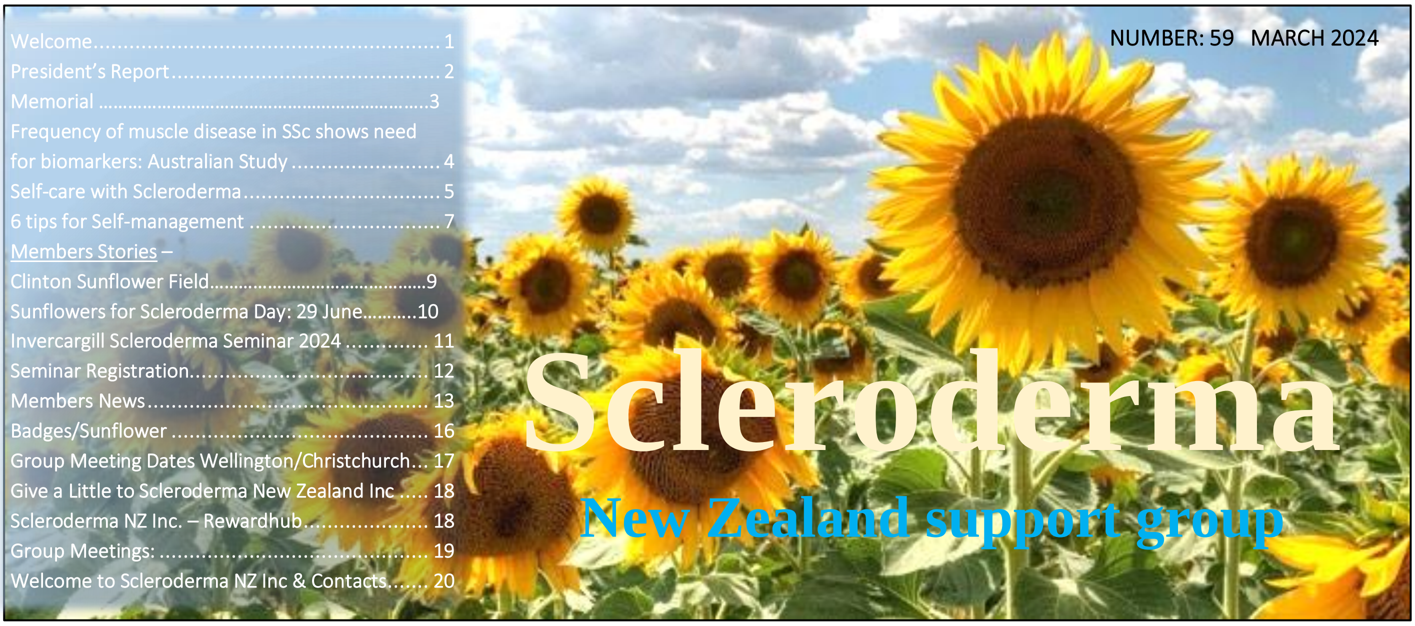


Members Stories –

NUMBER: 59 MARCH 2024

Scleroderma

New Zealand support group

AUTUMN 2024

Greetings to you all…

Welcome to the Autumn edition of our Scleroderma Newsletter…

We hope you and your family are well, and you are all looking after yourselves.

We are well into the year now with Christmas and New Year a long distant memory, the warm summer months have come to an end and soon we will be getting ready for shorter days and colder months.

With autumn upon us, it's time to think about getting the flu jab in readiness for the winter colds and keep up with your Covid booster.

Easter is coming early this year and we hope everyone is taking time to relax and take a break over this holiday period.

We are excited about the upcoming **Scleroderma Seminar** on the weekend after Easter. A reminder to get your registration in for the seminar on Saturday 6th April in Invercargill. Six fabulous speakers, morning and afternoon tea and lunch will be supplied. Fantastic raffle prizes too. Most importantly, a day where you get to speak to a room full of people who understand what you are feeling and going through. Please send Jenny an email to register. More details further in this newsletter.

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 around New Zealand.

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 2024

I sit at the table wondering what to write while my heater is on and I am feeling sad that today is the last day of Summer as I look out to yet another dismal day.

We had a wonderful summer break with lots of little jaunts away, our son and his girlfriend spent new year with us and we went to Highlands park for Quinn to drive a Radical. A belated 21st present. Then our daughter came down for her birthday and we celebrated that with her and her boyfriend in Queenstown for the day. Lots of food, fun and luge-ing. We adopted a 3 and a half year old dog who is Greyhound/Labrador cross. She is an ex pig dog, but due to the fact she didn't like hunting she is now living a life of luxury with us. We are really enjoying having a dog in the house again, although we are learning to not leave food on the bench as she is very tall and has stolen everything from a whole sponge cake, garlic bread that was to take to a BBQ and Maddy's birthday biscuits I made her. Just to name a few. Beautifully natured though and forgiveness is very easy with her.

We are flat out organising the seminar. We have our 6 speakers ready to go who are full of knowledge on everything scleroderma. They will be speaking on Blood Vessel Problems, Lungs, Skin issues, Hand Therapy, Gastro and a podiatrist to finish us off. We have some awesome prizes for the raffle which have all been so kindly donated, and the Disability Resource Centre will be coming along during the lunch break to show us what they sell to make life that little bit easier. They will have a variety of products for sale on the day. It is not too late to register for this. It has been a looonnnng time coming so will be so great to finally be able to all get together. A huge thank you to all those who are coming from around the country. It will be wonderful to all be in the same room.

We are looking at our options for World Scleroderma Day already, so if your town has something that can be lit up in Yellow, Orange, Teal and Blue contact them and see if they will do it for you. We have got wheels in motion for Queens Park in Invercargill and Invercargill Central Mall again. We have also applied for the Auckland Harbour bridge to be lit up. So fingers crossed. If you are able to, please take some pics and we can share them all here.

