., how to fill out insurance and health forms)
- Learning ways to cope with unwanted attention from having scleroderma

Dianne Purdie





# How scleroderma transformed me from a caterpillar into a butterfly:

From Scleroderma News website

I often see a butterfly symbol associated with various autoimmune diseases, including [scleroderma](#). While some conditions, such as [lupus](#), can cause a butterfly-shaped [malar rash](#), my research hasn't yielded any other explanations for this connection.

However, I do have my own theory.

Tucked safely away from the world, the butterfly's life starts inside an egg as a caterpillar, unaware of the impending dangers or worries to come. This phase is like my life pre-scleroderma — a time when I believed all illnesses had cures. Becoming a caterpillar

My diagnosis awoke me from my naive and simple understanding of the world. Before scleroderma, I thought I could overcome anything if I fought hard enough. If I saw the right doctors, ate the right foods, and lived a healthy lifestyle, I could win any battle and be healed.

For the first few years after my [scleroderma diagnosis](#), I waged war, aiming to become stronger than my disease. But the more I fought, the more I became a version of myself that I hated.

Because I was so focused on scleroderma, I put the spotlight on everything health-related. This included all the physical changes, which made me feel ugly and less than my potential.

My fingers tightened into awkward, bony sticks. I developed tiny, red blemishes all over my face called [telangiectasias](#), and I saw [disfiguring changes](#) happen to my mouth. I felt like I'd morphed into something grotesque and unwanted. I now think of this as my caterpillar stage.

During this phase of my life, I was angry and devastated. I felt as though my life would never be as beautiful as it was before I was exposed to the world of rare diseases. I battled myself as much as I battled scleroderma.

I was so appalled by my physical changes, disabilities, and inability to find the magic cure I so desperately wished for. And it was destroying me.

Inside my scleroderma cocoon

Physically and mentally broken, I started living inside a cocoon, where I was fully consumed by my disease. Scleroderma controlled every facet of my world and influenced all of my decisions. It was the lowest point of my life. I'd lost hold of who I was.

Instead, I worried about everything. How will my skin react if I get too much sun at my daughter's soccer game? What if my stomach doesn't tolerate that delicious dessert? Gee, my baby looks beautiful in her homecoming dress, but will I get to see her in her wedding dress someday?

I'd let my illness steal my life — even as I was still living it.

Emerging as a butterfly

But after eight years of living with scleroderma, something beautiful happened. I emerged from my cocoon and became the best version of myself — the butterfly I was always meant to be.

While I'm not cured and will never accept scleroderma as a blessing, I [found a sense of peace](#) and strength I'd never experienced before. After [years of hard work](#), I became strong mentally.

Now in control of my thoughts and focused on the present moments, I finally feel like [I'm living my life](#), and not the one scleroderma dictates. My illness rarely pops into my mind, and I no longer constantly think of myself as a sick person. I'm finally free!

Have my ailments disappeared? Absolutely not. In fact, I recently received devastating news that my lung function has worsened dramatically. If I'd heard this news two years ago, I would've researched options for days, cried for weeks, and worried for months.

But this time, I spent a few days refocusing. I cried a little and even got mad, but I didn't change my plans. As a butterfly, I actively choose to gracefully carry on with my life, fluttering away without worrying about what's to come.

The butterfly is a powerful symbol of growth and transformation. For me, it represents overcoming scleroderma with a [strong mindset](#). Since I can't control the physical changes, I work on [improving my perspective](#). I'm loving the view from up here, and I'd welcome more company!

Source: *Scleroderma news*: by [Lisa Weber](#) | March 3rd, 2023

## About the Author



Lisa Weber Lisa is the married mother of two beautiful girls. She holds a master's degree and currently teaches third grade. She is extremely passionate about overcoming challenges while living with a rare autoimmune disease called scleroderma. This systemic disease attacks her entire body inside and out. Still, she manages to continue doing the things she loves: cooking (poorly), building furniture, jogging (slowly), and making clothes. She will tell you everything she does is perfectly imperfect! One of her life goals is to help raise awareness for rare diseases and to continue her personal fight to survive and thrive until a cure is found.



# Approved Treatments for Scleroderma

From Scleroderma News website



## Overview

There is currently no cure for scleroderma, but there are treatments to manage its symptoms and therapies for conditions associated with scleroderma. Available therapies include topical treatments to manage skin symptoms, pain relief medications, anti-inflammatory agents, antifibrotics, and immunosuppressants.

