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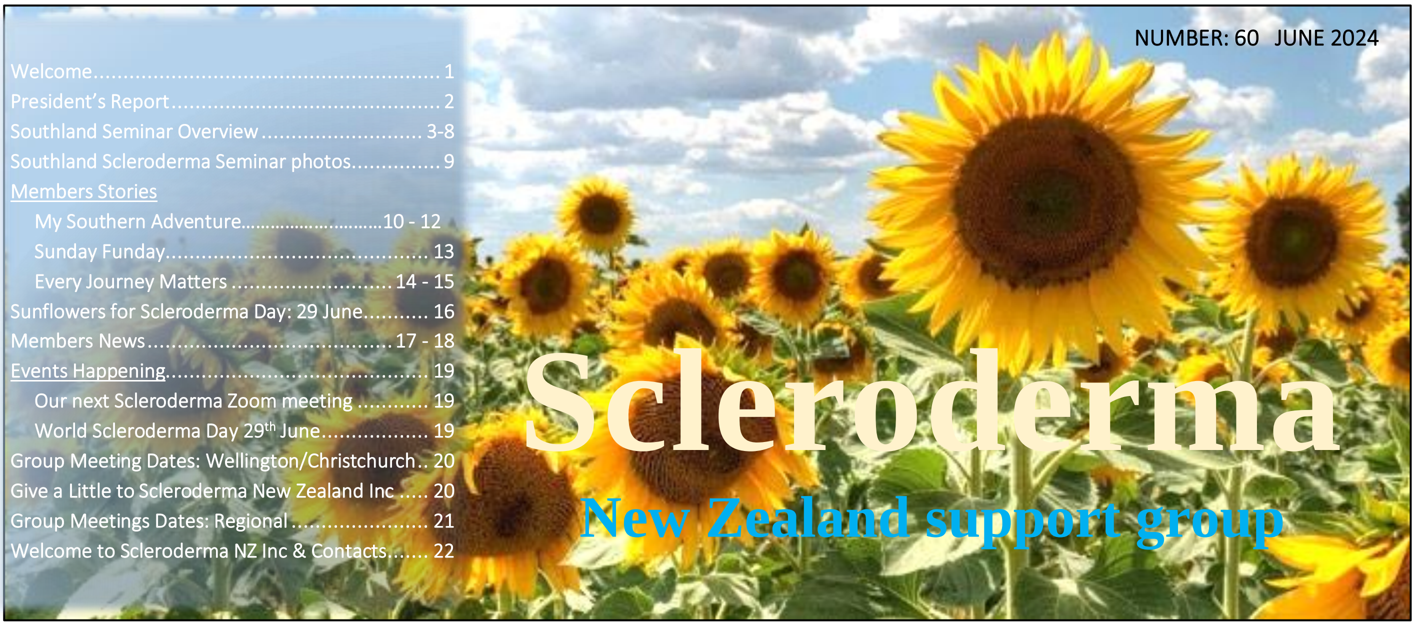

Scleroderma

New Zealand support group

Members Stories

WINTER 2024

Greetings to you all…

Welcome to the Winter edition of our Scleroderma Newsletter…

We hope everyone is well and keeping warm. Make sure you get your gloves, hats, scarfs and thermals on and wrap up well during these colder months. If you haven't had a flu injection, it's not too late to get your flu jab.

As I get older, I feel the months are going by so fast, and now we are already half way through the year - where has the time gone ?

I would like to take this opportunity to thank Jenny Andrews for all the hours you put in to make such a well organised, informative and enjoyable Scleroderma Seminar in Invercargill this year. It was a huge success with lots of information and friendships made.

Thank you also to your Southland team who helped to make the day enjoyable and welcoming.

There was a good line-up of speakers, who all gave their time freely to talk to us on their specialist topics. The seminar had a professional feel with amazing banners, brochures, and packs for us to take away on the day.

Many thanks to all our members who travelled from all parts of the country, with one attendee travelling from the United States of America. We learned lots of new information, met up with new faces and old friends and had heaps to eat.

In this issue we hear first from Jenny with her president's report. She keeps us up to date with what's going on around New Zealand.

We then have the presentations from the seminar. This year we were lucky to have five excellent speakers, who each had very valuable information to share with us. I am sure that each person was able to take away something that they learned from the day.

Thank you to Heather for providing us with the notes to share from the seminar in this newsletter

Take care everyone.
Warmest regards,
Tina

Presidents Report:

Winter 2024

Brrrr it is certainly getting cold these days. Great days for doing those in inside chores or projects. I have brought out my jigsaw case again for the evenings.

Welcome to all our new members who are reading this for the first time. We hope to make your journey with Scleroderma a slightly better experience with the knowledge that we are all one big family. My condolences to all those who have lost loved ones over the past few months.

It has been a busy few months since our last newsletter. Firstly with the seminar. A very huge thank you to all those who attended. It was wonderful to get such a great crowd. It was a very positive atmosphere and I loved meeting those people who I had only known by name beforehand. We had 11 attend from the North Island which was fabulous. Heather organised for those who wished to afterwards to go out for a meal together. So we wandered down a couple of blocks to Main Street and had a fun evening and small debrief of the day. Thank you Heather for organising this for us.

A very very big thank you to Heather for giving us an over view of the seminar. This was a huge undertaking and we really appreciate the time you have put into this. Never an easy task, made even harder for you when you got sick. Wonderful for those folks who were unable to attend to have a read through what was discussed.

I would like to thank Maree for her clever skills in making our sunflower collage to celebrate World Scleroderma Day on page 16. You have done a beautiful job and it is much appreciated. Thank you to everyone who sent in photos.

Our support groups are meeting regularly and we have doubled our numbers in Hawkes Bay. A big thanks to all those who are involved in organising these. We couldn't do it without you.

The committee are working away at different sources to get Scleroderma out in the public. Thank you all for your input and ideas. They are always welcomed. A very big thank you to Erena and Alumie for their work involving this. We are all very thankful. Some things take time but so worth it. Alumie is a bit of a star on the computer.

Hopefully by now you will all have had your flu vaccines. If not it is not too late. Contact your GP or your pharmacy to get this done. Covid seems to be very common around the country again so take care and do what you can to minimise contact with it. Think about number one to keep yourself safe.

Remember to rug up warm when you go outside. Hats and gloves are your best friend. Even when hanging at the washing put some gloves on to protect those fingers. I feel for those in Mosgiel today as I see it was -7 degrees there this morning. Wow that is cold…..

I sat here debating whether to go to golf or not. The heater was on, and my head was telling me to stay home. Luckily a friend rang and talked me into going. Yes I was frozen for the first hole but my hands thawed by the second hole even with 2 pairs of gloves on and boy did it help my mental health. Just being outside when it wasn't raining, wasn't windy and was just fresh was amazing. We won't get many more of these days for a while so it was silly not to go. Nice to catch up with the girls and I came home with a block of chocolate and a new golf ball. That is the advantage of only having 3 playing in our recreational group. I can often come home with a prize. Bonus.

I look forward to seeing you at the AGM on the 23rd.