We will have a sunflower collage in the June Newsletter to celebrate World Scleroderma Day so get your sunflower photos into Dianne before the end of May. Details further through the newsletter. We have some amazing ones in already. Also, if you don't have sunflowers in your garden but make sunflowers of some description then you can send photos of that to us to. Crochet, diamond Art, Jigsaw anything sunflower will be accepted. ☺

Our support groups have started up again for the year, so a very huge thank you to all those leaders who keep these happening. They wouldn't have a group if our members didn't come along so thank you to all of you. We have quite a few wee ones all around the country so that is fantastic. Let me know if you wish to attend something and I can try and point you in the right direction.

Our committee will be having the AGM in June, so if you would like to join us, please get in touch with one of our committee members. Many hands make light work so we welcome new members. Thank you heaps to our committee, you are all so amazing. I know how hard it can be when you are not feeling so well, so everything you do for Scleroderma New Zealand is very much appreciated by us all.

We have had new pens, shopping lists and notecards printed recently that are looking fantastic. Also we have a couple of new banners to display at seminars, stands etc.

…… I come back to this one month later. With the greens outside getting greener, the nights getting longer, and the winter pj's have made their appearance.

I went to the pharmacy the other day and got my Flu jab, paid the $55 to have the one that was 19% better, or I could have had the funded one. Messaged hubby and he said just pay, and he did the same with his. They also gave me my 6th Covid shot so feeling pretty great heading into Winter. Remember to get your flu jab..

I have decked myself out in waterproof shoes, jacket and pants for the golf I am intending playing through the Autumn/Winter. Brrrr. Did my very first 18 holes with my son Quinn yesterday and am certainly feeling it. Was a wonderful experience though, very peaceful and great Mum and Son quality time. My golf is very average at this stage, but I get lots of practise since I have to hit twice as many as Quinn does ☺

Take care all and stay warm.
Jenny ☺

Memorial

Southland Scleroderma Group Member

Marian Beynon

In remembrance of Marian Beynon

I had regular Messenger talks on a Saturday afternoon with Marian since April 2022 when she was diagnosed with Scleroderma, but alas did not get to meet Marian in person as she lived in Alexandra, Central Otago. I was in awe of Marian's ability to take on the computer world at an older age. She did enjoy finding out more about Scleroderma and I think was determined to know as much as she could about it. She did join us for Zoom meetings.

Marian and her family settled in various places in the lower South Island, but I get the impression that her favourite home was Okuru Beach on the West Coast. She did delight in the environment there. I was amazed at her logistics in organising not only her family, but also having a B&B in one of the remotest parts of New Zealand, she was quite nonchalant about her abilities. That's what she enjoyed doing. She took pleasure in telling me of the tramps and walks she had accomplished, being outside walking was her favourite thing to do, especially with her dogs. I was stunned to hear that she fell off a mountain, survived and really thought nothing of it, who would have thought!

It is so sad that her last few years were troubled by her husband's death and the changes that had to be made and her struggle with her many health issues that crowded in on her. I am amazed by her fortitude in dealing with these situations in her early 80s.

Heather

Frequency of Muscle Disease in SSc Shows Need for Biomarkers: Australian Study

7/3/2024

The condition is associated with inflammation, end-organ involvement by Patricia Inácio, PhD | February 27, 2024

Muscle disease is common in people with scleroderma and is associated with inflammation and specific end-organ involvement, according to an Australian study.

The findings underscore the "clinical, functional, and prognostic importance of simple biomarkers" for identifying SSc-related muscle disease, the study's researchers wrote in "Proximal weakness and creatine kinase elevation in systemic sclerosis: clinical correlates, prognosis and functional implications," which was published in *Seminars in Arthritis and Rheumatism.*

Scleroderma, also called systemic sclerosis (SSc), is a chronic disease that features excessive scarring of the skin and other organs due to abnormal immune responses against the body's own tissues.

Muscle disease, or myopathy, can be common in SSc and develop due to the indirect effects of the disease, such as malnutrition. A previous study using MRI scans showed muscle involvement was found in up to 40% of asymptomatic SSc patients. A lack of consensus remains about what SSc-myopathy is and of biomarkers for muscle disease in SSc, leading researchers to assess whether two routine clinical biomarkers of muscle disease — elevated blood levels of creatine kinase (CK) and proximal muscle weakness (PW) — could help identify those at risk for more severe outcomes.

The scientists analyzed data from patients enrolled in the Australian Scleroderma Cohort Study between 2007 and 2023 who had at least one assessment of PW and CK levels during follow-up.

ID'ing biomarkers for scleroderma

Muscle weakness was defined as upper or lower limb proximal muscle power of less than 5 in 5, as assessed by a physician. Proximal muscles are those closest to the trunk, such as ones in the shoulders, elbows, and hips. Elevated CK was defined as a minimum of 140 international units per liter, or IU/L.

Patients were divided into four groups — PW and elevated CK levels at the same assessment; only PW, but no CK elevation or vice-versa; and no signs of PW and CK elevation. The analysis included 1,786 patients (mean age, 46.6; 14.2% men). About a quarter (26.8%) had diffuse cutaneous systemic sclerosis (dcSSc), and interstitial lung disease (ILD) was present in 28.6%.

PW was detected in 390 participants (21.8%) and elevated CK in 565 (31.6%). Both PW and elevated CK were reported in 79 patients (4.4%), while no clinical feature of muscle disease (negative for PW and elevated CK) was reported in 1,015 patients (56.8%). PW alone was seen in 265 patients (14.8%) and elevated CK in 427 (23.9%).

Myositis, or muscle disease due to inflammation, was detected in 44 patients (2.5%), as shown by muscle biopsies. Patients with PW and elevated CK were the most common group with myositis (17.7%). This group was also more likely to have dcSSc, tendon friction rubs, digital ulcers, and an inflamed synovial membrane of a joint, called synovitis.

Consistent with a more severe presentation, these patients required immunosuppressive medications, such as prednisolone, more often and had a higher rate of ILD and impairments in pumping blood out of the heart's left ventricle with each contraction.

PW, either alone or accompanied by elevated CK levels, was significantly associated with older age at SSc onset, a higher rate of digestive problems, and heart and lung disease, including pulmonary arterial hypertension.

