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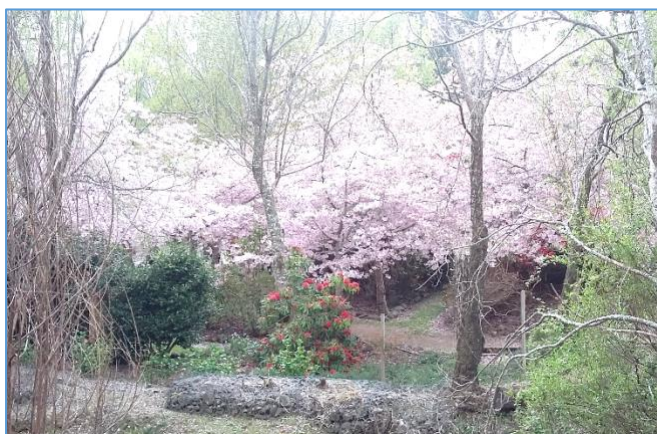
Scleroderma

New Zealand support group

SPRING 2023

Greetings to you all...

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



We hope everyone is doing well and have recovered from all the winter colds and flu's this year

Spring is finally here, and daylight savings has started, so longer days to enjoy more day time to be able to do more outside.

With Summer and Christmas only a few months away, I hope we will be having warmer days to come.

We hear first from Jenny Andrews with the Presidents report. Jenny keeps us up to date with what's happening with our community.

Heather Milligan tells us about her fantastic shoes. Helene Sunitsch shows us her beautiful hand crafted sunflowers. Heather Barker shares with us her scleroderma journey and we have Alumie Nguyen showing us some of her photos from a trip home to Vietnam. We have our regular Members News and Updates from our different support groups. There is a wee blurb about our new badges and a fun competition regarding sunflowers.

We have some information on our Invercargill Seminar and we also have some events happening in October for our members.

Be safe and take care everyone.
Warmest regards,

Tina and Jenny



Presidents Report:

Spring 2023



Hello to you all.

As I sit and write this I am sitting inside, the sun is shining and hubby is mowing the lawn. What a wonderful sound that is. It's the sound of warmer times.

I am in the process of getting things ready for our Southland Meeting which is tomorrow. Feeling a bit anxious about it as I have been treating sun damage on my face so have blisters and scabbing on my nose and under my nose. It looks terrible and I have been hiding myself away for the last couple of weeks. Still a few more weeks to go yet. Amazing how much it has affected my self-confidence. Was very grateful for my Granddaughter who told me when I had to attend my nieces 21st last weekend that if anyone laughs at my face she will tell them off. She is 5. Bless her.

We have had a few new members contact me in the last wee while so I would like to take this time to welcome you all to our group. The first stage of coping with Scleroderma I feel is the reaching out to others. This can be a very difficult time so good on you. I hope you can get something out of our newsletters, support groups and virtual education sessions.

As a committee we made the decision at our last meeting that it was time to try for another seminar now that Covid has settled down a bit and we are getting back to some form of normality. This will be on the **6th April 2024** in **Invercargill** at the **Kelvin Hotel Conference Room**. We are very excited to offer this to our members and supporters. We will update you on the details nearer the time, but at least you know the date so you could look out for cheaper flights to make your way down here. We have opened



registrations for this, and you will find everything you need to know on pages 8 and 9. If you are calling the Kelvin Hotel to book your accommodation tell them you will be attending **Scleroderma New Zealand seminar**. Their phone number is 03 218 2829. So looking forward to showing off our beautiful city to all those who haven't been here before.

We have got our Scleroderma New Zealand badges made up. These will be available to any member who wants them. Check out page 11 for details. We are always trying to put Scleroderma in the spot light and raise awareness of it. This is just another way of doing that. If anyone else has any bright ideas we are always open to anything.

We have been able to attend some great online events in the past couple of months. An amazing yoga and information session with Dr Nikki Tugnet. This was my first time doing chair yoga and it was fantastic. Thank you to Dianne for organising it with Nikki and to all those who joined in. We are so lucky to be able to join in with Scleroderma Australia and Scleroderma Victoria in their Virtual sessions. They are very interesting so if you are able to join in on one go try it out.