Take care all and stay warm.
Jenny ☺

Frost on the fence on my way to shift the cows
So pretty

Southland Scleroderma Seminar

An Overview of the Seminar written up by Heather Milligan

How does Scleroderma affect the blood vessels

Professor Stebbings Dunedin School of Medicine and University of Otago.

Doctor Stebbings has been involved for a number of years with research into scleroderma, an interesting journey taken him across the world and met fellow researchers.

Blood vessels how they are affected by scleroderma.

Key part of scleroderma.

Arteries usually muscular and pulsating, these take the blood away from the heart, passes through smaller blood vessels called the arteriole into the capillaries system come out in the veins

Problem that occur in scleroderma with blood vessels which are affected are the smaller ones rather than the big muscular, ones,

Raynaud's phenomenon is usually first symptoms of scleroderma. Was named after Maurice Raynaud in 1862.

Raynaud's is due to constriction of blood vessels in fingers and toes as a reaction to cold or emotional stress, it is a common condition and a less aggressive form is quite common in young women. When you have scleroderma, it tends to be a much more severe form of Raynaud's.

What happens when you get Raynaud's? There is not much blood flow, the area turns white then blue, when the problem resolves, body pumps blood back into the area. Affects, feet, tongue etc. in the hands it starts with one finger. It is not much of a problem with thumb. Fairly short lived, resolve 15 – 20 mins.

Triggers – sudden change in temperature e.g. going outside, going from warm to cold room, sorting the freezer. Hormonal changes esp. around menopause. Emotional stress. Vibrating tools sanders can cause this.

Raynaud's is common in the population. With poor blood circulation, fingers can swell – puffy fingers, causing scars or lumps, and localised loss of blood flow.

If there is a long prolonged restriction of blood it is painful, this can cause puffy fingers, scars, ulcers, loss of blood flow which then can compromise circulation in the tissues, a bit like frostbite.

Pain an important aspect.

Ulcers

Other blood vessels can be affected, less of problem than the hands. Lungs, kidneys, heart or stomach.

With the kidneys it doesn't cause too much of a problem as over the last 20 years we have good treatments to keep the blood flowing through the kidneys.

PAH. Pulmonary arterial hypertension. Fibrosis causes the pulmonary arteries to narrow, raising blood pressure within these vessels and placing additional strain upon the heart. This may lead to damage to the right side of the heart, so that it has to work harder. When the cause is narrowing of the small blood vessels.

How do we know blood vessels are affected in scleroderma?

Nailfold capillaroscopy is a non-invasive method for visualising the nailfold capillaries. Taking a microscope and looking at tiny capillaries. This shows loops, dilated and tortured meandering, Otago is the only place in NZ doing this

Sometimes in Scleroderma we find giant capillaries that are dilated, do not understand why that should be, but is a common feature so can be certain it is scleroderma. Not all are typical of scleroderma.

Nailfold capillaroscopy show something is going on and is helpful in making a diagnoses and can be used to monitor progress of Scleroderma.

How to manage Raynaud's. Don't smoke or vape, avoid too much coffee, dark chocolate, too much caffeine.

Sorting through the deep freeze can trigger, have gloves.

You may find your own triggers

Trigger preventing, such as keeping whole house warm, try preheating car before driving.

If stress is a problem, try thinking ways you can limit stress – mindfulness or work through the stress

Gloves always good, should encompass fingertips, electric heated gloves. Consumer.org has an article on heated gloves. Alas some did heat too much.

Thermal insoles, tin foil. Face mask can be helpful and now are not too unusual. Hand warmers- crystal ones are best. Resist the temptation to put your hands in very hot water, make it warm water.

How can Rheumatologists help with severe Raynaud's or ulcer

Control or prevent Raynaud's from getting worse?

If you have diabetes, you need to have good control,

High cholesterol; get it down with statin treatment, some evidence show statins help.

Southland Scleroderma Seminar continued:

How does Scleroderma affect the blood vessels continued:

Monitor blood pressure, not high or low, people with scleroderma tend to have low bp.
If simple methods are not helping; the following can tend to dilatate the little blood vessels, arterial blood flow to the area. Nifedipine, Zenetal and Viagra medications are a game changer, and we now have good access to this in New Zealand.
GTN patches, originally developed for angina, medication seeps through skin, but is not effective on its own.
Iloprost used much less nowadays, can be useful, by infusion over 5 days.
If a larger blood vessel is blocked can be stented.
Botox is being looked into for Raynaud's.
Repurposing other drugs may be helpful.
Complementary therapies.
Fish oil- have to take lots, is an anti-inflammatory. Ginkgo leaves, might be worth a try. Ginko trees have been through 3 mass extinctions, there must be something in them that keeps them going.
Acupuncture may help blood flow.
Otago since 1988 have published 12 papers. Collaborate internationally with Eustar, a European Scleroderma trials and Research group, studies.

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Attendees' comments
Tips for navigating referrals with such a rare disease, how do we increase awareness? Dr Stebbings commented 'Teach medical students. It can be challenging to educate health professionals. We hope GPs are aware and refer.'
No clinical trials in NZ at the moment. Always looking out for studies to take part in.

Lung Issues in Scleroderma and treatment

Dr Sarah Jordan *- Te Whatu Ora Southern*

Lung issues are a complicated topic.
Looking at the lungs
Primary role of the lungs is to bring in air from the atmosphere and pass the oxygen out of the lungs into our blood stream. A very important system!
Large airways divide almost like trees, right out flower-like alveoli. The alveoli are where the lungs and the blood exchange oxygen and carbon dioxide during the process of breathing in and breathing out.
The following treatment for aspiration (where something enters your airway or lungs by accident) and reflux

- Raise head of your bed to 30 degrees, avoid alcohol and have meals 2 hours before bed.
- Acid suppression e.g. PPIs omeprazole, pantoprazole.

There are blood tests and Lung Function tests for breathlessness.
Interstitial Lung disease -it can affect any part of the lungs.
The tissues around the alveoli become inflamed and can fibrosis and scar. Lungs are not good at healing, but treatments are improving.
Not everyone should be treated with drugs, but they can be watched, and it is important to keep checking.
There are a number of treatments that can be used.
Antifibrotic – nintedanib.
Vixarelimab – this is a drug that is being tested with a double blind test.
PAH this is caused only by Scleroderma
Advanced heart disease, hypoxia with advanced lung disease.
10 to 15% of those with scleroderma have higher risk of PAH. This shows up in anticentromere antibodies.
Treatment with medications and lung transplant.
Pneumonia aspiration – reflux oesophageal dysmotility.
Important to keep up with vaccinations.
Pleural effusions around the lungs.

- Uncommon
- Asymptomatic
- Pleuritis
    - Heart failure
    - Pneumonia
    - Cancer
- Pleuritic pain, breathlessness

There appears to be an increased risk of lung cancer with Scleroderma.

Southland Scleroderma Seminar continued:

Scleroderma and the skin

Katey Jenks, Rheumatologist **-**

Te Whatu Ora Southern

The extent of skin involvement used for classification

- Limited cutaneous systemic sclerosis (IcSSC)

  Skin involvement distal (a part of the body that is farther away from the centre of the body than another part.
- Diffuse cutaneous systemic sclerosis (dcSSC)

Skin above elbows, knees and trunk affected.