Participants with high CK levels alone were more often men positive for anti-Scl70 antibodies, which are related to SSc severity and lung involvement. No other significant clinical differences were seen between patients without any signs of muscle disease and those with high CK alone.

Patients with PW and elevated CK had a 3.6 times increased risk of death over those without muscle disease, according to a statistical analysis that accounted for age, sex and dcSSc. Having PW alone was associated with a 2.1 times increased risk of death.

PW, alone or combined with high CK, correlated with poorer physical function, as assessed by the health assessment questionnaire disability index. These patients also showed impaired exercise capacity, as measured by the 6-minute walk distance test, and shortness of breath. CK elevation alone had no significant impact on breathing capacity or physical function compared to no signs of muscle disease.

"Despite focusing only on clinical assessments of potential SSc-myopathy, we have identified important clinical, functional and prognostic correlates of these phenotypes in a longitudinal analysis of a large SSc cohort," the investigators said.

Source: https://www.scleroderma.org.au/news/frequency-of-muscle-disease-in-ssc-shows-need-for-biomarkers-australian-study

Self-Care with Scleroderma

People living with scleroderma, whether limited or diffuse scleroderma, deserve to feel their best. Obviously there are the important things you need to do, like seeking treatment, taking the right medication and knowing your limits, but there is also a lot you can do outside of this, allowing you to enjoy your lifestyle and feel like the best version of yourself. Interested? Read on to find out how!

- Treat your skin right, beyond what it needs.

This point might be one of the biggest ones on our list, because as anyone with scleroderma knows, your skincare is so important. However, we want you to go beyond the moisturising creams.

Yes, definitely invest in a calming, fragrance-free moisturiser (and use it after every time your skin gets wet), but don't stop there. Go all out! Make yourself feel special and focus on all of you, not just the scleroderma. If you like baths, get some natural bath oils or epsom salts and watch a movie, or maybe light your favourite candle. Remember to keep the bath water from getting too hot, as this dries out the skin (and also, baths are never fun when you're sweating!).

Treating yourself to a massage or facial once every few weeks is also a great option, because nothing feels better than a relaxing hour-long pamper session. You should also feel lighter afterwards, as according to the article Managing Skin Conditions In Scleroderma, any sort of massage "will improve the mobility of the joints and help drain excess fluid in the face". Massaging with an oil or moisturiser also decreases the dryness and itchiness of skin, making you feel great both during *and* after your session.

Invest in other self-care items that you can implement in your day-to-day life too, such as a heating blanket. This way, you don't have to wait for those appointments or nights to feel special, you can have a nice moment in the middle of the day if you choose to do so!

- Connect with others.

Keep in touch with those you love, whether that's catching up with a friend in person, or calling someone who makes you smile. We can get so caught up in our own busy-ness that weeks and months can pass by before you realise you haven't spoken to a friend in a while, and we all know connecting with others makes everything better. Aim to call or text someone at least once a week to check in, and try scheduling in-person catch ups. Perhaps you could host a morning tea with you and a friend or family member, where they bring those tiny finger sandwiches and you make the tea. Anything works, really. As long as you get to spend some quality time with the incredible people around you. (Also, don't forget to prioritise connecting with your partner and staying intimate. Plan dates, make it a goal to do or say something nice to them every day, even if that's just leaving a sticky note with a heart for them to find).

Connecting with new people is also so important for our self care. You can join in-person events, like our scleroderma support groups, or do something that focuses on another aspect of your life, like joining a local book club. Also remember that in today's world, everything can be virtual, so join online forum and talk to new people, or find a platform that allows you to help others from the comfort of your own home. For example, you could be a sighted volunteer through the company Be My Eyes, which connects you with others all around the world with visual impairments. Usually, you will get a FaceTime call to help someone find a dropped item, distinguish between food, describe pictures or help match colours and so much more! Be My Eyes say "90% of all calls are completed within a few minutes", so this is a great way to connect with others and make a difference without having to commit too much time or effort.

- Move your body in a way that feels good.

The best exercise is always going to be something you want to do, even if you can only manage it in small amounts. Exercise should always be about feeling good, both in your mind and body, so try different things until something sticks. However, we do have some fun exercise ideas that you can try, some that are even possible from your own home!

Warm-water swimming: this usually comes in the form of an exercise class and has great benefits, allowing you to connect with others while doing guided exercises without much thought.

Yoga: this is a great stretching exercise that builds your flexibility and strength over time, as well as having some evidence pointing towards breathing capacity. You can join classes, or look up tutorials online. As we said before, everything is virtual today, so try looking up some scleroderma focused tutorials online and follow them if it makes you more comfortable.

Tai Chi: similar to yoga, tai chi increases flexibility, strength and cardiovascular fitness. It is also a form of meditation, keeping you present and being aware of your body and its capabilities in slow, measured movements.

Dance: dancing is a great way to get moving, and doesn't require you to do everything perfectly if you don't want it to. Just turn on one of your favourite songs a day and let yourself feel the music. Swing and sway in any way that feels good for you, even if that's a simple head nod and foot tap!

Remember, while we're encouraged to work out 3-4 times a week, this is a goal, and it's not for everyone! It may not even be a possibility. As long as you are moving your body and feeling good, even just for five minutes per day, you will thank yourself.

Self-care with Scleroderma continued...

- Eat right.

Everyone deserves to eat well balanced meals, because they give us more energy, fulfilment and strength. Research the best foods to make you feel good, or perhaps, if planning meals are your thing, get meal kits that bring all of the ingredients and recipes you need to your door. This way, you only need to spend time making yourself good food, and not have to spend time figuring out all of the details. Buying pre-cut vegetables is also a great way to save time and energy if you need, allowing you to easily get the nutrition you deserve with minimal effort. You can also make larger batches of food when you do have the time and energy to cook, and then just freeze the leftovers. This gives you amazing meals for the future that you only need to defrost and reheat!

- Be mindful.