Jenny 😊



Scleroderma Members News:

Heather Milligan – Hoka Footwear



At the Wellington seminar in 2019 we talked about footwear, and I am sure that it was Jane Sainsbury commented that HOKA footwear worked well for her. I noted that, but reeled back in horror at the price, the cost 1 pair of shoes was about the quarter cost of a Dyson Vacuum cleaner!!! (Dyson vacuum cleaners

are my price comparison) so put that on the back burner.

Fast forward four years later, alas I was struggling with my feet, with a list of fat atrophy, sore calluses and hard to walk on the soles of my feet, remembering Jane's comment about HOKA footwear, thought I would give them a try. They are still quarter cost of a Dyson Vacuum cleaner! Reading through the HOKA website found Bondi style, men's wide fitting with plush cushioning (there are other styles with plush cushioning), they sounded delicious, took a very, very deep breath and purchased a pair online. When they arrived they looked so wide and long, but I put them on and was away walking, wow they do indeed have so much sole cushioning and do make walking easier.

Thank you, Jane, I think I would never would have looked at HOKA footwear as I thought they were aimed at professional marathon type people. Now I worry I might be walking along, and a group of runners might zoom past and because I am wearing HOKA footwear I would feel obligated to join them.

Views expressed are my own on HOKA footwear. If you are interested in purchasing, there are a number of New Zealand shoe retailers that stock HOKA footwear.

Heather Milligan



Helene Sunitsch – Making Sunflowers



Helene has now retired from work which has given her more time for the things she loves, like crochet and knitting. Helene has made these beautiful sunflowers and is selling her craft at the local market and online. Well done Helene they are lovely. 🌻



Members Stories:

Heather Barker: My journey



I'd like to start by thanking those people who have shared their stories about living with scleroderma. I often find the information, thoughts and ideas helpful when I read our newsletter.

I'm 67 now, and my journey with scleroderma started when I was in my early 20s. I had a young family and had

had several operations for endometriosis. My first recognizable symptoms for an autoimmune disease was Raynaud's which at the time was quite frightening.

My local GP advised that I take some paracetamol and join a tennis club to keep occupied, this was not particularly helpful and I often thought I must be imagining the discomfort and difficulties I was having with swallowing, pneumonia and painful joints. Luckily for me my GP was away and the locum was married to a rheumatologist. After a few minutes she suggested I needed a referral and further testing. The next 20 years had many challenges and there were times when it was difficult to imagine I would get to my 40th birthday. Before the internet it was hard to get information about specific blood tests and helpful hints dealing with Raynaud's or dry mouth.

My rheumatologist scheduled me for regular blood tests but was unable to give me a diagnosis. It was possible I had lupus or maybe a mixed connective tissue disorder or Sjogren's. I joined a lupus support group and discovered many others living with a chronic condition. Like many of you I had been prescribed some fairly harsh medications which in hindsight made me feel worse. Eventually in my 30s I was diagnosed with scleroderma and was given information about a local Auckland support group. This is where I met a friendly group coordinated by Jenny Gadd and her family. I met people who were in their 60s and 70s so that gave me some hope that I would be one of the lucky ones.

As the years have gone by, I better understand my condition and have tried to make sure I don't get over tired and if possible, reduce my stress levels. It seems sometimes I get one bit of my body that works, while another battles with my immune system. Currently I am frustrated with colorectal issues, joint pain and more recently breathlessness with heart palpitations. I'm

pleased to say that throughout covid lockdowns I've still been able to receive excellent medical care both from my GP and Auckland Hospital with the exception of my ongoing bowel issues.

I thought some of our extended group throughout New Zealand maybe interested to know that I recently attended as a 'patient' for the Australasian doctors' exams. I'm not sure if anyone else has had this opportunity but I find it very interesting. I had to wear a mask and casual clothing. The doctor candidates only know I have painful hands. They examine my hands and have to give a differential diagnosis to the specialist doctors who are in the room observing. I'm pleased to say that most of the candidates come up with a diagnosis of scleroderma within five minutes. They must give evidence to the doctors and justify their opinions. The final part of the examination is when the candidates are handed a list of my most recent blood test results. Usually at that point they add lupus as a possibility but generally each of the candidates sum up my general health and further testing for pulmonary hypertension and renal failure. All of the examination takes place in a small consultation room with me not talking (which isn't easy for me) and wearing a mask. It is a great opportunity to spread information about our unusual autoimmune disease and would recommend it to others in similar circumstances.

Best purchases for me have been an ORBI can opener, the design makes it easier for me to grip and leaves a smooth and safe cutting edge. They seem to retail between \$22 and \$35.



