

Welcome .....	1
President's Report .....	2
Memorial for Leeanne Buckingham.....	3
Members Stories —.....	4
COVID-19 Vaccination, Prevention, and Treatment for Patients with Scleroderma .....	5
How to get the most out of your Appointments....	7
YouTube Video Clips on Scleroderma from SRUK..	8
Taking Charge of Systemic Sclerosis (TOSS) .....	9
Ultrasound Plus Manual Therapy Helps in Healing Digital Ulcers .....	10
Rituximab May Ease Arthritis in Longtime SSc.....	11
Covid-19: Update (17June 2022).....	12
Covid-19: Help when you are self-isolating.....	13
If your support worker or carer gets COVID-19 ....	14
Emergency Care Planning Tools .....	15
Members News .....	16
Scleroderma NZ Inc. Fundraising - Cards .....	18
Notice Board / Contacts.....	20
Scleroderma NZ Inc & Zoom Link .....	21

# Scleroderma

## New Zealand support group

## Winter 2022

Greetings to you all.

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



We hope everyone is well and keeping safe.



We are already half way through the year, and winter is upon us. I hope everyone is keeping warm and well wrapped up. If you haven't had a flu injection, it's not too late to get your flu jab, I hear that this year's flu is going to be pretty bad.

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 a Memorial page for Leeanne Buckingham, our member from the Southland Scleroderma group. Leeanne was very positive and will be very much missed by her group.

We have stories to share from our members.

We have an interesting article from **Scleroderma Foundation** regarding COVID-19 Vaccination, Prevention, and Treatment for Patients with Scleroderma.

There are some links to **YouTube** video presentations produced by **SRUK** (Scleroderma & Raynaud's UK) that members may be interested in watching. We also have some interesting articles from **Scleroderma News** about Digital Ulcers and a study of the use of Rituximab to ease arthritis in long term Systemic Sclerosis.

For our members who have recently been diagnosed, you may find a website called Self-Manage Scleroderma useful. This website has information and module lessons on **Taking Charge of Systemic Sclerosis** (TOSS).

We have our regular **Covid-19 updates**, including Help when self-isolating and if your Carer gets Covid-19.

We have our regular Members News from our different support group a small section about information on our **Scleroderma fundraiser**.

Be safe and take care everyone.  
Warmest regards,

Tina and Jenny



# Presidents Report:

## Winter 2022



A big welcome to all our new members. I wish you all the very best in your journey with Scleroderma. We have 11 different support groups throughout the country and there will hopefully be one near you. Thank you to all those wonderful people who have put their hands up to organise the support groups. Without you they would not exist so it is very much appreciated.

We are on track with our gift card fundraiser. I am seeing some beautiful artwork and photography coming in which is fabulous. Please get your work in to me asap as we will close it off in the next week or so.

Thank you so much to our committee for your continued support. Maureen, Linda, Erena, Cushla, Heather, Dianne and Catherine. Sadly, we had Julie and Adrienne resign this year. We are sorry to see you go but appreciate what you have done for us, thank you so very much. We have our AGM in June which is open to all members of Scleroderma NZ so please nominate yourself or someone else to come and join us on the committee. Feel free to nominate someone for our office bearer positions also.

Thank you to Tina for all your help during the year as Vice President and also fellow editor of the newsletter. I appreciate what you do for Scleroderma NZ.

Thank you to Gordon for his continued work as Treasurer and also for keeping our website up to date.

Thank you to Jane for continuing on as Secretary even though she and her husband John have moved back to the US. Now that is an awesome commitment.

We are all volunteers and together we make a pretty great team.

I know that Covid has entered some of your homes during the past 6-12 months and has been really rather difficult for some. It is important to keep in touch with each other and reach out if you need help, or if you know someone who is struggling. Please take care of yourselves and do what you can to stay safe.

Rug up warm when venturing outdoors, keep your core warm, and don't forget your hat and gloves.