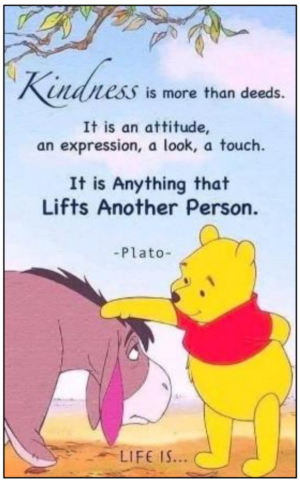
One of the best things we can do as a form of self-care is practise gratitude and be intentional with our time. Getting a gratitude journal you can write in every day, or saying three things you're grateful for first thing in the morning, have incredible impacts on our mindset, and set us up to have a better day.

Filling your home with things that make you happy will also help having a positive mindset. Get a bouquet of your favourite flowers delivered to fill your home with colour, or perhaps spend some time crafting with a young loved one so you can put their drawings on your walls!

Finally, feel the sun once a day (while wearing sunscreen). This might be in the form of an outing to the beach or just spending some time by an open window, but any time you can spend being intentional in the sun is also highly beneficial, warming our skin and grounding us. Try to take some time to be mindful with your breathing when you're in the sun, and take some deep breaths to further be present.

If you have any more tips to self-care with scleroderma, or try out any of the ones above, let us know!

Source:
https://sclerodermavictoria.com.au/self-care-with-scleroderma/



6 Tips for Self-management

What is self-management and how can it help?

Self-management is what an individual can do to manage their condition and to help maintain their wellbeing. How this is approached will differ from person to person, but fundamentally it revolves around making decisions to support a healthy lifestyle, whilst recognising the physical and emotional effects the disease can have. Both Raynaud's phenomenon and scleroderma can affect individuals to varying extents, so each person will need to understand what works best for them in helping them maintain a good quality of life.

It's important to learn as much as possible about your condition and to determine whether changing certain lifestyle factors may help, such as diet or stress levels. Paying attention to your emotions and communicating with a support network, be it family, friends or SRUK, will also be of benefit. Evidence has shown that people who have the knowledge and confidence in self-management skills tend to have better health outcomes.

Physical self-management

1. Staying warm

Most people living with scleroderma will also have Raynaud's, where small blood vessels in extremities are over-sensitive to changes in temperature. For this reason, it is important to stay warm to avoid Raynaud's attacks. Here are some basic tips:

- Avoid sudden changes in temperature where possible
- Try and keep your body warm, especially your hands and feet
- Dress in thin, loose layers for maximum warmth. This means that layers can be taken off if too warm, and can be piled back on when cold
- Wear gloves and long socks when cold, and try hand-warmers and thermal insoles.

In addition to the weather, exposures to other cold environments can also trigger symptoms, such as cold aisles in supermarkets or air-conditioning in shops. Preparing for these situations may lessen the likelihood of a Raynaud's attack.

Wax bath therapy is intended to moisturise, soften the skin, improve blood circulation and reduce pain of joints. This approach uses paraffin wax that is soft and melts at a lower temperature than normal, therefore it does not cause any burns or blisters. Paraffin wax is also known to help muscle relaxation and muscle movement. Those being treated with a paraffin wax bath are encouraged to build up several layers of wax and then gently peel it off, rounding into a ball of wax to use later. This action also can contribute to gentle manipulation of the soft tissue, encouraging wider blood flow.

2. Healthy lifestyle

Stress can also bring on Raynaud's symptoms, therefore by managing stress levels, such as by pacing yourself and being aware of when you may be taking on too much, can help you reduce Raynaud's symptoms. This can be achieved by gentle exercise, which can also help boost circulation by getting the blood flowing to the extremities. Exercise is also beneficial for keeping the heart, lungs and muscles healthy, and for keeping the skin supple. It is important to find something that is suitable to your own abilities; walking, yoga and swimming are popular, low-impact exercises.

Stopping smoking is one of the most helpful ways of limiting symptoms, as this will help lower blood pressure and maintain good circulation throughout the body. There is lots of support available at pharmacies and at GP surgeries to help you stop smoking; visit https://www.nhs.uk/smokefree for more advice and to download a Personal Quit Plan.

Whether or not an individual suffers from gastro-intestinal symptoms, it is crucial for people living with either Raynaud's or scleroderma to be aware of how nutrition plays a role in their symptoms. This is especially as the gut is affected in up to 90% of people with systemic sclerosis. You may need to try a combination of methods, either together or separately, to find a regime that works for you. Some people have trouble swallowing, digesting or maintaining weight, and it may be necessary to ask your doctor for referral to a dietician if you are struggling. Eating a balanced diet will help you manage your condition and stay healthy; some elements to ensure you include in your diet are:

- **Calcium:** essential for healthy bones. Sources include dairy products, fishes, green vegetables, seeds, nuts and fortified cereals.
- **Vitamin D:** needed to help absorb and utilise calcium. Obtained from sunlight, eggs, butter, margarine and cereals.
- **Iron:** important in making red blood cells, which carry oxygen around the body. Found in red meat, poultry, fish, eggs and leafy vegetables.
- **Omega-3:** helps to protect against many diseases, including heart disease, can reduce inflammation and is suggested as having a positive effect on mood. Sources include oily fish (sardines, salmon, tuna), rapeseed oil, walnuts and fortified eggs.

It is important to aim for 5 portions of fruit and vegetables per day. Apart from helping to maintain a healthy weight, they can also help to reduce pain and inflammation, provide fibre and help to regulate blood pressure and blood fats. Protein-rich foods such as fish, beans, eggs and meat will help the body to grow and repair, hence aiding you in recovery from surgery or ulcers.

6 Tips for Self-management continued...

3. Skin care

Routine skin care is incredibly significant when living with Raynaud's and scleroderma. Keeping skin clean, dry and well moisturised are three simple things to remember. We especially recommend using moisturisers containing lanolin. Harsh, deodorised soaps should be avoided, and instead non-soap cleaners should be used.