Also, an onion chopper from Kmart or The Warehouse less than \$10

Heather Barker - heatherandbrian@xtra.co.nz



Members Stories:

Alumie Nguyen – Going Home to Vietnam



This winter, I experimented with exchanging the coldest time in New Zealand with a warmer time in Vietnam. After two years of Scleroderma and learned how to manage my symptoms, during this trip home, I felt better than the last.

I spent a whole month away, but it was the wrong time of the year to visit a tropical country with all the heat and torrential rain!

Despite spending a lot of time indoors, more than I should have, I did manage to sneak out when the weather was kind enough and enjoy the moments. Here are my three best photos of the trip (unfortunately, either I was too quickly gobbling down the food or I preferred leaving the photo taking task to my siblings) Singapore Airport has never disappointed me! I love how they have united theme indoor garden spaces throughout the airport. I took too many photos of their orchids, but I want to share this photo of the lovely snail pot! The only kind of snail I would allow in my garden!



Apart from a chance to catch up with my family and friends and escape the winter, food is the real reason for my trip home. This is one of my favourite dishes - crispy pork with woven fine rice vermicelli noodles. Even though there are so many Vietnamese eating places in New Zealand now, the selection and amount of herbs you get to have with the dishes in Vietnam is what I miss the most.



The last photographic highlight of my trip is Wat Arun Buddhist temple in Bangkok, Thailand, decorated with colourful porcelain shards and Yaksha guardian figures. I love how different Buddhist temples are in each country. There were a lot of tourists at the place, and we were walking around in single file with not many photo taking opportunities. However, a sense of humbleness and tranquillity washed over me as I looked up at these structures.



Southeast Asia is full of small countries but our cultures and development are so distinctive that I learned so much with each trip. I definitely need to keep my health in check so that I have more opportunities to go out there.



Scleroderma Treatment Options:

From Johns Hopkins Scleroderma Center website:

The following is an excerpt from chapter 23 of Systemic Sclerosis, 2nd Edition written by Dr. Laura Hummers and Dr. Fred Wigley. Download the full chapter at the bottom of this page.

Because no two cases of Scleroderma are alike, identifying your disease subtype, stage, and involved organs is very important in determining the best course of action for treatment. Current therapies use medications that focus on the four main features of the disease: inflammation, autoimmunity, vascular disease, and tissue fibrosis. Your physician will work with you to identify the treatments that are best for you, but here are some common treatment options:

ANTI-INFLAMMATORY MEDICATIONS

Many medications are thought to directly or indirectly affect inflammation. In scleroderma, there are two major types of inflammation that are related to the disease process. The first is a more conventional type that can cause arthritis (inflammation in the joints), myositis (inflammation in the muscles), or serositis [inflammation in the lining of the heart (pericarditis) or lining of the lung (pleuritis)].

This type of inflammation responds to traditional anti-inflammatory drugs: [NSAIDs](#) (e.g. [ibuprofen](#)) or [corticosteroids](#) (e.g. [prednisone](#)). The duration of therapy and the dose of medication are dictated by the specific situation. Some patients will need chronic administration and others will recover after a limited course of therapy.

The other type of inflammation relates to the skin and other tissue injury caused by the scleroderma process. This phase of the disease does not appear to respond to NSAIDs or corticosteroids, although the exact role of corticosteroids is not fully studied. There are risks associated with the use of these agents, including gastrointestinal disease, fluid retention, and renal toxicity. Corticosteroid use is also associated with an increased risk of scleroderma renal crisis. Therefore, it is recommended that the use of NSAIDs and corticosteroids be limited to inflammatory states that demonstrate responsiveness.

IMMUNOSUPPRESSIVE THERAPY

The most popular approach to controlling the inflammatory phase of scleroderma is the use of immunosuppressive therapy. The rationale is that an autoimmune process is causing the inflammation and the downstream result is tissue damage and fibrosis. In this model, the fibrosis is an “innocent bystander” that is driven by the cytokines (chemical messengers) produced by the immune system. There are several drugs that are being used, but only a few well designed studies have been performed. These [immunosuppressing drugs](#) include [methotrexate](#),

[cyclosporine](#), [anti-thymocyte globulin](#), [mycophenolate mofetil](#) and [cyclophosphamide](#).