## Actemra

Actemra (tocilizumab) is approved to treat systemic sclerosis-associated interstitial lung disease. It works by directly blocking the action of interleukin-6. Interleukins are proteins that white blood cells produce to regulate the immune response.

## Angiotensin 2 Receptor Antagonists

Angiotensin 2 receptor antagonists or blockers are a group of medications that help dilate blood vessels to lower blood pressure. They are used for treating high blood pressure, heart failure, and Raynaud's phenomenon, a common symptom of scleroderma.

## ACE Inhibitors

Angiotensin 2 receptor antagonists (ACE) inhibitors are a type of medicine that prevents the production of a hormone, called angiotensin 2, by blocking the action of the angiotensin-converting enzyme. They are used for treating high blood pressure, heart failure, and Raynaud's phenomenon.

## Anti-fibrotic Medications

Anti-fibrotic medications work to reduce the formation and build-up of scar tissue in scleroderma patients. While these medications may slow or partially reverse organ damage caused by fibrosis, they cannot halt fibrosis or scar tissue build-up.

## Anti-malarial Medications

Anti-malarial medications may be helpful in managing the symptoms of both systemic and localized scleroderma. These therapies work to modulate the immune system. First used to treat systemic lupus erythematosus, they are known to be effective in treating connective tissue diseases.

## Calcium Channel Blockers

One of the first-line medications prescribed to treat scleroderma and Raynaud's phenomenon are calcium channel blockers, which are a type of vasodilator therapy. They act to relax the walls of the blood vessels, opening them and improving blood flow. They also help relax the muscles of the heart.

- Nifedipine

## Corticosteroids

Corticosteroids are immune-suppressing medications that reduce the inflammation present in active scleroderma lesions, and slow the progression of scar tissue formation by preventing the immune system from mistaking healthy tissue as foreign and attacking it.

- Prednisone

## COX-2 Inhibitors

COX-2 inhibitors are a type of anti-inflammatory agent that may be prescribed to treat disease symptoms, such as the joint and tendon pain, in scleroderma patients. They are a subset of non-steroidal anti-inflammatory drugs that act specifically on the enzyme cyclooxygenase-2, or COX-2.

- Celebrex

## Immunosuppressants

Immunosuppressants are a type of medication that help reduce the symptoms of scleroderma. They act to reduce or prevent the immune response from occurring. Immunosuppressants are not specifically approved to treat scleroderma, but they are often prescribed off-label.

- Cyclosporine
- Imuran
- Methotrexate

## IP Receptor Agonists

Scleroderma can damage the lungs in such a way that a patient also may develop pulmonary arterial hypertension (PAH) as a related condition. IP receptor agonists can help to manage PAH symptoms by widening the arteries and reducing the resistance to blood flow.

## Narcotic Analgesics

In cases where over-the-counter pain medications such as Tylenol (acetaminophen) are insufficient, narcotic analgesics may be prescribed to alleviate severe pain in scleroderma patients. These therapies act to decrease pain signalling in the nervous system.

## Treatments for Scleroderma-related Conditions

In more severe cases of scleroderma, scarring can damage organs in ways that lead to the patient developing one or more related conditions. A variety of treatments are available to treat these coexisting conditions.

Source: <https://sclerodermanews.com/approved-treatments-for-scleroderma/>





# Non-Drug Treatments for Scleroderma

From Scleroderma News website



[Scleroderma](#) is a rare disease characterized by the hardening and tightening of the skin and [connective tissues](#). In some people, the condition affects only the skin; in others it may involve other tissues and organs such as the blood vessels, muscles, lungs, kidneys, and digestive tract. In such cases, it can lead to [symptoms](#) that make it difficult for patients to stay active.

Physical therapy can help [alleviate some of the symptoms of scleroderma](#), reduce pain, and improve mobility.

## Physical therapy for Scleroderma

Physical therapy conducted under the supervision of a physiotherapist can help stretch the skin, muscles, and joints affected by scleroderma using exercise. This can improve posture, [increase the range of movements](#) that a patient can perform, and prevent loss of muscle mass and strength. It also can reduce pain by promoting the release of [endorphins](#), which are natural proteins that reduce the perception of pain, improve heart and lung function, and help maintain bone strength.

Physical therapy also can be used to help reduce other symptoms of scleroderma, including gastrointestinal, lymph node, and nervous system problems.

Case studies on the effects of physical therapy in a [35-year-old patient](#) and a [71-year-old patient](#) showed that therapy led to improvements in pain, movement ability, and muscle strength in the body and hands.