For people with secondary Raynaud's, there is a risk of developing digital ulcers on fingers and toes. Ulcers should be dressed regularly and the frequency with which the dressings are changed will vary from person to person. Dressings will help to alleviate and prevent dirt and germs from entering the wound. Dressings must be as sterile as possible to reduce the chance of infection. We recommend that you see a nurse or GP initially to show you how to dress an ulcer so that you then know the best way to do it at home. They will also be able to tell you the best dressing for you, as there are several options. These include:

- Inadine: this is impregnated with iodine. This is licenced for use on infected ulcer wounds. If allergic to iodine these should not be used.
- Mepitel: made of a flexible polyamide net coated with soft silicon. It is easy to put on and shape to the ulcer.
- Allevyn: consists of a layer of foam about 4mm thick providing a cushion for maximum protection.

Dressings and medication can be expensive, so a prescription pre-payment certificate (PPCs) may help to reduce costs, if you do not already receive free prescriptions. If you think an ulcer looks or feels infected, see a medical professional.

If you are concerned about the appearance of telangiectasia (clumps of tiny, broken blood vessels), you can learn to cover the area with specialist make-up, called skin camouflage. Our helpline (0800 311 2756) can direct you towards these services.

Mental self-management

4. Mindfulness

The psychological impact of Raynaud's and Scleroderma is equally important as the physical impact. Whether it is the stress of day-to-day activities or the impact of the conditions on work and relationships, it is vital to recognise this side of living with these conditions.

Mindfulness can be described as paying more attention to the present moment, to your own thoughts and feelings, and to the world around you. This can help all of us enjoy the world around us more and help manage levels of anxiety and stress, thus acting to improve mental wellbeing.

Here is a suggested mindfulness technique:

- Find a quiet, relaxed space.
- Close your eyes and focus on your breathing; inhale slowly for 3 seconds and exhale slowly for 3 seconds.
- Do not worry if your mind wanders, just acknowledge that this has happened and then bring your thoughts back to your breathing.
- Repeat this for as long as you like.

It may help you to pick a regular point in your day to do this. Yoga and tai-chi are also said to be effective in helping you become more mindful. Head to the Mental Health Foundation's website (www.bemindful.co.uk) for more information, an online mindfulness course, and details of mindfulness teachers in your area.

5. Fatigue

It is common to suffer from fatigue when living with an autoimmune condition, with people often describing how they 'hit a wall' of fatigue that makes it challenging to continue without rest. After a proper rest, the fatigue may improve, so this is a potential way of reducing its impact. Tips on avoiding fatigue are:

- Use technology where possible, e.g. a dishwasher or ergonomic device.
- Use a shopping trolley when out shopping.
- Place items you use frequently in easy to reach places.
- Buy pre-chopped vegetables.
- Simplify your day-to-day activities and ask for help when you need it.

If you think your drug treatment may be causing your fatigue, talk to your doctor about reviewing your treatment. They can also look for signs of other conditions that may be causing fatigue, as well as checking inflammation or anaemia levels.

6. Finding support

If Raynaud's or scleroderma are limiting your ability to work and lead a fulfilling life, please get in touch with us and we will do our best to help you. If your concerns are surrounding financial concerns, visit our UK benefits page on our website to find out more on government schemes.

We can also help put you in touch with local groups and other individuals who have the condition. You can also chat with other people who also have Raynaud's and scleroderma through our online community.

Source: https://www.sruk.co.uk/about-us/news/6-tips-self-management/

Members Stories:

Clinton Sunflower Field –

I was sent this article from our Southland Member Terry Gentle telling me about the field of sunflowers that had been planted in Clinton. On my way to Dunedin I convinced hubby to stop and get some photos of them. He even wandered through them with me. There was a sign that read “Peas, help yourself”. Looking around we couldn’t see the peas, then looking down, the ground was absolutely covered in them. And very yummy peas indeed. That turned out to be our snack for our journey. Such an absolutely fabulous idea of the Clinton Lions club to do this for the community. The fact that you are allowed to walk amongst the flowers is incredible as a lot of fields do not allow this but then you also get to eat some peas while doing it and get to take the odd photo too. I loved it and we spent a bit of time just savouring the beauty of the flowers.

Me in the Sunflower field

Blooming gorgeous ... Poupoutunoa Kindergarten pupils and staff (from left) Casey Waddel, 1, Charlotte Ellis McGartland, Luna Perry, 1, Reef Kahukura, 1, Tayla Hannah and Reggie Burgess, 1, last Thursday checked out the sunflower patch which is beginning to bloom in Clinton. PHOTO: EVELYN THORN

Sunflowers seeding joy

EVELYN.THORN
@alliedpress.co.nz

Sunflowers seem to turn heads.

Well, in about three weeks or so, the sunflowers in Clinton will be in full bloom with their heads turned to the sun.

The Clinton sunflowers are back again and beginning to bloom.

The idea was created by the Clinton Lions to create a “positive environment” for people to stop in, according to Clinton Lions member Benji Perry.

“We want to promote them so people can enjoy the sunflowers.

“We’re more than happy for people to go out and take photos in them.”

The gate for access into the paddock is off Gorge Rd in Clinton.

The sunflower seeds were donated to the Clinton Lions by Pureoil NZ.

They were first planted in November, 2022, but more were planted last year.

Cultivation and spraying of the area was completed by local businesses to get the sunflowers in.

“Last year they brought people from all over New Zealand to Clinton to get photos with them, which was fantastic,” Mr Perry said.

“We hope to have that same energy again this year.”

“We will be running some competitions including our popular annual scarecrow competition, a colouring competition and a sunflower competition around the sunflowers, as it is a great way of bringing the town together for events.”

People can enter the scarecrow competition, which begins on March 8, via the Clinton Scarecrow Competition Facebook page.

“I think every event we have going will build on last year and be bigger and better, which we’re looking forward to.”

Tired

“My body may be tired, but my soul is energized.”

“True happiness comes from being tired but fulfilled.”