All the best  
Jenny





# Memorial for Leeanne Buckingham

**BUCKINGHAM, Leeanne Marie (nee Stratford):**

**Aged 54, on Sunday, March 13, 2022**



**Scleroderma New Zealand Member**

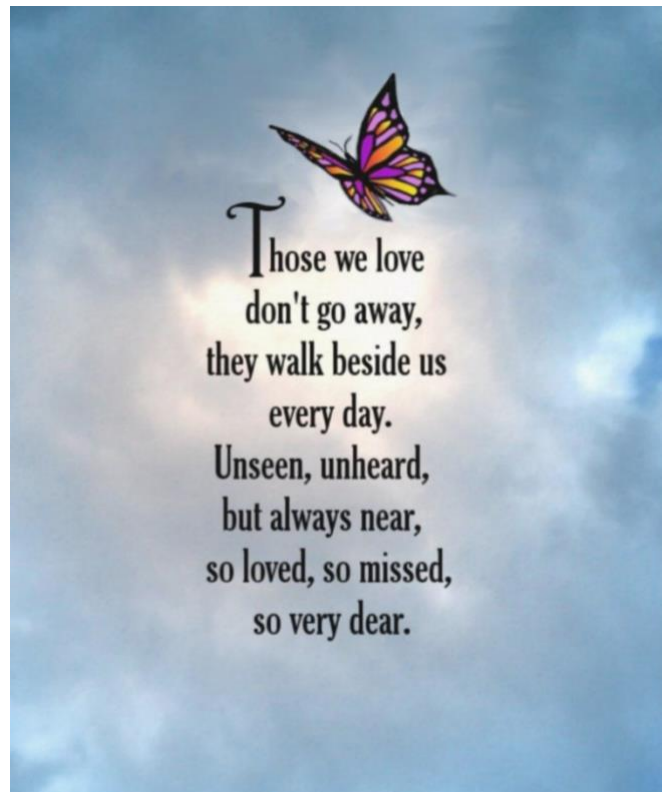
**Leeanne Buckingham**

Leeanne passed away peacefully surrounded by her family at home, after a year long journey with cancer. Leeanne was a dearly loved partner, mother, mother-in-law, Grandma, daughter, sister, sister-in-law and Aunt.

Leeanne joined the Southland Group a few years back and was a respected member of the group. She was a very positive person and would never complain even when she had so much pain going on. Leeanne attended our last get together in November and had been fighting very very hard against cancer. She was looking lovely in her wig and was always smiling. She had many trips to Auckland where she was under a specialist up there so had to be away from home a lot. It took great courage.

Leeanne will be sadly missed by the Southland Group.

Do not stand at my grave and weep  
I am not there. I do not sleep.  
I am a thousand winds that blow.  
I am the diamond glints on snow.  
I am the sunlight on ripened grain.  
I am the gentle autumn rain.  
When you awaken in the morning's  
hush  
I am the swift uplifting rush  
Of quiet birds in circled flight.  
I am the soft stars that shine at  
night.  
Do not stand at my grave and cry;  
I am not there. I did not die.



# Members Stories:

## Helen Parsons – “Sunflower Lanyard”

Thank you to Helen Parsons for giving us some information about the Hidden Disabilities Sunflower Lanyard from Auckland Airport.

The Sunflower Lanyard acts as a discreet sign that the wearer (or somebody who is with them) has an invisible disability and requires additional assistance. There is no qualifying list to being able to access a lanyard as we do not exclude people who have yet to be diagnosed and whose daily life is made more challenging by their hidden disability. The Hidden Disabilities Sunflower ID card holder is inside a clear wallet that is clipped to your lanyard. You can add your details on its back.

It is made out of waterproof and writable paper which is 100% recyclable.

**What to expect when you are wearing a lanyard**  
Auckland Airport staff recognise the Sunflower Lanyard and can support you with the assistance you may need at different stages of your journey through the airport.

**What the lanyard does not do** - The Sunflower Lanyard does not entitle you to fast track or jump queues and does not provide you with a personal staff escort through the airport.