## Types of physical therapy for Scleroderma

Scleroderma can affect the entire body, so physiotherapy regimens for the disease usually involve [multiple areas of the body](#).

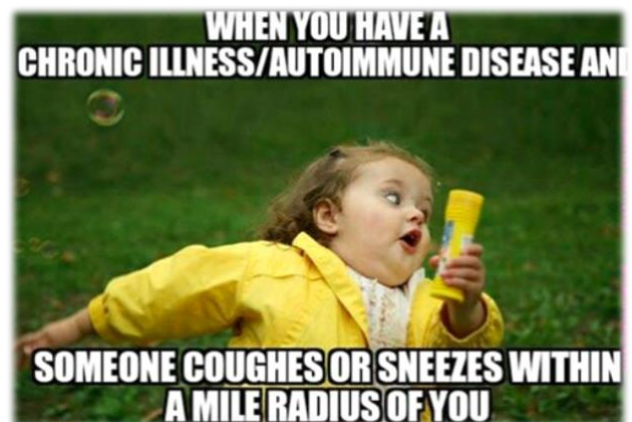
A physiotherapist may recommend stretches of the shoulders, elbows, wrists, neck, fingers, and back. The face and mouth may be included, as needed. Stretching exercises usually are done three times a day and held for 10 seconds each for the best effect.

Mild exercises that can help patients with scleroderma include walking, cycling, and ellipticals. These raise the heart rate, strengthen the heart muscle, and increase endurance, while also encouraging mobility of the limbs and body, as well as helping with digestion.

Other physical therapies may include reducing nerve pain through [neural mobilization](#) exercises and [draining enlarged lymph nodes](#) through the adoption of special postures combined with soft tissue massages.

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

Source: <https://sclerodermanews.com/physical-therapy-for-scleroderma/>



# Members News



## Bay of Plenty Scleroderma Group

We have had 2 catch-ups since the new year. The first one was on 21 January at Alimento where the photo was taken. We met again on 25 February at Chrome cafe in Katikati, hoping that more of us could make it. The cafe was quiet (no music), has comfy couches that we can sit on and there is a fireplace as well so maybe it would be toasty in Winter. Everyone has their ups and downs but overall, we feel positive in coping with it. We caught each other up with our life as friends, gave out advice and shared any exciting changes. We are planning another one in May so that more could make it - no concrete date yet.



## Hawkes Bay Scleroderma Group

Well it's been a terrible and very traumatic time in Napier/Hastings. Francis and I are cut off from each other so have used the phone often. It's not the same though and miss our meetings. They will resume asap. On a positive side had a really good visit 2 my rheumy 2day. It was overdue 4 months however she is wonderful and answered many questions I had. What a relief -my scleroderma has progressed rapidly since I got bursitis 12 months ago and anxiety is a problem. Sleeping not good as the pain is unbearable. She put me on pregabalin so cross fingers. Hope everyone is well and staying positive. Cheers Gail 🌻🌻🌻



## New Plymouth Scleroderma Group

The New Plymouth group have had a wee spell from meeting but will be up and running again soon. Thank you to Elle for organising these, and now the baton has been passed on to Kelsi. We look forward to seeing some photos of your next catch up.



## Waikato Scleroderma Group

The Waikato Group met up this week for a catch up, organised by our wonderful Linda. It was a small group meeting but it was lovely to be able to chat with their friends.



## Christchurch Scleroderma Group

It's Christchurch group's first meeting of the year coming up on the 25<sup>th</sup> March. It has been a rather sad time for this group as they have lost an amazing member, Carolyn. Our thoughts go out to them all.





# Members News continued...



## Wellington Group

## Scleroderma

Thank you to Dianne for organising our Wellington group's lunch. We met in late February at the Chocolate Fish café in Shelly Bay. It turned out to be a lovely sunny day and we all had wonderful chat while enjoying a lovely lunch.



*Wellington Group enjoying a sunny day*

## *Southland Group enjoying their catch up*



## Southland Scleroderma Group

Thank you again to Jenny for organising our Southland Group's lunch at Gore. It was lovely to meet everyone again.

Great going to one of our group who decided to take the scenic route to get to us from Invercargill, left in plenty of time, but was dogged with detours, road closures, yes, he arrived fine albeit a bit late, he was going to take the direct road home.