Raynaud's

Often the first symptom of systemic sclerosis.

Can be primary (not associated with Connective tissue disease).

It is common

Lifestyle measures to improve

Medication, particularly if tissue damage.

Calcinosis

Often seen with limited cutaneous systemic sclerosis (Crest)

Subcutaneous calcium deposition.

Modified Rodman, this is a skin score (mRSS) is a semiquantitative score, ranging from 0 (normal) to 3 (severe), used to evaluate the skin thickness in 17 different cutaneous sites (for a total score from 0 to 51), and is correlated with histological skin thickness. You will be able to find images via an internet search.

General advice

Avoid cold: warm clothing, gloves, hats, and good working gear if outside.

Stay active

Physical and hand therapy to maintain a range of movement.

Heathy diet

Smoking cessation

Stay connected with friends' family and support groups.

Skin thickening

Depending on severity immunosuppression with Mycophenolate or Methotrexate may be appropriate.

Autologous hematopoietic (bone marrow) stem cell transplant (AHDCT); Severe disease.

Rituximab (anti CD20), Tocilizumab (anti-IL-6), cyclophosphamide

Side effect profile needs to be considered.

Risk/benefit.

Summary

Many forms of skin involvement in Systemic Sclerosis. This is a complex disease. Treatment depends on severity and extent of organ involvement. While there is no cure, treatments offer improvement in quality of life. An ongoing area of research.

Gastrointestinal Manifestations

Dr Wei Zhang **-**

Te Whatu Ora Southern

90% of patients with scleroderma have some degree of GI involvement, of which 50% have symptoms.

There is equal frequency between diffuse cutaneous systemic sclerosis (dcSSC) and limited cutaneous systemic sclerosis (IcSSc)

The oesophagus most frequently affected.

However any part of the GI tract may be involved.

Pathogenesis (*the origination and development of a disease*) is not fully/clear proven

Microvasculature (*the system of tiny blood vessels including capillaries, venules and arterioles, that perfuse the body's tissues*) and autonomic nervous system *(a reaction in the body happens without conscious effort*) dysfunction.

Immune dysfunction leading to fibrosis

Interplay with gut microbiome.

Oropharynx

Reduced mouth opening

Xerostomia (dry mouth)

Pharyngeal dysfunction

  Difficulty initiating swallow

  Food sticking.

Oesophagus

Problems present in 50 – 80 % of patients

Oesophageal dysmotility and efflux

  Difficulty/pain with swallowing

  Heartburn

  Regurgitation/structuring

  Oesophageal candida

Endoscopy, Barium swallow, manometry.

Stomach

Gastroparesis

Gastric antral vascular ectasia.

Small Intestine

Symptoms often non-specific

Southland Scleroderma Seminar continued:

Gastrointestinal Manifestations continued:

Bloating, flatulence, diarrhoea
Weight loss
Malnutrition
Small intestinal bacterial overgrowth
Carbohydrate breath test or jejunal aspirate.
Reduced mobility and secondary complications.
Large intestine
Symptoms similar to small bowel involvement
Alternating constipation/diarrhoea
Ano-rectal disease
Haemorrhoids
Prolapse
Diverticulosis.
Summary
GI involvement is common and can affect any part of the tract.
Management symptom- specific
Very limited role for immunosuppression
Nutrition important, but the role of specific diets unclear.

Joe Wheeler – Podiatrist

Complemented the attendees on their choice of sensible shoes. No stilettoes, but there is no reason why you can't wear them

Scleroderma can weaken and "break up" the tissues in the body, causing changes to the cushioning and surfaces of your feet. Many people with systemic sclerosis suffer changes in the pad of the foot, causing them to feel like they are walking on gravel.

Cushioned shoes, to absorb and spread the pressure over all the foot, use an orthotic with an arch which increases the area. You will come up with the most suitable.

Tight skin won't be supple. You may not be aware of an area e.g. a toe rubbing on your shoe, even good shoes can cause vascular and tissues effect of scleroderma that pressure can cause a systemic area, it can produce a corn or callous.

When you get new shoes, don't overdo the distance.

No tight socks – squeeze toes, you need to get the blood on that area.

Verruca or a wart, it is thought there are 5 layers in the epidermis. Types of Warts and verruca's, Plantar warts result from human papillomavirus (HPV) , very common and important to treat them if you have an at risk foot. Gentle actions, regular debriding. Scalpel or filing to be more pliable and replace with a pad to offload the pressure.

Podiatrist come up with all types orthotics. Need to be soft, cushion that area, cut away areas or add to offload the pressure. Keep debriding, collagen needs to come out. Verruca still has the virus, it will grow rapidly, and hurts the veins and capillaries. The wart may go away but the hard stuff stays and causes neurovascular corn. Same process to relieve soft, cushion that area, cut away areas or add so as to offload the pressure

Your feet are not being looked at all the time, like your fingers. People hate getting injections in the feet as the feet are so sensitive.

Callouses. You can get them on your hands if you keep putting pressure on it will get harder and form a corn. The deeper the corn is, the baby skin cells proliferate in the area under the corn, even if you get rid of the pressure you still get corns,

Corns can pop up due to bones and joints pushing from the inside. E.g. corn on top due to rubbing on the shoe, get rid of the shoes, but the baby cells are still there and will form a corn. Scleroderma an extra bit that is not supple. Standing up a lot causes chronic venous; an insufficiency occurs when your leg veins don't allow blood to flow back up to your heart. Pressure stockings for venous ulcers can be problem. You must put your feet up above your hips. Lie down with your feet up.

A reaction like eczema or fungal infection. Get the pressure off and circulation improved. Cramps at night, may be caused by arterial blockage or low blood pressure. Walking will make the cramps worse.

Have done studies with shoes, people with no shoes have similar problems as those who wear shoes. Shoes appear to make not too much difference. Material such nylon skin which doesn't breathe, causes sweating can lead to problems. Socks inside Crocs are fine.

There can be genetic causes for foot problems and tight shoes can aggravate what is already there.

If you have flat feet you use muscles e.g. your back. With flat feet, metatarsalgia support a lot of weight to push off when walking/running. Pinched or inflame surrounding tissues. Good shoes have a metatarsal dome, which spreads the metatarsals apart. Can be operated on if needed,

Pressure is the enemy and getting good circulation if possible is paramount.

Joe finished off his talk with the invitation to attend the Edendale pub at 8pm that evening, where his band is playing.

Southland Scleroderma Seminar continued:

Caring for the Scleroderma hand

Dr Miranda Bűhler, Physiotherapist and Hand Therapist
TeWhatuOra Southern, TeKākahu – Dunedin Hospital Hand Clinic

Aspects of scleroderma hand from a patient perspective, general management treatment and strategies. Tips and tricks that can help, resources

Commonly affects the hands and has a huge impact. Hands are everything. Patients often comment on this. "Hands are everything"

Problems include

Thickening and hardening of the skin on the hands

Stiffness and pain in the muscles and/or joints, 'clawing'

Swelling of the hands, especially in the morning

Thinning of the pads on the fingertips

Small chalky calcium deposits under the skin

Raynaud's phenomenon

Some or all of your (fingers) turn white or blue and become numb when exposed to cold or sudden temperature change.