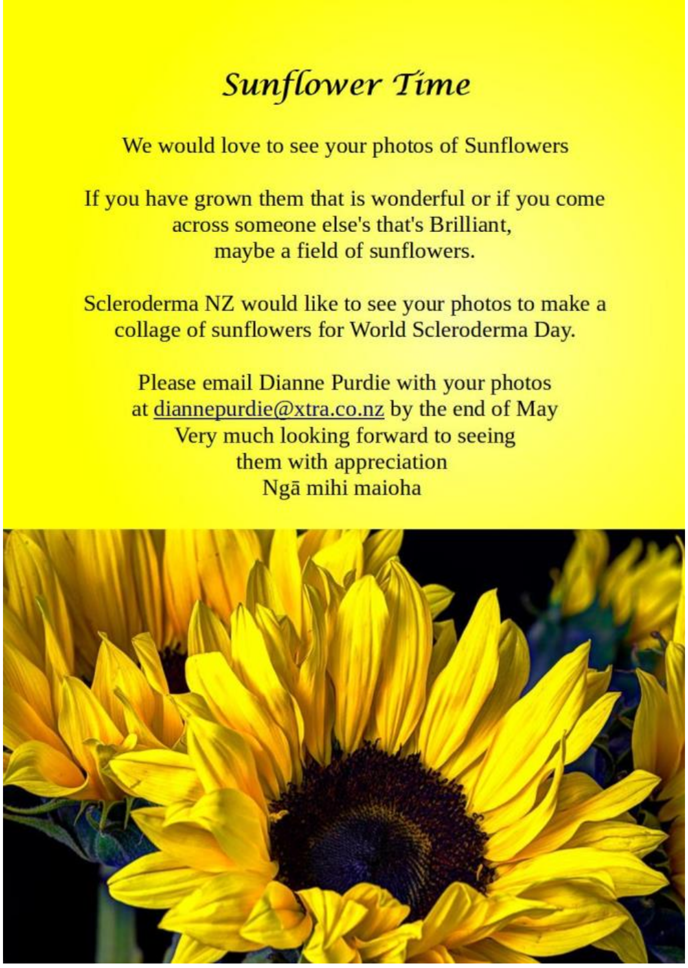
“After a long day, the sense of satisfaction is incomparable.”

“Fatigue is temporary, but happiness is everlasting.”

“There's something delightful about being exhausted from enjoying life.”

Sunflowers for Scleroderma Day: 29 June

From Scleroderma NZ



Sunflower Time

We would love to see your photos of Sunflowers

If you have grown them that is wonderful or if you come across someone else's that's Brilliant, maybe a field of sunflowers.

Scleroderma NZ would like to see your photos to make a collage of sunflowers for World Scleroderma Day.

Please email Dianne Purdie with your photos at diannepurdie@xtra.co.nz by the end of May
Very much looking forward to seeing them with appreciation
Ngā mihi maioha

Committee member Heather Milligan with her homegrown sunflowers. Looking very pretty in her yellow and lovely sunflower skirt. Love the crocs.

Committee member Jane Sainsbury in a sunflower field on her recent trip home to New Zealand. What a beautiful pic amongst the flowers. Now that is what summer looks like.

Sunflower Pics..

Send us the photos of your sunflowers, whether they be real in your garden or someone else's, or of your craft work. We will display them in the Winter Newsletter.

You can also load them up on our Scleroderma NZ Facebook page

https://www.facebook.com/SclerodermaNewZealand/

This will be a great way to brighten up mid-winter and celebrate World Scleroderma Day.

Follow us on our Scleroderma New Zealand Facebook page:

https://www.facebook.com/SclerodermaNewZealand/

DID YOU KNOW?

that sunflowers are not just pretty faces? They're often planted to help clean up contaminated soil. Sunflowers are known as phytoremediators, meaning they can absorb and accumulate heavy metals and toxins from the soil, effectively detoxifying it. These cheerful flowers not only brighten up gardens but also contribute to environmental cleanup efforts!

GARDENTABS.COM

Invercargill Seminar 2024:

Scleroderma New Zealand Inc

ILT
For Our Community

Scleroderma New Zealand and the
Southland Scleroderma Support group presents

Scleroderma Seminar 2024

Experts and friends come together for a day of education, discussion and support

Saturday April 6th, 2024

The Kelvin Hotel
20 Kelvin Street, Invercargill
Opens 8.30am – Presentations from 9.00am
$25 per person – registration
To be paid direct to Scleroderma NZ account
38-9017-0107454-00
Please use your name and seminar as reference

This seminar is open to anyone interested in learning more about all types of Scleroderma including health workers, patients, carers, family and friends. Morning tea, lunch and afternoon tea provided.

INCLUDES PRESENTATIONS FROM:

- **Prof. Simon Stebbings, Rheumatologist Dunedin: Blood vessel problems in Scleroderma**
- **Dr. Sarah Jordan, Rheumatologist Dunedin: Lung issues in Scleroderma and treatment**
- **Dr. Katey Jenks, Rheumatologist Dunedin: Skin problems and treatment**
- **Dr. Miranda Buhler, Hand Therapist: Hand Therapy**
- **Dr Wei Zhang, Dunedin: Gastrointestinal issues for people with Scleroderma**
- **Joe Wheeler, Podiatrist Invercargill – Feet**

Scleroderma
New Zealand Inc

For more info or to register before March 22nd please contact Jenny: jennyred@xtra.co.nz or 027 3166 124

Invercargill Seminar:

Invercargill Seminar: Registration is open

To register for the Invercargill Seminar email/phone with the following details to jennyred@xtra.co.nz or 0273 166124:

NAME:
ADDRESS:
PHONE NUMBER:
EMAIL:
DIETARY REQUIREMENTS:

Thank you to all those who have registered for the seminar on 6th April 2024.

If you wish to attend please email me with your information as above as soon as possible, it says it closes on the 22 March but I will still take them up to a couple of days before.

It is $25 per head and Scleroderma New Zealand will be subsidising the rest. Morning tea, Afternoon tea and lunch will all be provided. If you wish to book accommodation at the *Kelvin Hotel* where the seminar is to be held then give them a call on *03 218 2829* and let them know you will be attending the seminar.