There was lots of talking, mingling. We all appreciated the candour of others dealing with Scleroderma, two of the group having a deep discussion of coping with their fingertips being removed, it does help to make dealing with Scleroderma a bit more bearable when discussing with others who are managing the same problems. ....

An aside the meals were delicious, especially the highly prized battered Blue Cod which was eagerly consumed.



# Members Update

## Wellington & Regional Zoom meeting on:

27th May 2023 at 1:30pm



It was lovely to see the ten of us at the last zoom meeting. The next zoom meeting will be on **27th May 2023**, but if anyone would like a catch up before then just let me know and I can organise one.

Dianne Purdie

## Wellington Scleroderma Support Group Dates:

Wellington Scleroderma Support Group Get Together  
January 2023 – July 2023



Date & Time	Venue	Address
Saturday 25th February 2023 12.00pm	Chocolate Fish Cafe	100 Shelly Bay Road, Miramar
Saturday 22nd April 2023 12.30pm	The Farm Cafe & Bar - Boulcott's Farm Heritage Golf Club	33 Military Road, Boulcott, Lower Hutt
Saturday 27 May 2023 1.30pm	Zoom meeting Sharing experiences with managing Scleroderma <b>People from other regions most welcome.</b>	Zoom Link <a href="https://otago.zoom.us/j/92333389235?pwd=YnhUZk56ekc5c3BUUnM3WINnempXUT09">https://otago.zoom.us/j/92333389235?pwd=YnhUZk56ekc5c3BUUnM3WINnempXUT09</a>
Saturday 22nd July 2023 12.30pm	Chocolate Fish Cafe	100 Shelly Bay Road, Miramar

## Information wanted:

Has anyone been using the drug Pirfenidone or other name of (Esbriet)

We have had some members asking about it and Rare Disorders NZ were wondering if anyone had received it through the NPPA program. If you have anything you would like to share, please contact me on : [jennyred@xtra.co.nz](mailto:jennyred@xtra.co.nz) Thank you

## Congratulations to Annette & Perry:

Congratulations to Annette and Perry for becoming grandparents to Jack Perry Woods, born on Wednesday afternoon, 8<sup>th</sup> March 2023 in Invercargill, 7 pounds, 2 ounces (3.23kg).



### Special Poem for Senior Citizens (and all of us)

A row of bottles on my shelf  
Caused me to analyse myself.  
One yellow pill I have to pop  
Goes to me heart so it won't stop.  
A little white one that I take  
Goes to my hands so they won't shake.  
The blue ones that I use a lot  
Tell me I'm happy when I'm not.  
The purple pill goes to my brain  
And tells me that I have no pain.  
The capsules tell me not to wheeze  
Or cough or choke or even sneeze.  
The red ones, smallest of them all  
Go to my blood so I won't fall.  
The orange ones, very big and bright  
Prevent my leg cramps in the night.  
Such an array of brilliant pills  
Helping to cure all kinds of ills.  
But what I'd really like to know.....  
Is what tells each one where to go!

Supplied by: Betty Wilson





# Give a little: Scleroderma NZ Inc.

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

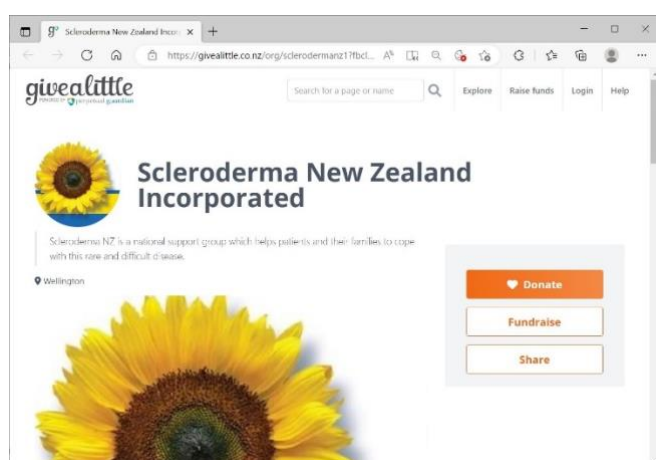


## Scleroderma New Zealand Incorporated

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

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

[Scleroderma New Zealand Incorporated - Givealittle](#)