You may also have pain or pins and needles or have difficulty moving

Attacks can last minutes or hours.

Different for everyone. Some can be mild, some can be severe.

She complemented https://scleroderma.org.nz/ website on the huge amount of information available there.

As an Individual with Scleroderma

Acknowledge your expectations.

Keep skin supple and intact.

Make tasks easier. Changing way of doing things, problem solving.

Especially maintain general fitness

Other people's stories

Maintain Range of movement

General management strategies

General principles

Maintain ROM (range of movement) but do not overdo.

Maintain circulation

Maintain skin condition

Make everyday tasks as doable as possible, make less stress and strain. Look at a new way of doing things – problem solving.

Maintain general fitness and conditioning –shoulders, core, hips and legs stability, strength and endurance. All play an important role in how your hand will function

Physiotherapists and Hand Therapists can help with an individualised management plan. Occupational therapist,

Worth asking if the therapist has treated someone with scleroderma before or worked with rheumatology.

Manage pain and swelling down to help keep moving.

Healthy

Exercises for hand, wrist and finger mobility.

Treatments that help

Learn more about scleroderma: scleroderma differs from person to person but can be treated effectively.

Discuss treatment options with your doctor and healthcare team.

Exercise: one of the best things you can do is to follow a regular exercise regime. It will help to keep your joints flexible and improve blood flow. Good for feeling good. Important to be regular.

Manage swelling and pain which can stop you from moving and keep your mobility: light compression, gentle heat, movement

Look after your skin: avoid strong detergents that can irritate your skin, keep your skin clean and well-lubricated to prevent dryness and infection. If you have particularly sensitive skin, soaps and creams may be available on prescription.

Manage Raynaud's phenomenon: avoid, where possible, exposure to cold and sudden temperature changes. Keep your whole body warm and protect your hands with gloves.

Avoid smoking and nicotine products: tobacco smoking products which contain harmful substances that damage skin and blood vessels.

Manage stress: ensure you get sufficient rest and relaxation, and balance work and leisure. Talk to your support people. Find the things that make you glow.

Healthy diet

Exercise hands wrist and finger mobility at home. Iron your hand out on a cushion with your other hand. Avoid lots of repetitive gripping, e.g. with a squeezy ball as it can lead to inflammation of the long tendons.

Find scleroderma leaflet

Manage swelling, pain, and temperature – arthritis gloves

IMAK arthritis gloves–light compression and thermal control

$20-$45 for pair

Southland Scleroderma Seminar continued:

Caring for the Scleroderma hand continued:

Dick Smith, HatoHone (St John), BraceYourselfOnline, Whitely AllCare
Suggest turn them inside out for comfort, and so seams are not causing pressure
Measure circumference at palm to size if buying on line. Hand wash only

Wax bath can be a worthwhile investment for some. It is therapeutic for pain relief, can improve quality of skin, Heat enables easier mobility of stiff joints, muscles and skin. It is fun and smells nice. Can cost $800 to $900. Can be worthwhile investment for some people. (Research concludes there is no added benefit over luke warm water Kristensen (2019) J Hand Ther, 24(1):13-21)

Splints –
However there is no evidence that the use of splints maintains or improves finger mobility unfortunately. 'Seeger & Furst (1987) American Journal of Occupational Therapy, 41 (2): 118-121
There may have some functional role in some functional activities e.g. typing.

Managing Reynaud's
There is no cure, but there are practical things you can do
When you have an attack, stay calm and gently re-warm your fingers as soon as you can.
Placing your hands under your armpits or swinging your arms during an attack often helps.
Go inside if you are outdoors, as this is usually warmer.
Try wiggling your fingers or rubbing your palms together. Move or walk around to try and improve your circulation.
If you can, run warm (not hot) water over the affected part of your body.https://www.consumer.org.nz/articles/9-gadgets-to-keep-your-hands-and-feet-warm
If your symptoms are severe or cause a lot of problems, your doctor may be able to prescribe medication to help improve blood flow.
Measures to prevent an attack Aim for constant temperature
Exercise and reduce stress
Skincare
Household tips
Tips and Tricks slides

Digital device touch screens -things we can think about
Clean the screen
Take off the screen protector
Stylus
Change device settings for larger targets
Touch screen thumb or finger 'cot'
Touch screen gloves
Keep your fingernail length short.

More info and resources:
https://healthify.nz/health-a-z/s/scleroderma/

https://www.arthritis.org.nz/forms-of-arthritis/scleroderma/

https://www.arthritis.org.nz/forms-of-arthritis/scleroderma/

https://scleroderma.org.nz/

https://www.nhs.uk/conditions/scleroderma/

winter jokes

1. How do snowmen read their texts?
With an icy stare.
2. What kind of ball doesn't bounce?
A snowball.
3. What bites but doesn't have teeth?
Frost.
4. What do you call a penguin in the Sahara Desert?
Lost.
5. What do you call a snowman in December?
A puddle.
6. Where do snowmen love to dance?
At a snowball.
7. What do you call a slow skier?
A slope-poke!
8. What do snowmen eat for lunch?
Ice burgers.
9. What do snowmen win at the Olympics?
Cold medals!
10. Which one is faster: hot or cold?
Hot. You can catch a cold.
11. How do snowmen buy birthday presents?
With cold, hard cash.
12. What did the tree say after a long winter?
What a re-leaf!
13. What does Frosty's mom put on her face at night?
Cold cream.

Southland Scleroderma Seminar photos:

Members Stories:

My Southern Adventure:

Written by Kelsi Tidswell

As soon as I saw the seminar was in Waihōpai/Invercargill, my mind was made up. 'I'm going to that, and I'm going to do the Otago Rail Trail, finally!' An experience that had been on my mind for some time (years) it was now or never. After spending the few nights in Waihōpai/Invercargill, Mum and I made a side trip down to Rakiura/Stewart Island. We were blessed with a smooth ferry crossing and Oban was picture perfect.

We completed a beautiful walk out to Ackers Lighthouse, part of which was a bush track next to the ocean. To top it off a kororā (little blue penguin) showed itself in one of the bays!

A night in Tāhuna/Queenstown was followed by a beautiful deep south autumn morning. Think crisp morning air, golden hues of gold, yellow, orange, and red, mists rising in the sunny morning…almost enough to make a northerner consider making the move! The bus ride to Areketanara/Alexandra really was a treat, which was our starting point of the trail. We collected our e-bikes; Mum and Rozalie zoomed off to do Lake Dunstan while I had a more relaxing day around Areketanara. I knew I needed to pace myself on this trip and fully expected aches, pains, and fatigue as penitence for all the fun and awesome adventuring to come. I couldn't help myself on such a gorgeous day though, and took my e-bike around town, and a little way down the Roxburgh River Trail. I'm so glad I did! My face hurt from all the smiling, and the e-bike made quick work of any tired muscles.