A recent study suggested that methotrexate did not significantly alter the skin score (a measure of skin thickening) compared with placebo (no treatment). Cyclosporine is not completely studied due to reports of renal toxicity. The most promising drugs are mycophenolate mofetil or cyclophosphamide with or without anti-thymocyte globulin. Unfortunately, there is no placebo-controlled study (i.e., half the patients get the medication and half get a sugar pill) to define their exact role in treating scleroderma, but if used during the active inflammatory phase of the disease, they appear to work.

A major area of current research is the use of aggressive immunosuppressive therapy either with very-high-dose cyclophosphamide or with autologous bone marrow transplantation. Because these aggressive forms of immunosuppressive therapy have potential risks, they should be used in severe cases of scleroderma and administered as part of a research protocol.

DRUG THERAPY OF VASCULAR DISEASE

The vascular disease in scleroderma is widespread and affects medium and small arteries. It is manifest clinically as Raynaud’s phenomenon in the skin, and there is evidence that repeated episodes of ischemia (low-oxygen state) occur in other tissues. Low blood flow into the skin and tissues is thought not only to damage tissue by the lack of nutrition and oxygen but to activate fibroblasts and promote tissue fibrosis. Therefore, treatment of the vascular disease is now considered crucial to controlling the disease as a whole as well as preventing specific organ damage. There are three major features of the vascular disease that potentially need treatment: vasospasm (spasm of blood vessels), a proliferative vasculopathy (thickening of blood vessels), and thrombosis (blood clots) or structural occlusion of the vessel lumen (blockage of blood vessels).

Vasospasm is best treated with vasodilator therapy (drugs that open blood vessels). The most effective and popular [vasodilator therapy](#) continues to be the [calcium channel blockers](#) (e.g., [nifedipine](#)). Studies demonstrate that the calcium channel blockers can reduce the frequency of Raynaud’s phenomenon attacks and reduce the occurrence of digital ulcers. It is now known that the microcirculation of each organ has a unique mechanism for controlling its own blood supply. The skin blood flow is regulated by the sympathetic nervous system; the kidney blood flow by locally produced hormones such as renin; and the circulation in the lung by endothelin, prostaglandins and nitric oxide.



Scleroderma Treatment Options continued

From Johns Hopkins Scleroderma Center website:

There are very specific agents to counteract the negative influence of the scleroderma vascular disease on each involved organ. For example, the calcium channel blockers are reported to help blood flow to the skin and heart; angiotensin converting enzyme inhibitors (ACE) inhibitors reverse the vasospasm of the scleroderma renal crisis; and bosentan (a new endothelin-1 receptor inhibitor) or epoprostenol (prostacyclin) improve blood flow in the lung.

Although there are several vasoactive drugs on the market that are being used to treat vascular disease, there is no agent that is known to reverse the intimal proliferation (thickening of the inner layer of the blood vessel) that is part of the scleroderma vascular disease. Drugs that reverse vasospasm (calcium channel blockers, bosentan, prostacyclin, or nitric oxide) all have the potential to modify the course of the disease. There is evidence that these vasodilators may also directly affect the tissue fibrosis. For example, bosentan may be of benefit because it inhibits endothelin-1, a molecule produced by blood vessels that can also directly activate tissue fibroblasts to make collagen.

The final outcome of untreated scleroderma vascular disease is occlusion of the vessels by either thrombus formation or advanced fibrosis of the intima. Therefore, anti-platelet therapy in the form of low-dose aspirin is recommended. Good studies to determine if antiplatelet or anticoagulation therapy is helpful do not exist. In an acute digital ischemic crisis (sudden development of threatened loss of a digit), anti-coagulation (use of blood-thinning medications) is often used for a short period.

ANTI-FIBROTIC AGENTS

It has been known for years that, in scleroderma, excess collagen is being produced in the skin and other organs. Several drugs are used that have in vitro (in the tissue culture) ability to reduce collagen production or to destabilize tissue collagen. The older medications in this category include [colchicine](#), [para-aminobenzoic acid \(PABA\)](#), [dimethyl sulfoxide](#), and [D-penicillamine](#). Although there is evidence for and against the use of these agents, most experts are disappointed with them and believe that the benefit either does not exist or the drug is not potent enough to warrant its use. D-penicillamine remains a popular alternative for some experts, despite a controlled trial demonstrating no difference between low and high doses of the drug.