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

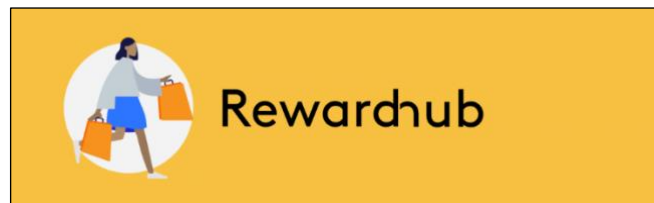
<https://givealittle.co.nz/org/sclerodermanz1?fbclid=IwAR29Znk701JSOwf9n0Ew-O63nj0FrySOCpV44mBCpIPhtXV7Uff9KIAnAzM>

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

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

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

# Scleroderma NZ Inc. Shopping



## REWARDHUB

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

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

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

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

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



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

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

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



# Group Meetings:

## Wellington support group meets:

Saturday 22<sup>nd</sup> April, 2023, 12.30pm

**Venue:** The Farm Café & Bar, Boulcott's Farm Heritage Gold Club, 33 Military Road, Boulcott, Lower Hutt

Saturday 27<sup>th</sup> May, 2023, 1.30pm

**Zoom Meeting:** Sharing Experiences with managing Scleroderma. People from other regions most welcome. See link below:

<https://otago.zoom.us/j/92333389235?pwd=YnhUZk56ekc5c3BUUnM3WlNnempXUT09>

Saturday 22<sup>nd</sup> July, 2023, 12.30pm

**Venue:** Chocolate Fish Café  
100 Shelly Bay Road, Miramar

For any enquiries please contact Dianne:  
[diannepurdie@xtra.co.nz](mailto:diannepurdie@xtra.co.nz)

## Christchurch support group meets:

**Venue:** The Great Escape Café, Burwood Hospital, 300 Burwood Road, Burwood, Christchurch

Saturday March 25<sup>th</sup>, 2023, 2.00pm to 4.00pm

Saturday May 27<sup>th</sup>, 2023, 2:00pm to 4:00pm

Mid-Year lunch Saturday 22<sup>nd</sup> July 2023, 12pm, **Venue tba**

Saturday September 23<sup>rd</sup>, 2023, 2:00pm to 4:00pm

Saturday November 25<sup>th</sup>, 2023, 2:00pm to 4:00pm

We welcome any new members to come along too.  
Please contact Dianne Purdie if you would like to join in;  
[diannepurdie@xtra.co.nz](mailto:diannepurdie@xtra.co.nz), 04 479 5548

## Southland support group meets:

Sunday April 30<sup>th</sup>, 12pm. **The Cabbage Tree, Invercargill**

Sunday June 25<sup>th</sup>, 12pm. **Croydon Lodge, Gore**

Sunday September 10<sup>th</sup>, 12pm. **venue TBA**

Sunday November 19<sup>th</sup>, 12pm. **venue TBA**

Please contact Heather if you wish to join us.  
[milliganseeds@xtra.co.nz](mailto:milliganseeds@xtra.co.nz)

## Waikato support group meets:

**Venue:** Robert Harris Café, Chartwell Hamilton.

We will be meeting again on 14<sup>th</sup> March, at 10am. If you would like to join in with the Waikato Group, please contact Linda Bell. [linda.bell@hotmail.co.nz](mailto:linda.bell@hotmail.co.nz)

Phone: 07 8535434

Mobile: 027 548 1214

## Waipa support group:

All welcome, if you would like to join in with the Waipa Group please contact

Erena Bruce, Mobile: 021 186 9680.

## Palmerston North support group:

See Wellington Support group.

## New Plymouth support group meets:

The New Plymouth group will be meeting again soon. So if you would like to attend the New Plymouth Support Group please get in contact with

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

## Blenheim/Nelson support group:

Jen Soane is organising the Blenheim/Nelson support group so if you would like to attend please get in touch with Jen.

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

## Hawkes Bay support group:

The Hawkes Bay group have had to have a pause on their meeting due to the weather issues. They will be meeting again as soon as they are able. To join in with the Hawkes Bay Support group please get in touch with Gail Neilson [gail\\_neilson@hotmail.com](mailto:gail_neilson@hotmail.com)

## Bay of Plenty support group meets:

We will be meeting again in May. Date and venue to be advised. Please contact one of us for information.

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

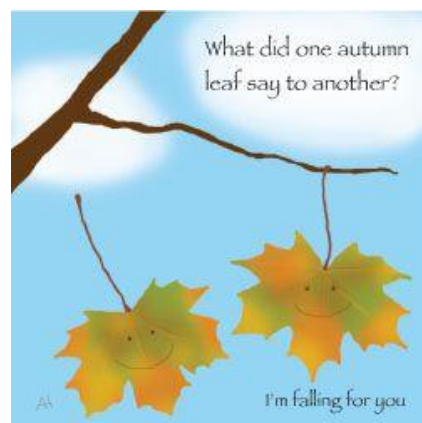
Mary: [marybestrd3@gmail.com](mailto:marybestrd3@gmail.com)

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

## Otago support group:

Please contact Vanessa if you wish to join us.