It does ensure that our staff are aware of a hidden disability or access need and can support you if extra assistance is needed while you are in the terminal. All airlines operating from Auckland Airport offer wheelchair and other assistance to help passengers with reduced mobility. If you have limited mobility or other access needs it is important that you inform your airline and speak to them about the kind of assistance you need. Please do this either when you book your flight or at least 48 hours before you start your journey. This will help ensure that your airline is able to provide you with the right support within the airport terminals and on board the aircraft.

[https://www.mobilitycentre.co.nz/shop/daily-living-kitchen-aids/disability-aids/sunflower-lanyard-combo/?gclid=CjwKCAjw77WVBhBuEiwAJ-YoJJJ8UOcCyaa47mFUZAbXWEeqLsIQ8kK11SqOyElFD8WCRG0r13uN2BoChBcQAvD\\_BwE](https://www.mobilitycentre.co.nz/shop/daily-living-kitchen-aids/disability-aids/sunflower-lanyard-combo/?gclid=CjwKCAjw77WVBhBuEiwAJ-YoJJJ8UOcCyaa47mFUZAbXWEeqLsIQ8kK11SqOyElFD8WCRG0r13uN2BoChBcQAvD_BwE)



# Members Stories:

## Linda Bell – “Covid”

Yes I have had Covid..

The Grandchildren and their families got it first as they have school age children who became unwell and passed it around. So we were busy helping, no contact, seeing them through the window.. They were all very unwell even the 4 month old baby.

Then the other Granddaughter and family went down, they also were very unwell.

My daughter and her husband both work in retail and came home and said they felt unwell, coughing, tired.

During the night both became very unwell.

Next day took a test and were both positive. So I kept out of the way, they reported on covid site and I then became a close contact and had to have a test on 3<sup>rd</sup> and 7<sup>th</sup> day.

Which I did, 3<sup>rd</sup> day negative, but both my daughter and her husband were very bad mostly sleeping, coughing. But then during the next day I started feeling hot then cold and strange. So did another test which was positive. I reported this on covid site and received a phone call from my GP which he rang every other day He was very concerned but so was I.

I always said that I would probably end up in hospital. But no I felt very tired, slight cough, hot and cold, stayed in PJs and in and out of bed during the day. I found that I could not concentrate and unable to do my jigsaw puzzle.

I still had my Strawberry the cat to look after .

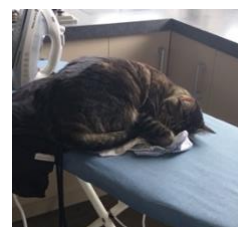
After their 7 days my daughter and her husband went back to work. And I just rested but I was OK, just took Paracetamol and my usual meds.

When my 7 days was up I still was not up to going out.

I am all back now as I was before Covid.

I have had Covid vaccines, my 4<sup>th</sup> booster was due the day after my daughter and her husband became positive so that has been put back now until June for me, I was more annoyed about that then getting covid.

*Strawberry the cat  
asleep on the  
ironing board*



# COVID-19 Vaccination, Prevention, and Treatment for Patients with Scleroderma:

From National Scleroderma Foundation website...

UPDATED April 11, 2022

By Jiha Lee, MD, MHS, and Dinesh Khanna, MD, MSc,  
Department of Internal Medicine, Division of  
Rheumatology, University of Michigan

Patients with systemic sclerosis (scleroderma) are potentially at higher risk of poor outcomes related to COVID-19 because of an altered immune system, the presence of cardio-pulmonary involvement such as lung fibrosis and pulmonary arterial hypertension, and the use of immunosuppressive drugs. Therefore, vaccination is critical to reduce transmission and severity of COVID-19 infection in the vulnerable scleroderma population. In the US, three vaccines are currently available; two mRNA vaccines made by Pfizer (Cominarty®) and Moderna (Spikevax) both of which are FDA approved, and one viral-vector vaccine made by Janssen (J&J) with Emergency Use Authorization (EUA). None of these vaccines contain the live virus. Approval of a drug by the FDA means that the agency has determined, based on substantial evidence, that the drug is effective for its intended use, and that the benefits of the drug outweigh its risks when used according to the product's approved labeling.<sup>1</sup> In contrast, the FDA can issue EUA during a public health emergency, such as the COVID-19 pandemic, to allow the use of unapproved medical products to diagnose, treat or prevent serious or life-threatening diseases. Prior to issuing EUA, safety and efficacy must be demonstrated, certain FDA criteria must be met; and there also must be evidence that strongly suggests that patients have benefited from a treatment or test, and there are no adequate, approved or available alternatives.<sup>2</sup>