Thank you gifts are wrapped and ready to go to our Seminar speakers. Platters kindly handmade and donated by Jeff Andrews (someone's amazing Hubby), engraved by CSDesignz, and the beautiful cards are created by Scleroderma Members Kimberley Small and her Mum, Maureen Small. What a talented bunch you are. Your hard work is very much appreciated. ☺

Members News…

Bay of Plenty Scleroderma Group

The Bay of Plenty group met in February and will be meeting again in the coming months. If you would like to join them get in touch with Alumie Nguyen: alumie.uow@gmail.com

Hawkes Bay Scleroderma Group

Frances and Gail caught up recently to discuss their trip to Invercargill for the Seminar. They are looking forward to putting faces to names of other members.

New Plymouth Scleroderma Group

We have just had a catch up with a great turn out of seven members in the group!
And I got some photos!! .
Kelsi

Seated (left to right) Elle and Jenny.
Standing (left to right) Barbara, Judy, Kelsi, Wendy, Chris

Christchurch Scleroderma Group

The Christchurch group have had their first meeting of the year in March. A smaller turn out but they look like they had a lovely time catching up.

Jaqs and Maureen

Southland Scleroderma Group

The Southland Group met up at the Croydon Lodge in Gore on the 11th February. We had 21 turn up and it was so nice to see everyone. Sadly Heather woke that morning feeling poorly so we missed her and Graham and it means we don't have her awesome write up. It was wonderful to see Betty who hadn't been able to make it for the past year and her sister Fay who is from Auckland. We talked about the up-coming seminar and made some final decisions on that. Fleur bought along some beautiful zucchini from her garden to share with the group and Lorraine took them and turned them into a yummy relish. Gwenda showed us some of her photos from her recent wedding which was pretty special. It was a nice long lunch as "Everyone was in for a bit of a yarn" noted by Barney on the way home. Thanks all for coming along.

Members News continued...

Waipa and Waikato Scleroderma Group

Salute Masseur, Madams, here in the Mighty Waikato we have been busy in our own little paradises in the region. At least one of our families have welcomed Grandchildren into the World recently, the wonder of a new-born is still amazing folks. Our arty peoples have indulged in their passions. From garden splendour to sketching, canvass awesomeness. In light of Autumn mornings and changes during the day we have had to check out the gloves, put on an extra layer or two and shake out some long sleeve assortments. We have yet to meet as a whole group, however the use of technology is well utilised. Cricket season has meant I have seen a long-lost scleroderma mum looking very happy indeed. Our very own Rachael and I spent some time with Linda Bell. A lovely visit full of positivity and wisdom with her 36 years of scleroderma history. Warm wishes to her Coffee Group that also gave friendship and great yarns over a coffee monthly. They spend their days with fellow Rest home companions.

Out of our group we had but one successful Sunflower grower. Leah Hunt holds the flag up with her diligence in the flower scene.

Below are pictures of Rachel and her garden design over Summer. A full-on project working in with her farm jobs and mum to 3 children. Absolutely stunning folks.

Also, a picture with Linda after a Summer of ups and downs still intelligently guiding and thinking of others. She has done a hand over with resources for up-coming Seminar and fundraising she has initiating and managed over her years at the helm in the Waikato here. With a supportive whanau Linda has also donated to Waikato a Cheese board and knives for a raffle sometime. Big Thank you to son in law Baden for contributing as part of his woodwork lessons the board.

Rachel, Linda and Erena

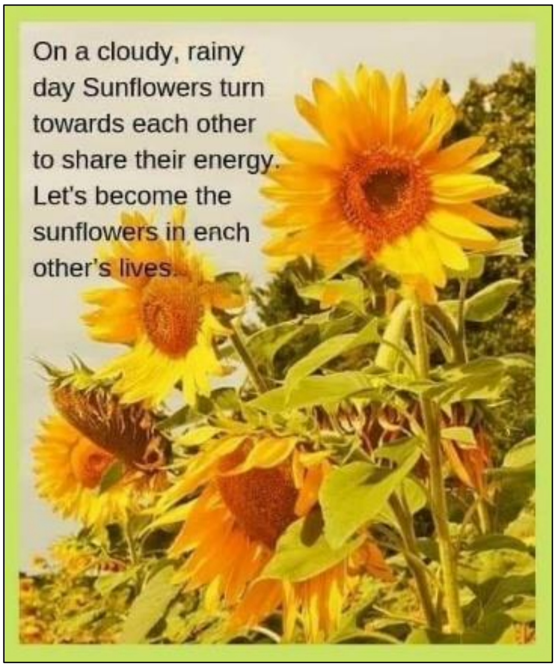
Cheese board made by Linda’s Son-n-law Baden

Auckland Scleroderma Group

Late last year Catherine Johnstone and Helen Parsons began an informal monthly coffee group for Auckland people with scleroderma and for their friends and families. This has continued to be quite a small group of supportive people. Catherine was diagnosed only recently. Helen was diagnosed just under four years ago.
We meet at the cafe (newly renamed 'Daily Bread') in Kings Garden Centre, 11 Porana Road, Takapuna.
We would like our group to grow a wee bit larger.

Our next Auckland coffee meetup is 10.00am on Monday 15th April.

Do contact us with any questions or suggestions.
Catherine Johnston
sassycat@xtra.co.nz 021 165 9511
Helen Parsons
HelenParsons@artcardsandposters.co.nz
021 248 3869



Wellington / Kapiti and Wairarapa Scleroderma Group

A huge thank you to Dianne for organising another wonderful get together for the Wellington / Kapiti and Wairarapa Scleroderma Group who met on Saturday 24 February for a lovely lunch at the Chocolate Fish café in Shelly Bay. We had a lovely turn out. Some of our members came all the way from Masterton as well Upper Hutt, Petone and Wellington. It was a lovely late summer's day with the usual Wellington breeze, so we all sat inside to keep warm. We welcomed two new members Michael and Jan returning to our group. Michael and Jan used to attend the Wellington Scleroderma meetings in the early days when the group was run by Arthritis NZ, so it was lovely to see them both again. Unfortunately, we had so much fun talking that I forgot to take photos of the group. Our next lunch get together will be in Lower Hutt at the Boulcott Farm Bar Café & Bar, on the 27th April.