The next day was the beginning of the Otago Rail Trail. Mum, Rozalie and I packed up our daypacks, leaving our suitcases for our fabulous tour operator, Altitude Bikes, to collect, jumped on our e-bikes, and hoped we didn't get rained on!

The first day was 33 km to Ōmakau. This part of the trail had these spectacular rock formations, parts of which had been carved away by the railway workers way back when and all by hand.

We wound our way through farm land, got buffered by wind, and I realised no matter how many layers of gloves I put on, the vibrations from biking on the gravel gave my hands Raynauds. Our accommodation in Ōmakau was fantastic, and came with a bath! HEAVEN! Before I could soak my weary bones we made a little side trip to Ophir. The preserved town was neat to look around, and the historic architecture included the post office and Pitchers Store, where we had a fabulous dinner.

The next day was another 30kms to Oturehua. We had great weather after some morning drizzle; it turned into a humid day that had us removing layer after layer. The scenery on this part was my favourite; we crossed many bridges, rode through tunnels and were treated to the rolling expanse of Otago farmland.

After a very comfortable night at the Inverlair Lodge (under floor bathroom heating, yes please!) our next stop was Waipiata. The day was overcast, still a little humid but I layered up all the same. The scenery was wide, expansive farmland, and was also the highest point of the slight incline of the Rail Trail.

We arrived at our country pub accommodation just as the rain started coming down and before dinner went to the little town of Naseby to try curling. I layered all my clothes for this, but could still only spend ten minutes or so in the 8C rink, but I had a great time pushing the 20kgs stones around the ice! Mum and Rozalie were pros by the end of it!

The last day was the biggest ride of them all, 54kms to Middlemarch. This day also happened to be the coldest, the rain really started to set in, and there was a chilly wind in exposed places. I was also dealing with an unreliable gut, so very nearly took the option to ride in the van with the luggage, but decided to ride. Let me tell you, it was a hard slog. I wanted it to be over as fast as possible so cranked up the assist on my e-bike and flew through to Middlemarch. I achieved my top speed of 25km/h this day ;)

But I did it!! And I loved it! It was such a joy to tick an experience off my bucket list with my Mum and Aunty, who were supportive and encouraging, keeping me going when it was tough. I hurt for a week or so after, and needed many hot showers, thermals, and pain relief to keep me going but can't wait to do more. I just have to buy an e-bike and start training again ☺

Members Stories:

Sunday Funday: by Jenny

I wanted to share with you an interesting day we had on the day after the seminar. We were having a conversation the evening of the seminar and Frances had asked me if I knew a lady called Diana McDougall who owns The Cabana and runs a Facebook page for knitters etc. Frances had been following her for a while and had bought from her and was really keen to go and visit the store. They had looked into getting a taxi but it would be about $200. I messaged Diana at dinner and asked if she would be open on Sunday and she kindly opened for us. So, Sunday arrived and because I had woken up early, I contacted the ladies, Jane, Frances and Gail and ended up picking up Jane and we went to Bluff for a look. The other ladies had been awake most the night with strange happenings in their room next door, so they stayed and slept a bit later. Jane and I went to the Bluff point signpost, then drove up Bluff Hill but sadly it was very foggy and we couldn't see a thing so didn't actually get out of the car. Leaving Bluff, we saw a young lady hitchhiking and needed to get to Invercargill so we picked up this lady. She was a 26-year-old German girl who had spent 4 months on the Te Araroa Trail on her own. She spoke beautiful English and the three of us talked all the way to Invercargill. I told her we were about to pick up another couple of ladies and drive for 45 mins to the country to go to a little wool store and did she want to join us. She said Yes! While we waited for Frances and Gail to come out of the hotel, we explained that we had been at the seminar yesterday and we all had Scleroderma. Amazingly Ursula knew about it, as she had studied medicine and was just about to start her first doctoring job. It was a wee surprise to Frances and Gail to see someone else in the car also, but we all headed out the road. We drove 45 minutes to Benmore and Diana met us at the Cabana and Gail and Frances were in their happy place. Frances having a wee purchase while she was there. We said our goodbyes and got a photo taken with Diana then stopped in at home and had some lunch together and had quite the conversation about Scleroderma. I think Ursula learned a lot in that lunch time. When hubby came in for lunch, I think he was quite surprised by our extra guests but as always, took it in his stride. A fabulous way to end what had been a very eventful weekend.

Jenny ☺

Jane at Bluff signpost

Hawkes Bay ladies, Frances, (Diana), Gail and Jane

Ursula and I jumped in with them all

Members Stories:

Every Journey Matters

June 1, 2024 by Perry

Throughout the month of June to coincide with the theme "**Every Journey Matters**" Perry has been sharing stories of people from here and the U.S. on his blog [The life and Times of Perry...] each Friday ☺

At the time of writing this email note for the newsletter we have heard from Dianne Purdie whom many of you will know quite well, and 'The Sclero Guy', Michael Bessert from America. Next week we will hear from Helen in Auckland.

To mark the start of Scleroderma Awareness Month he wrote the following post about how to become an effective coper by adopting the **BRIGHT IDEAS** approach - I hope that you find this both informative and helpful ☺

Today marks the commencement of Scleroderma Awareness Month and this year's theme is:

Every Journey Matters.

Every person's experience with scleroderma is unique, no two cases are the same. Making Scleroderma extremely difficult to diagnose and complicated to manage.

So what is scleroderma?

Scleroderma (or systemic sclerosis) is a rare incurable disease that affects the skin and results from an overproduction and accumulation of a fibrous type of protein called collagen which is in our body's tissues.

The thing is, when there is an overabundance of collagen in the body it leads to the thickening and tightening of the skin and can also affect internal organs; such as the lung, GI tract, heart and kidneys.

Unfortunately, having scleroderma can present many medical challenges, at least that is what I've found. And I've endeavoured to share my journey over the past few years or so, so that others can be informed and encouraged as they either deal with it themselves, or want to understand more about how this rare, incurable disease can affect loved ones.

After getting an initial diagnosis, (or working towards getting a diagnosis) you'll need to find health professionals that are familiar with this disease, and who are able to assist in managing your treatment going forward.

You will undoubtedly have to go to quite a few medical appointments, make important and sometimes difficult decisions about your overall well-being and care, take medications (often a lot of medications), manage side effects, and deal with aches and pains, fatigue, amongst other things.

You may also have strong emotional reactions like depression and anxiety and this can be especially true when scleroderma affects the way you look. As well as, when you have to start navigating the many new normals along the way, as your symptoms change over time.

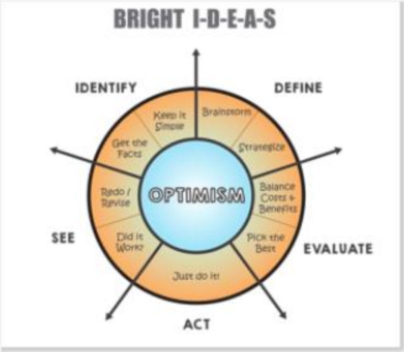
But we all know people who seem to manage even very difficult situations with great skill and success.