The search for new drugs that alter the fibrotic reaction is probably one of the most active areas of scleroderma research. Strategies include directly suppressing the fibroblast and its ability to make collagen, inhibiting the cytokines that activate the fibroblast, and the use of agents that might break down collagen faster and promote tissue remodelling.

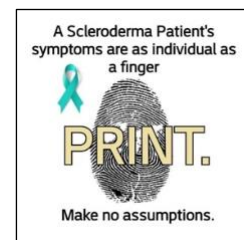
ACTIVE CLINICAL TRIALS

The Center is actively participating in clinical trials of new therapies that may improve our patients' quality of life and better control disease activity. Current, active clinical trials are listed here.

FURTHER READING

For a more in-depth understanding of the comprehensive care related to scleroderma download [Chapter 23 of Systemic Sclerosis](#) (pdf) by Dr. Laura Hummers and Dr. Fred Wigley.

<https://www.hopkinsscleroderma.org/patients/scleroderma-treatment-options/>



Invercargill Seminar:



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 pp - registration



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:

TO BE CONFIRMED BUT WATCH THIS SPACE ☐



**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: 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:



Members Update:

Podiatrists and Fingernail cutting

We are waiting to hear from Podiatrists throughout the country who are able to cut fingernails as well as toe nails. This is fantastic news as there has never been anyone specifically able to cut our fingernails. So far we have heard from a couple of them. Please see below.

**Jessica Dobbs Podiatry is a Hamilton based Podiatry clinic in Flagstaff, Hamilton and also specialize in mobile podiatry across the Waikato.*

Our Podiatrist are trained in fingernail cutting and are happy to assist your members

**Dr Althea Carruth – Central Otago*

Dr Carruth does this only as part of general foot care. To get in touch with her, her contact details are 02041785262

Information Wanted:

Is there anyone out there who has a PeG or PeJ fitted and if so, has it helped to increase weight? We have a member whose weight has dropped to 39kg and was wanting to know some information about it before going ahead with it. If you can share any info please get in touch with me on 0273166124 or jennyred@xtra.co.nz



Information Shared:

We have a member who shared the following with us: I was diagnosed in April and Raynaud's Phenomenon developed with it to the extent that quite large ulcers developed on the ends of both middle fingers plus numerous small sores on other fingers.

About 3 weeks ago I decided to apply vitamin E oil on all these wounds and have been quite successful so far to the extent that the ulcer on the middle right finger has lost its raw scab and looks like it may heal. Although the hardness around the top of the finger is still there the pain felt when knocking it is markedly reduced.

The sores which appear along the fingers disappear after many days treatment.

I put 2 or 3 drops in the palm of one hand and dab it on the affected parts of the other hand 2 or 3 times a day.

Andrew, Otago



Members News



Bay of Plenty Scleroderma Group

The Bay of Plenty group haven't had a catch up during the Winter months and will be looking forward to seeing each other again soon.



New Plymouth Scleroderma Group

We had six members come on a lovely sunny winter's day, and a new member joined us, so welcome to Chris. And our thoughts are with those currently fighting flare ups and challenges.

Next time I'll have a photo too!

Kelsi



Waikato Scleroderma Group

The Waikato Group are having some changes, Linda has stepped down due to health reasons. We thank you so very much Linda for everything you have done for the members in the Waikato area over many years. It is very much appreciated. Erena and Rachel have taken on the job as organisers at this stage. Check out our Group Meetings page to see what is happening.



Hawkes Bay Scleroderma Group

The Hawkes Bay group met up on the 15th of September in Hastings. ☺



Auckland Scleroderma Group

We have a new group starting up in Auckland thanks to Helen Parsons and Catherine Johnston. They met up recently and are now organising casual monthly coffee meetings. Check out our Group Meetings page.



Christchurch Scleroderma Group

The Christchurch group had their coffee meeting at the Burwood Travis Courtyard Cafe.

Looks like they all had a great time ☺. Thank you Jacqui for the lovely photo from the Sunflowers in CHCH and thank you to Dianne for organising this.



Wellington Scleroderma Group

Thank you to Dianne for organising another wonderful Wellington group lunch this month. We all met on a lovely sunny day in early September at the Fisherman's Table in Paekakariki. . We had a lovely turn out, and enjoyed catching up with each other while having a delicious lunch. We welcomed new members Fiona and Allan to our group and was wonderful to be able to catch up with everyone. Tina ☺



Members News continued...