Scleroderma patients on moderate-to-high doses of steroids (defined as >15 mg of prednisone daily) and/or immunosuppressive medication such as Cellcept (mycophenolate mofetil), methotrexate, or Actemra (tocilizumab) are considered immunocompromised. Plaquenil (hydroxychloroquine) monotherapy is not considered an immunosuppressive therapy. COVID-19 vaccination in immunocompromised patients pose unique challenges as they may not mount adequate immune response after initial vaccination and vaccine effectiveness wanes over time. Studies have shown additional primary dose(s) and booster dose improve protective immune response against COVID-19, and the highly transmissible Omicron variant, leading to fewer emergency room visits, hospitalizations, and death. In addition to efficacy, safety is an important consideration, and some scleroderma

patients may be hesitant to receive COVID-19 vaccination. In a recent study focusing on scleroderma patients, localized arm pain, muscle ache, and fatigue were most commonly reported after vaccination, and the proportion experiencing these adverse reactions were similar to the general population.<sup>3</sup>

In March 2022, the CDC updated vaccination guidelines for immunocompromised patients as shown in the Figure and up to date information can be found on the CDC website.<sup>4</sup> Immunocompromised patients who initiated vaccination with either Pfizer or Moderna should receive 3 doses of either mRNA vaccine to complete their primary series. Those who received the J&J vaccine as their first shot, should get a second dose of vaccine with either Pfizer or Moderna at least 28 days after the first J&J dose, to complete the primary vaccination series. For better vaccine efficacy, the American College of Rheumatology (ACR) recommends immunocompromised patients complete primary vaccination series with either Pfizer or Moderna, over the J&J vaccine.<sup>5</sup>

All immunocompromised patients should receive at least one booster with either Pfizer or Moderna, 3 months after the last dose of their primary series. This means that for immunocompromised scleroderma patients, the first booster will count as their fourth dose if the primary series was completed with either Pfizer or Moderna, and as their third dose if the primary series was started with J&J. In addition, according to the most recently updated CDC guidelines<sup>4</sup>, immunocompromised adults 18 years of age and older, may choose to receive a second booster of an mRNA vaccine (Pfizer or Moderna) at least 4 months after their first booster.

Additional CDC updates recommend patients on B-cell depleting therapy such as Rituximab who received doses of COVID-19 vaccine prior to or during treatment to be revaccinated. Furthermore, on a case-by-case basis, mRNA COVID-19 vaccines may be administered outside of the FDA and CDC dosing intervals when the benefits of vaccination are deemed to outweigh the potential and unknown risks. Immunocompromised scleroderma patients should discuss with their rheumatologists need for further vaccination and timing of certain immunosuppressive medications, as recommended by the ACR, to improve vaccine effectiveness.



# COVID-19 Vaccination, Prevention, and Treatment for Patients with Scleroderma: continued...

From National Scleroderma Foundation website..

Vaccination is critical to prevent progression to severe COVID-19 infection in the immunocompromised population, however, patients with a history of severe allergy to vaccination or ongoing severe infection should not receive vaccination. For unvaccinated scleroderma patients or those who have not had an appropriate antibody response after vaccination Evusheld may be of benefit. Evusheld (tixagevimab co-packaged with cilgavimab) is a long-acting monoclonal antibody therapy, administered as two intramuscular injections, available under EUA for the prevention of COVID-19 infection in immunocompromised patients. The use of Evusheld does not replace need for vaccination against COVID-19, and Evusheld should be deferred for at least two weeks after vaccination. The comparative effectiveness of additional booster doses versus Evusheld is yet unknown and Dr. Dinesh Khanna at the University of Michigan is co-leading a multi-center NIH clinical trial to address this scientific question. More details are available at <https://www.autoimmunecovidbooster.org>.