These people are often referred to as "effective copers." And you too can become an effective coper as well, by using the BRIGHT IDEAS approach:

BRIGHT means that you should look at problems with an optimistic, or positive, "can-do" attitude.

The thing is, it's easy to become overwhelmed with problems when you are chronically ill and sometimes it's hard to feel optimistic.

It's okay if you're not completely confident in your abilities at the beginning however, working through the following "**IDEAS**" may well help build your confidence as you begin to have success in coping with specific problems.



IDENTIFY the problem – Be very specific when identifying problems and issues that you may face. Don't settle for generalisations such as; *"I need to find better ways to cope with my illness."*

Members Stories:

Every Journey Matters continued…

June 1, 2024 by Perry

Be specific! Once you define the problem more specifically it'll become more manageable to come up with potential solutions.

DEFINE your options – After you've identified the problem you need to cope with, brainstorm solutions:

- Make a list (as long as you can) of all the ways you could try to cope with this. Don't stop at two or three alternatives, try for at least a dozen. Research shows that people who think of lots of alternate ways to cope are better at eventually solving their problems.
- The challenge is that we usually skip this brainstorming step. We tend to just do what we always do and what we are comfortable with, for we all act in a predictable manner. Brainstorming can help us think differently about our problems and help us to discover new ways to cope. Don't skip this important step.
- When you are brainstorming, write down everything that comes to mind. Don't think, "*But that won't work*" as you'll get to evaluate strategies in the next step. During the brainstorming step just list everything you can think of.
- Don't think that you have to come up with all the solutions yourself. Ask other people (spouse, kids, healthcare providers) what approaches they would use to try to solve the problem you've identified. You'll be surprised at all of the things you never even considered!

EVALUATE your options – Now look at each coping strategy that you've written down.

Carefully evaluate the pros and cons of each one and avoid making any quick decisions about any of the strategies.

After you've carefully considered all of the pros and cons of each approach, choose the approach that you think has the best chance of success, with the fewest negative costs.

Now let's get ready for change!

ACT on your plan! Start putting your coping approach into action. This may mean getting some instruction, getting some equipment, or even learning and practicing new skills.

You'll more than likely need some help from other people to begin using your coping strategy. This is where having a good support system in place can come in handy. This is something we'll explore in a future post ☺

EVALUATE your plan – It's really important to always learn from what you are doing and the plans that you've enacted. After you've tried to implement a coping strategy, evaluate it.

Ask yourself, did my plan work the way I hoped?

If 'YES'… Great! It's time to reward yourself.

If 'NO'… consider: Was it because the coping strategy itself didn't work, or was it just too hard for you to implement it?

Ask yourself:

1. Did I stick to my plan? If not, what did I end up doing instead?
2. Did anything limit my ability to implement my plan?
3. Should I revise my plan?

Hopefully, these can assist you in either coping with some of the problems presented by scleroderma, or help in your understanding of what people affected by scleroderma have to work through.

Much of the above information was gathered from one of the modules on the Taking Charge of Systemic Sclerosis (TOSS), an internet self-management program on the Self-Manage Scleroderma site.

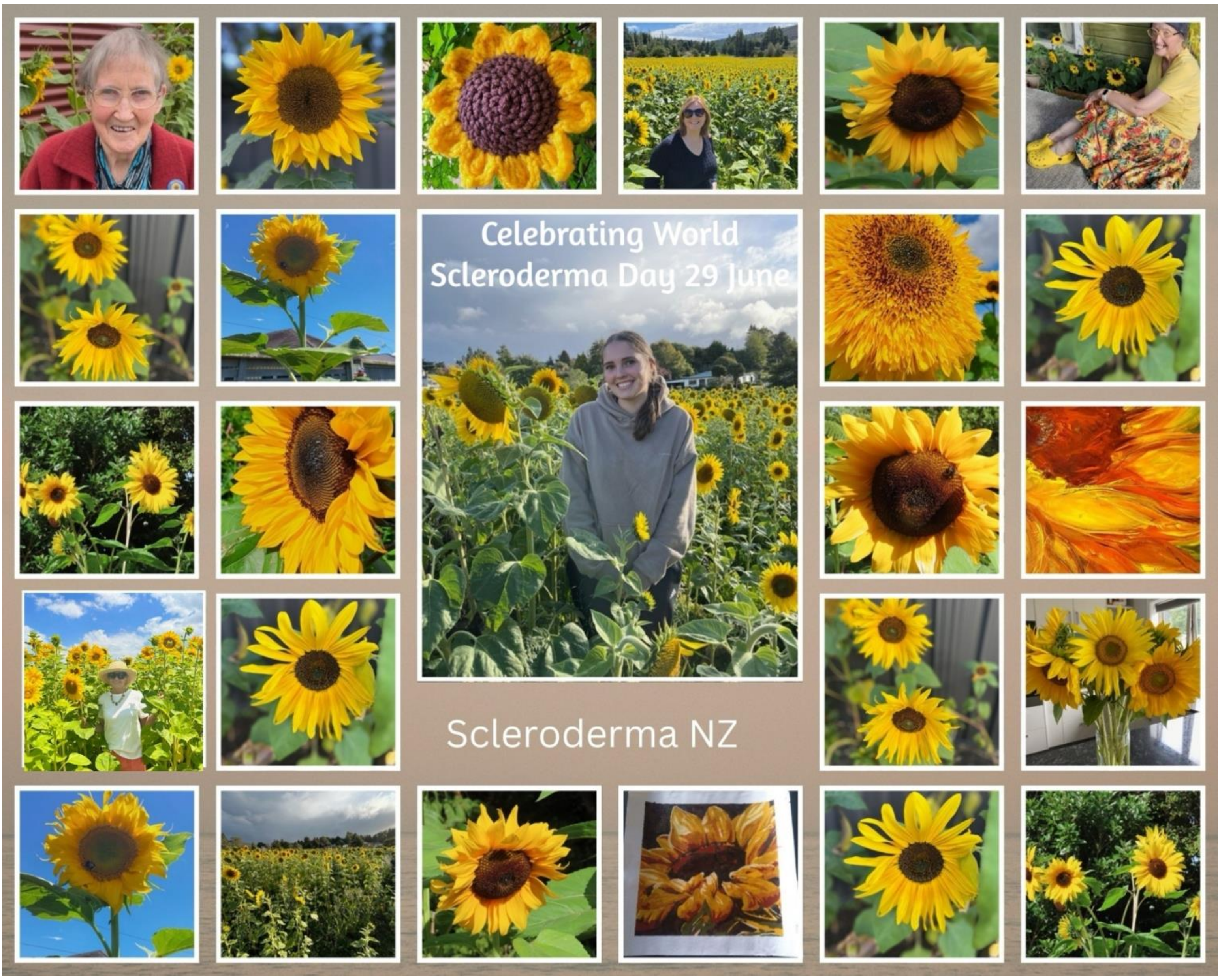
Over the coming weeks I'll be asking a few people that I have come to know over the course of the past few years or so to share their stories about scleroderma so that we can help raise awareness throughout June.