Southland Scleroderma Group

Southland Group get together 10th September.

Thank you to Jenny for organising our get together in Invercargill and thank you to those who were able to attend. A warm welcome to a new member Fleur.

Lovely to catch up with everyone. We all seemed to have got through winter pleasingly, but one of our members Mary said she had quite a time in the very cold days with putting Nitroderm patches in areas that looked and felt as if they were going to develop into ulcers, she did succeed as she did not develop any ulcers.

It's not often we get good news in our group, one of our members was put on a high dose of Mycophenolate (CellCept) which works on lymphocytes (white blood cells) to lower the activity of the immune system to see if it would bring her haemoglobin levels up..... and yes it is working. We were also delighted to meet Gwenda's fiancé Ronnie.

A new beginning for Kimberley who shifted up to Ashburton 2 days after our get together. Best wishes Kimberley and remember your promise that you will be back for the seminar in April.

We did enjoy Lorraine's banter with one of the waiters when ordering her lunch, she was unsure if she wanted pork or whitebait. He kidded her into the whitebait, as he so rightly said it is so rarely on the menu, she and others who ordered the whitebait were very impressed with the meal. A good choice Lorraine.

We are now looking forward to our last meeting of the year.

Heather Milligan



Scleroderma New Zealand Badges

Yes, the Scleroderma New Zealand badges are here 😊



Thank you to our wonderful president **Jenny** who has got our Scleroderma New Zealand badges completed and ordered. 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 than 1 badge to give to your family, support person, friends or colleagues, 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.

Planting Sunflower Seeds in October..



Thinking of doing something fun this year as part of our Scleroderma New Zealand group?

Why not plant sunflower seeds this summer.

Take Photos of your sunflower growing and load them up on our Scleroderma New Zealand Facebook page:

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

We will discuss and compare pictures, check who has the tallest sunflower, who has the largest flowers, who has the prettiest, who has the fastest growing sunflower?

We will send further information..

Follow us on our Scleroderma New Zealand Facebook page:

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



Events Happening:

In 2023, Mental Health Awareness Week (MHAW) was held on: 18 – 24 September...

MHAW is run annually by the Mental Health Foundation and has been since 1993. MHAW is endorsed by the World Federation for Mental Health and is marked in over 150 countries at different times of the year.

This year's Mental Health Awareness Week theme is **Five Ways, Five Days**. Life has been a rollercoaster lately, with stress and overwhelm hitting us from all angles. We've faced uncertainty, unfamiliarity, and hardships that have left us with mixed emotions. That's why we're bringing you the **Five Ways** for the **Five Days** of MHAW, to give us a set of proven tools to boost our mental health when we need it.

<https://mhaw.nz/explore/about/>

Take Notice | Me Aro Tonu – Monday Take Notice refers to the practice of mindfulness. Mindfulness can be thought of as open and receptive attention to, and awareness of, what is occurring in the present moment.

Give | Tukua – Tuesday Give refers to actions based on kindness, altruism, or generosity. Carrying out acts of kindness boosts our happiness, life satisfaction, and overall wellbeing.

Be Active | Me Kori Tonu – Wednesday Widely recognised as being crucial for physical health and fitness, being active is also a powerful mood booster. Being active can not only make us feel good, it also enhances our thinking and learning abilities.

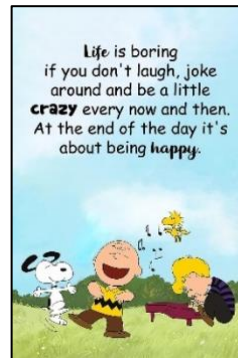
Connect | Me Whakawhanaunga – Thursday Connection is the ngākau/heart of our wellbeing. It weaves us together, making us feel seen, heard, and understood. When we nurture meaningful connections with others, we fuel our own happiness.

Keep Learning | Me Ako Tonu – Friday Keep Learning refers to 'exercising our mind' – almost like taking our brain to the gym. Any activity that challenges our thinking and expands our consciousness improves our ability to think.



Each of the daily activity suggestions in this guide are also informed by a Te Ao Māori perspective and Te Whare Tapa Whā, a holistic model of health developed by leading Māori health advocate and researcher Tā Mason Durie in 1984.

For further information on the Five Ways to Wellbeing visit www.mentalhealth.org.nz/wellbeing.



Don't forget to register for the seminar!!!!