Take care everyone and have a Happy Easter 😊

Tina McLean

Events Happening:

Scleroderma New Zealand Badges

Yes, the Scleroderma New Zealand badges are here ☺ The badges have now been delivered and are all ready to be sent out to our group leaders who will distribute to their members in their group catchups to any member who would like one.

These badges are free to all members, but if you would like more then 1 badge to give to your family, support person, friends or collegues, a donation is greatly appreciated to cover costs.

If you are not able to go to a group catchup or there isn't a group in your region, please feel free to email Jenny and I am sure she will be happy to send you one.

Helen Parsons with her badge

Heather Milligan with her badge

A unintentional consumer test.......
Yes, the Scleroderma badge can survive going through the washing machine, but wouldn't recommend it on a regular basis. They are made as tough as us.

Quote of the season

From Betty

People can be divided into 3 groups

Those who make things happen

Those who watch things happen

And….

Those who wonder what happened

Group Meeting Dates for 2024:

Wellington Scleroderma Support Group Get Togethers:

November 2023 – 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 27th April 2024 12.30pm	The Farm Cafe & Bar-Boulcott's Farm Heritage Golf Club	33 Military Road, Boulcott, Lower Hutt
Saturday 25th May 2024 1.30pm	Zoom meeting Sharing experiences with managing Scleroderma People from other regions most welcome.	Zoom Link to be advertised closer to the time.
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 Get Togethers:

November 2023 – November 2024

All Welcome

We welcome any new members to come along too.
Please contact:

Jenny Andrews: jennyred@xtra.co.nz 0273166124

Date	Venue and Time	Address
25th May 2024	Burwood Hospital Travis Courtyard Café Saturday 2pm – 4pm	300 Burwood Road, Burwood, Christchurch
20th July 2024	Mid Year Lunch Venue to be Adviced 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

We would like to take this opportunity to thank Dianne Purdie for her amazing support of the Christch

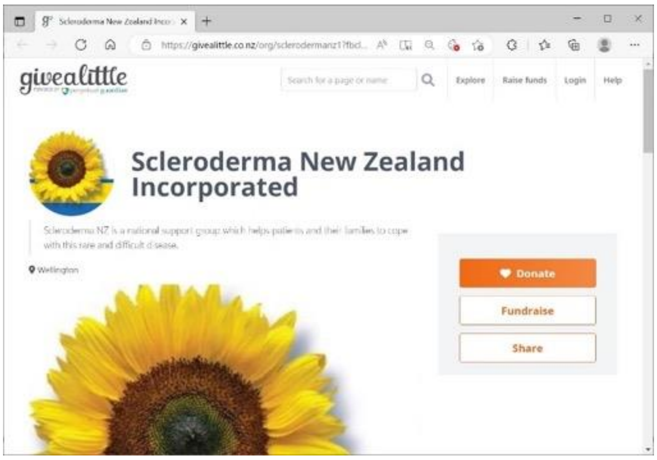
Give a little: Scleroderma NZ Inc.

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.

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
Life Pharmacy
Paper Plus
Ezibuy
Mighty Ape
Cotton On
Bargain Box
My Food Bag
Hello Fresh
Rodd & Gunn
Lego
Bras N Things
Hallensteins
Skechers

Vans
Uggs.com.au
Vistaprint
Wotif
Booking.com
Forever New
Converse
Bedpost
Bedpost
Contiki
Airbnb
Fishpond
Specsavers
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:

Venue*:* *The Farm Café & Bar*
Boulcott's Farm Heritage Golf Club
33 Military Road, Boulcott, Lower Hutt
Time: Saturday 27th April 2024 at 12.30pm
Wellington meeting dates and venues for the new year of 2024 are published above on page 17.

For any enquiries please contact Cushla:
cushla.marsters@solnet.co.nz

Christchurch support group meets:

Venue*:* *Burwood Hospital - Travis Courtyard Café*
300 Burwood Road, Burwood, Christchurch
Time: Saturdays 2 - 4pm.
Dates: 25th May 2024, 21st September 2024,
23rd November 2024
Mid Year Lunch: 20th July 2024, Saturday 12pm
Venue TBA

We welcome any new members to come along too. Please contact **Jenny Andrews** if you would like to join in:
Jennyred@xtra.co.nz **Phone:** 0273 166 124

Southland support group meets:

Saturday April 6th, Seminar, Kelvin Hotel, Invercargill

Sunday June 30th, 12pm

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.

Auckland support group:

Venue: *Kings Garden Centre Café*
11 Porana Road, Wairau Valley, Auckland
Time: Monday 11th March, 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*: TBA*
Time: April 20th 2024
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. To be part of the Hawkes Bay Group please contact Gail.
Gail Neilson: gail_neilson@hotmail.com

Bay of Plenty support group meets:

Venue: Katikati Gold Club Cafe
Meetings will be on the 1st Saturday bi-monthly.
So the next one is April 6th. More info will come out nearer the time.
Please contact one of us for information.
Jane: janepuckey99@gmail.com
Mary: marybestrd3@gmail.com
Alumie: alumie.uow@gmail.com

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

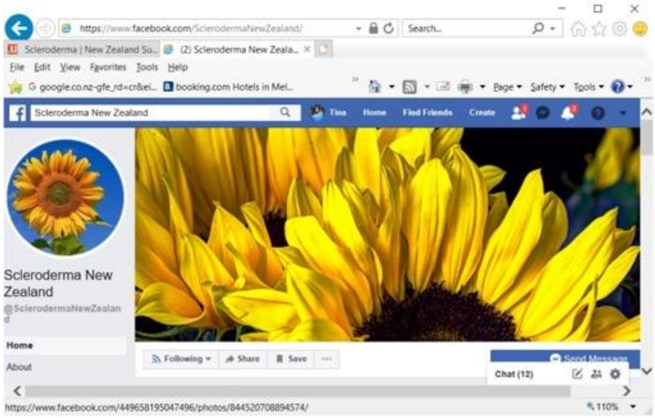
Welcome to Scleroderma New Zealand Inc.

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:	**Dianne Purdie**, Email: diannepurdie@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