Blessings 'til next time ☺

Perry Bray

Sunflowers for Scleroderma Day: 29 June

Maree Meredith has kindly put our sunflower photos into a fantastic collage.
Thank you Maree, you are such a gem.



Thanks to everyone who shared your photos with us. Certainly makes for a beautifully bright space.

Members News...

Hawkes Bay Scleroderma Group

Hawkes Bay group is growing. It was fantastic to get new members. They are lovely and enjoying our sessions. We meet every 3-4 weeks in a different café. Thanks to Jenny for making it possible to meet new members.

Gail, Frances, Diana, & Lorraine

Christchurch Scleroderma Group

Christchurch group met on the 25th May and had a lovely catch up with each other. Thank you to Nicky for taking on the leadership role of the group.

Back: Chris, Nicky, Julie; Front Barb & Paul

Southland Scleroderma Group

The Southland Group haven't met up since February. As we had the seminar at our usual meeting time. We are meeting in a couple of weeks though so will be lovely to see everyone again.

Bay of Plenty Scleroderma Group

Our last gathering at Nourish Cafe was a delightful and cosy affair, with Mary, Barb, Donna, and myself enjoying each other's company. Despite Donna's first time meeting us, she quickly warmed up to our group. Donna shared valuable insights from her health and supplement research, which proved to be quite enlightening. Barb was completely engrossed in Dr. William Li's 'Eat to Beat Disease' book, and we're all looking forward to tapping into her newfound knowledge next time.
If you would like to join them get in touch with Alumie Nguyen: alumie.uow@gmail.com

New Plymouth Scleroderma Group

Check out Kelsi's story from her trip to Invercargill and around.
If you would like to attend the New Plymouth Support Group please get in contact with **Kelsi Tidswell**: kelsitidswell@gmail.com

Members News continued…

Waipa and Waikato Scleroderma Group

Waikato Scleroderma group gathered on May 25th. It was a small and intimate lunch. This provided a safe place to share each other's journeys, families, treatments, etc. However, it's not solely a disease that our members have in common. There is bravery, honesty, compassion, and determination. How blessed are we to be able to be supported and support each other. We look forward to our next gathering.

Auckland Scleroderma Group

Helen Parsons and Catherine Johnston continue to host Monday coffee mornings for people with Scleroderma, their friends, and families.
However our numbers remain very small.
Please email Helen Parsons.
helenparsons@artcardsandposters.co.nz
if you have requests or ideas for this group.
We find it friendly and informative. We talk about our travel adventures, our families, our hobbies, and of course the scleroderma medical journey that we are all travelling.
Catherine Johnston
sassycat@xtra.co.nz 021 165 9511
Helen Parsons
HelenParsons@artcardsandposters.co.nz
021 248 3869

Catherine Johnston, Janet Miller, Helen Parsons

Wellington / Kapiti and Wairarapa Scleroderma Group

On April 27 we held our scleroderma support group meeting at The Farm at Boulcott's Farm Heritage Golf Club on a beautiful cool autumn day. The days leading up to this had been pretty dreary, weather wise, so it was good to see familiar faces that were happy to be out and about, chatting and catching up over lunch.

Unfortunately, I didn't remember to get a photo on the day ☹ But from the amount of banter that was happening and the fact that people stayed well into the afternoon it was a fun-filled time for all, as we each touched base with others that are sojourning the scleroderma trek with us, what with its many up's and down's.

See the poster for our next gathering, which will be happening at the Fisherman's Table Restaurant on **Saturday 20 July @ 12:30pm**.

Perry Bray

Events Happening:

Our recent Scleroderma Zoom meeting:

NZ Wide Online Support Group

On 25 May we had the Online Scleroderma Support Group Meeting which was well attended by people up and down the country ☺ It was an informal gathering held on Zoom with the main intention for participants to share aspects of their scleroderma journey and 'what's on top' for them at the moment, sharing support and encouragement to each other. As we all have differing symptoms and experiences that may assist others that are dealing with the challenges that this disease brings.

It was widely intimated that people would like to be able to do this more often. With that in mind we will be looking at holding these bi-monthly on the last Saturday of the month (to start) and assess how they are going towards the end of the year and what participants would like moving into the following year.

Perry Bray

Our next Scleroderma Zoom meeting:

The next NZ Wide Online Support Group will be held on:

Saturday 31st August at 1.30pm so as to not conflict with any of the other in-person support groups at this stage. Keep an eye out for the poster and email advising of the relevant links in due course.

Online
Scleroderma
Support Group
Meeting
Saturday 31 August
@ 1:30pm

Check the Scleroderma Website
or Facebook page for the Zoom link

Scleroderma
New Zealand Inc

https://scleroderma.org.nz/
https://www.facebook.com/SclerodermaNewZealand

World Scleroderma Day

29th June 2024

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

Scleroderma
New Zealand Inc

Scleroderma Awareness the of Month June
coming soon.......

What will you do to mark the occasion ?

Group get together via zoom or in Person

Share Tips on how you manage Scleroderma

Show us your new warm woollies

Bring your Questions to our facebook

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

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

Wellington / Kapiti and Wairarapa Scleroderma Support Group:

Wellington
Scleroderma
Support Group
Meeting

Saturday 20 July
@ 12:30pm

Scleroderma
New Zealand Inc

Fisherman's Table Restaurant
29 State Highway 59, Paekākāriki

RSVP to perry.pacpe@gmail.com by 5pm 18/07/2024

Group Meeting Dates: Wellington & Christchurch

Wellington / Kapiti and Wairarapa Scleroderma Support Group:

July 2024– November 2024

All Welcome

Co leaders contact details:

Tina Mclean:	altinamclean@xtra.co.nz
Cushla Marsters:	cushla.marsters@solnetsolutions.co.nz
Perry Bray:	perry.bray@salvationarmy.org.nz

Date &Time	Venue	Address
Saturday 20th July 2024 12.30pm	Mid Year Lunch Fisherman's Table	29 State Highway 59, Paekakariki
Saturday 21st September 2024 12.30pm	Chocolate Fish Cafe	100 Shelly Bay Road, Miramar
Saturday 23rd November 2024 12.30pm	The Farm Cafe & Bar - Boulcott's Farm Heritage Golf Club	33 Military Road, Boulcott, Lower Hutt

Christchurch Scleroderma Support Group:

July 2024 – November 2024

All Welcome

We welcome any new members to come along.
Please contact:
Nicky Moore: nicky.moore@xtra.co.nz

Date	Venue and Time	Address
20th July 2024	Mid Year Lunch Koji Japanese Buffet 257 Lincoln Road, Christchurch Saturday 12pm	TBA
21st September 2024	Burwood Hospital Travis Courtyard Café Saturday 2pm – 4pm	300 Burwood Road, Burwood, Christchurch
23rd November 2024	Burwood Hospital Travis Courtyard Café Saturday 2pm – 4pm	300 Burwood Road, Burwood, Christchurch

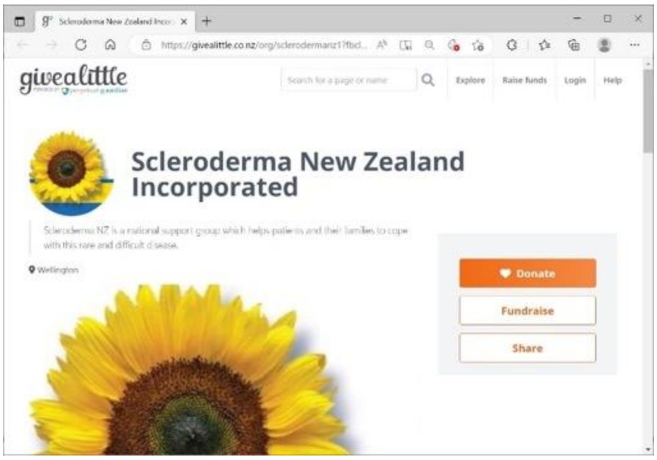
givealittle Give a little: Scleroderma NZ Inc.