See page 9



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Scleroderma New Zealand Inc

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



Events Happening in October:

Webinar Seminar invite from Arthritis NZ



Invitation to a transformative breathwork experience

We are thrilled to invite you to our **upcoming event** that explores the breath for **pain and stress management**.

Date: **Thursday, 12 October 2023 - World Arthritis Day!**
Time: **7 pm to 8 pm**
Place: **Online via Zoom**

Living with arthritis comes with many challenging moments. Moments of frustration, anger, sleeplessness, and relentless pain and fatigue. During this workshop, various **breath techniques** will be covered to help ease some of the frustrations that come with living with arthritis.

Controlling our breathing is a **powerful tool** when it comes to our health. There is a whole system that comes from ancient teachers of yoga, Buddhists, monks and various other practices to develop peak performance health at the physical level, as well as the mental and spiritual level, by using the breath alone.

This event will be led by an **experienced facilitator** who will guide us through a series of breath techniques and meditative practices, creating a safe and sacred space.

During our time together, Natasha will guide you through some breath techniques to help:

- **Regulate** your immune system
- **Calm** your mind when anxiety or overwhelm kicks in
- Fall **asleep** at night
- **Ease** tension and pain in the body

You will leave with techniques to use anytime to **support your health**. The beautiful thing about this is that you leave with the power in your hands.

Feel free to pass this email invitation on to friends, family, or colleagues who may be interested in joining us. We look forward to sharing this experience with you.

[Click here to register for the webinar](#)



Our Voice of Rare Disorders survey 2023 is now open – please share!

It's time for Rare Disorders NZ's biannual survey on living with a rare disorder in Aotearoa New Zealand!

Currently, no comprehensive data is collected on rare disorders in New Zealand, which is why our biannual surveys are so vital to fill the current data gaps.

Through this survey we hope to collect much needed data on what it means to live with a rare disorder in New Zealand in 2023 and what barriers people continue to face within the health and social systems to access the care they need.

This data will be used to inform and educate stakeholders and policy makers and to continue to push for meaningful change for people living with a rare disorder.

It is crucial to the success of our survey to have as many respondents from the rare disorder community as possible. We therefore kindly ask that you share this information with your networks and anyone you have contact with in the rare disorder community and encourage them to participate as well.

This survey is open to anyone who is living with a rare disorder in New Zealand, as well their whānau and carers. **The survey will close on October 31st.**

[You can find the survey here.](#)

Thank you for your help and support.

Rare Disorders New Zealand

<https://rdnz.nationbuilder.com/>



Group Meeting Dates for 2023/2024:

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

Dianne Purdie: diannepurdie@xtra.co.nz Ph 04 479 5548

Date & Time	Venue	Address
Saturday 4 th November 2023 Time TBC	Zoom meeting Sharing experiences with managing Scleroderma People from other regions most welcome.	Zoom Link to be advertised closer to the time.
Saturday 25 th November 2023 11.30am	The Farm Cafe & Bar- Boulcott's Farm Heritage Golf Club	33 Military Road, Boulcott, Lower Hutt
Saturday 24 th February 2024 12.30pm	Chocolate Fish Cafe	100 Shelly Bay Road, Miramar
Saturday 27 th April 2024 12.30pm	The Farm Cafe & Bar- Boulcott's Farm Heritage Golf Club	33 Military Road, Boulcott, Lower Hutt
Saturday 25 th 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 20 th July 2024 12.30pm	Mid-Year Lunch Fisherman's Table	29 State Highway 59, Paekakariki
Saturday 21 st September 2024 12.30pm	Chocolate Fish Cafe	100 Shelly Bay Road, Miramar
Saturday 23 rd 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:

Dianne Purdie: diannepurdie@xtra.co.nz Ph 04 479 5548

Date	Venue and Time	Address
25 th November 2023	Burwood Hospital Travis Courtyard Café Saturday 2pm – 4pm	300 Burwood Road, Burwood, Christchurch
23rd March 2024,	Burwood Hospital Travis Courtyard Café Saturday 2pm – 4pm	300 Burwood Road, Burwood, Christchurch
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 Advised 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](#)