[Nessie332@gmail.com](mailto:Nessie332@gmail.com)







# Welcome to Scleroderma New Zealand Inc

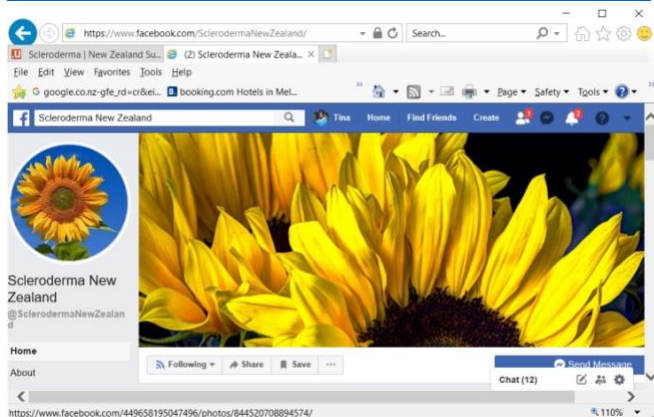
To all our new members, who have recently joined us – Welcome....

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.

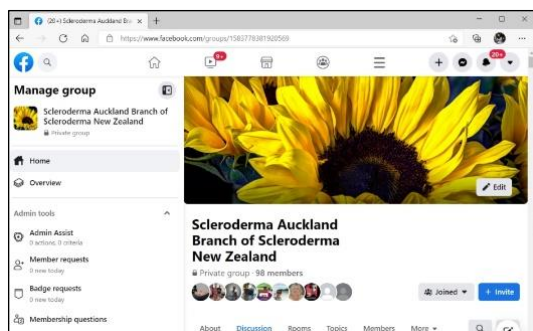
Link to our Website address below: -  
<http://scleroderma.org.nz/>



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

President:	Jenny Andrews <a href="mailto:jennyred@xtra.co.nz">jennyred@xtra.co.nz</a>
Vice President:	Tina McLean <a href="mailto:altinamclean@xtra.co.nz">altinamclean@xtra.co.nz</a>
Secretary:	Jane Sainsbury <a href="mailto:jsainsbury@xtra.co.nz">jsainsbury@xtra.co.nz</a>
Treasurer:	Gordon Purdie <a href="mailto:gordon.purdie@xtra.co.nz">gordon.purdie@xtra.co.nz</a>
Newsletter:	Tina McLean <a href="mailto:altinamclean@xtra.co.nz">altinamclean@xtra.co.nz</a> Jenny Andrews <a href="mailto:jennyred@xtra.co.nz">jennyred@xtra.co.nz</a>

## Contacts:

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

Bay of Plenty:	Alumie Nguyen, Email: <a href="mailto:alumie.uow@gmail.com">alumie.uow@gmail.com</a>
Waikato:	Linda Bell, Email: <a href="mailto:linda.bell@hotmail.co.nz">linda.bell@hotmail.co.nz</a>
Hawkes Bay:	Gail Neilson, Email: <a href="mailto:gail_neilson@hotmail.com">gail_neilson@hotmail.com</a>
Waipa:	Erena Bruce, Email: <a href="mailto:glenanderena@xtra.co.nz">glenanderena@xtra.co.nz</a>
New Plymouth:	Kelsi Tidswell, Email: <a href="mailto:kelsitidswell@gmail.com">kelsitidswell@gmail.com</a>
Wellington:	Dianne Purdie, Email: <a href="mailto:diannepurdie@xtra.co.nz">diannepurdie@xtra.co.nz</a>
Blenheim/Nelson:	Jen Soane, Email: <a href="mailto:jennasoane@gmail.com">jennasoane@gmail.com</a>
Christchurch:	Dianne Purdie, Email: <a href="mailto:diannepurdie@xtra.co.nz">diannepurdie@xtra.co.nz</a>
Otago:	Vanessa Gray, Email: <a href="mailto:Nessie332@gmail.com">Nessie332@gmail.com</a>
Southland:	Heather Milligan, Email: <a href="mailto:milliganseeds@xtra.co.nz">milliganseeds@xtra.co.nz</a>