From Scleroderma New Zealand Incorporated - Givealittle

Scleroderma New Zealand Incorporated

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

An example of what our give a little website page is shown below:
Scleroderma New Zealand Incorporated - Givealittle



Scleroderma New Zealand Incorporated

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

Our give a little URL link address is shown below: -
https://givealittle.co.nz/org/sclerodermanz1?fbclid=IwAR29Znk701JSOwf9n0Ew-O63nj0FrySOCpV44mBCpIPHtXV7UFf9KIAnAzM

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

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

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

Group Meetings Dates: Regional

Wellington / Kapiti and Wairarapa support group meets:

Venue*:* *Fisherman's Table*
29 State Highway 59
Paekakariki
Time: **Saturday 20th July 2024** at **12.30pm**
For any enquiries please contact Cushla:
cushla.marsters@solnet.co.nz
or Perry: perry.bray@salvationarmy.org.nz

Christchurch support group meets:

Venue*:* *Koji Japanese Buffet*
257 Lincoln Road, Christchurch
Mid-Year Lunch: 20th July 2024, Saturday 12pm
(*Please RSVP to Nicky ASAP so she can book for the correct number)*
Dates: 21st September 2024, 23rd November 2024
Time: **Saturdays 2 - 4pm.**
We welcome any new members to come along.
Please contact **Nicky Moore** if you would like to join in:
nicky.moore@xtra.co.nz **Phone:** 021 110 6123

Southland support group meets:

Sunday June 30th, 11.30 am. *Croydon Lodge, Gore*

Sunday September 8th 12pm

Sunday November 24th 12pm

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

Waikato/Waipa support group meets:

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

Palmerston North support group:

See Wellington Support group.

Otago support group:

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

Waimate/Oamaru support group:

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

Helene Sunitsch at: hkjsunitsch@gmail.com

Auckland support group:

Venue: *Catherine's Home*
9 Woodstock Road, Forrest Hill, Auckland
Time: **Monday 15th July, 10am**
A reminder email to be sent out one week prior to each meeting to all in the Auckland area. If you would like added to this email list contact either Helen or Catherine.
For any enquires please contact either:-
Helen Parsons: 021 248 3869
HelenParsons@artcardsandposters.co.nz
Catherine Johnston:
Sassycat@xtra.co.nz

New Plymouth support group meets:

Venue*: Coffee Club, Fitzroy*
Time: June 22nd 2024 (this Saturday) at 12pm
So if you would like to attend the New Plymouth Support Group please get in contact with **Kelsi Tidswell**:
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

Hawkes Bay support group:

The Hawkes Bay group have regular catch ups every 3-4 weeks. To be part of the Hawkes Bay Group please contact Gail.
Gail Neilson: gail_neilson@hotmail.com

Bay of Plenty support group meets:

Venue: *Nourish Cafe in Te Puna*
Time: 6 July 2024, at 11.00 am - our go-to cafe as they have a fireplace and nice drink and food menu. Come join us for more informative discussions and good company! Can't wait to see you there!
Please contact one of us for information.
Jane: janepuckey99@gmail.com
Mary: marybestrd3@gmail.com
Alumie: alumie.uow@gmail.com

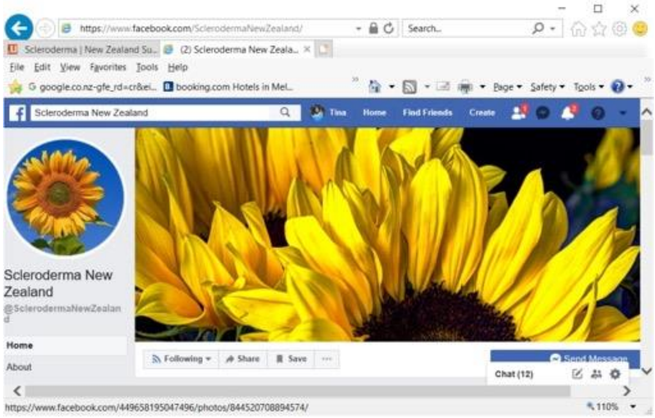
Welcome to Scleroderma New Zealand Inc.

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

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

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

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



Link to our **Auckland Facebook** page: -
https://www.facebook.com/groups/sclero.akl/

Scleroderma New Zealand

President:	Jenny Andrews jennyred@xtra.co.nz
Vice President:	Tina McLean altinamclean@xtra.co.nz
Secretary:	Jane Sainsbury jsainsbury@xtra.co.nz
Treasurer:	Gordon Purdie gordon.purdie@xtra.co.nz
Newsletter:	Tina McLean altinamclean@xtra.co.nz Jenny Andrews jennyred@xtra.co.nz

Committee Members:

Linda Bell, Erena Bruce, Cushla Marsters, Dianne Purdie, Heather Milligan, Alumie Nguyen, Frances Tod, Rachel Burgoyne, Helen Parsons

Contacts:

Find a Scleroderma a Support Group near You:

Auckland:	Helen Parsons, Email: helenparsons@artcardsandposters.co.nz Catherine Johnston, Email: sassycat@xtra.co.nz
Bay of Plenty:	Alumie Nguyen, Email: alumie.uow@gmail.com
Waikato/Waipa:	Rachel Burgoyne, Email: rachieb1981@gmail.com Erena Bruce, Email: glenanderena@xtra.co.nz
Hawkes Bay:	Gail Neilson, Email: neilson_gail@hotmail.co.nz
New Plymouth:	Kelsi Tidswell, Email: kelsitidswell@gmail.com
Wellington	Cushla Marsters cushla.marsters@solnetsolutions.co.nz Perry Bray perry.bray@salvationarmy.org.nz
Christchurch:	Nicky Moore, Email: Nicky.moore@xtra.co.nz
Blenheim/Nelson:	Jen Soane, Email: jennasoane@gmail.com
Waimate/Oamaru:	Helene Sunitsch, Email hkjsunitsch@gmail.com
Otago:	Gay Meddings, Email: gaymeddings@gmail.com
Southland:	Heather Milligan, Email: milliganseeds@xtra.co.nz