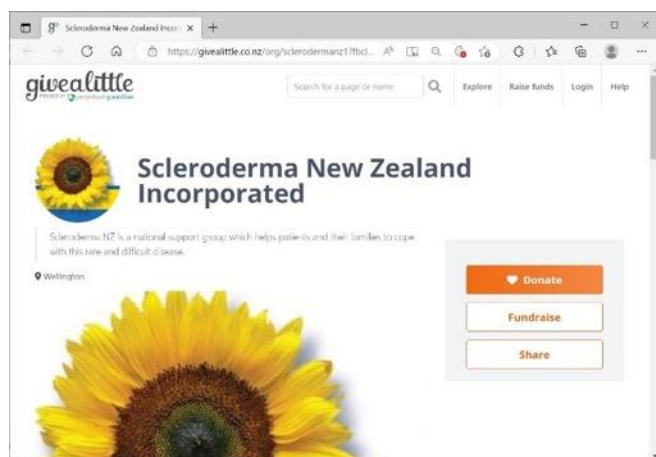


Scleroderma New Zealand Incorporated

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](#)



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

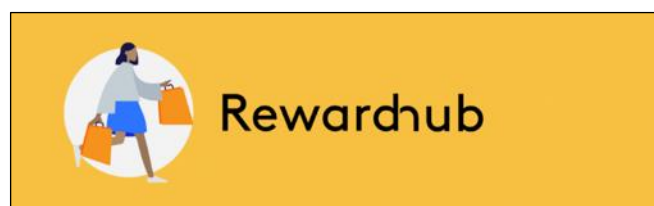
<https://givealittle.co.nz/org/sclerodermanz1?fbclid=IwAR29Znk701JSOwf9n0Ew-O63nj0FrySOCpV44mBCpIPhtXV7Uff9KIAnAzM>

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

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

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

Scleroderma NZ Inc. Shopping



REWARDHUB

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

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

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

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

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



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

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

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



Group Meetings:

Wellington support group meets:

Venue: *The Farm Cafe & Bar - Boulcott's Farm Heritage Golf Club.*
33 Military Road, Boulcott, Lower Hutt

Time: Saturday November 25th 2023, 11.30am

Wellington meetings have new dates for the remaining year of 2023 and the new year of 2024 are published above on page 14.

For any enquiries please contact Dianne:

diannepurdie@xtra.co.nz

Christchurch support group meets:

Venue: *Burwood Hospital - Travis Courtyard Café*
300 Burwood Road, Burwood, Christchurch

Time : Saturdays 2 - 4pm.

Date : November 25th 2023

23rd March 2024, 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 Dianne Purdie if you would like to join in:

diannepurdie@xtra.co.nz Phone: 04 479 5548

Southland support group meets:

Sunday November 19th, 12pm. venue TBA

Sunday February 11th, 12pm. Venue TBA

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/Waipara support group meets:

We have confirmed our end of year function for Waikato/Waipara

Venue: *Matamata, Venue be Advised,*

Time : Saturday, November 11th, 12.30pm

More information will be made available closer to the time but mark date, time and town in your diaries.

If you would like to join in with the Waikato/Waipara 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:

Auckland's New Group have their first meeting:-

Venue: *Kings Garden Cafe*
Kings Plant Barn
TAKAPUNA
11 Porana Road
Wairau Valley
Auckland 1025

Time: Monday 30th October, 10.00am

To be held monthly. And a reminder email to be sent out one week prior to each meeting.

For any enquires please contact either:-

Helen Parsons

HelenParsons@artcardsandposters.co.nz

Catherine Johnston

Sassycat@xtra.co.nz

New Plymouth support group meets:

Venue: *The Bach on Breakwater*

Time: Saturday 21st, October, 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, to be part of the Hawkes Bay Group please contact Gail.

Gail Neilson: gail_neilson@hotmail.com

Bay of Plenty support group meets:

Venue: *Tauranga Bethlehem Palmers Garden Centre*

Time : Saturday, October 7th, 10.00am

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.

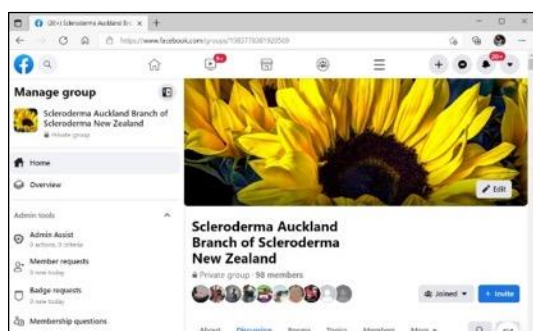
Link to our Website address below: -
<http://scleroderma.org.nz/>



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/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