Scleroderma patients who develop mild to moderate COVID-19 that does not require hospitalization or oxygen therapy should contact his/her rheumatologist or primary care provider within 5 days of symptom onset to discuss treatment options. Two antivirals and one monoclonal antibody are available as primary therapeutic agents in the outpatient setting, as summarized in the Table. The antiviral Paxlovid and the monoclonal antibody Sotrovimab are equally efficacious (88% vs 85% risk reduction of hospitalization or death due to COVID-19). Paxlovid is the preferred therapeutic agent and effective against Omicron which is the current dominant variant in the US. However, Paxlovid is contraindicated in patients with severe kidney or liver disease and is a protease inhibitor with a lot of drug-drug interactions. Scleroderma patients who take certain medications, including over the counter and herbal supplements, should discuss with their physicians whether Paxlovid can be safely administered with holding of medications or an alternative COVID-19 therapy such as Sotrovimab would be more appropriate. REGEN-COV (casirivimab/Imdevimab) is another monoclonal antibody authorized for treatment, however, distribution in the US has been paused due to lack of clinical benefit for patients with Omicron infection. Under revised CDC guidelines, there are no recommendations to defer COVID-19 vaccination after monoclonal antibody treatment.

In summary, patients with scleroderma should receive COVID-19 vaccination, including booster dose, preferably with either Pfizer or Moderna, to reduce the risk of developing severe infection that requires a visit to the emergency department and/or hospitalization. Unvaccinated patients and immunocompromised patients with inadequate vaccine response may be able to prevent COVID-19 infection with Evusheld therapy. Following vaccination and/or Evusheld, patients with scleroderma should continue to follow all public health guidelines regarding physical distancing and other preventive measures including masks and good hand hygiene. Should scleroderma patients develop symptomatic COVID, they should contact their physician within 5 days of symptom onset to discuss treatment options. For current guidelines, and data on management and effectiveness of COVID-19 vaccination published on a weekly basis, patients should consider monitoring the CDC website at <https://www.cdc.gov/coronavirus/2019-ncov/vaccines>.

Source: <https://scleroderma.org/covid-19-vaccination-prevention-and-treatment-for-patients-with-scleroderma/>





# How to get the most out of your Appointments:

From the SRUK – Scleroderma & Raynaud's UK website

SRUK – Scleroderma Raynaud's UK website presented on YouTube "How To Get The Most Out Of Your Appointments". I found these video presentations very helpful and informative:

<https://www.youtube.com/watch?v=xOjb74y84BU>

How To Get The Most Out Of Your Appointments

## What we will cover today

- Why it is important to make the most of appointments
- Shared decision making
- How to prepare for an appointment
- Additional preparation for a virtual appointment
- Communicating during your appointment
- What will happen after the appointment
- Top tips

 SCLERODERMA & RAYNAUD'S UK

## Why appointments matter

- There is an array of health information
- But an appointment with your doctor or nurse specialist is an opportunity to ask questions and have a more personalised conversation
- It is also an opportunity to be signposted to trusted information from charities like SRUK

Being prepared can help you make the most of appointments, particularly if you are seeing lots of different specialists.

## Shared Decision Making

- You have a right to be involved in decisions about your care
- Appointments are the ideal time to make clear to your doctor or nurse what matters to you
- You should be given information on the benefits and risks of any treatments or procedures you are offered
- It is okay to ask questions

BRAN – benefits, risks, alternative and doing nothing.

## How to prepare for an appointment

- Decide on your main priority for the appointment
- Make a list of questions you want to ask
- If it is your first appointment with a new doctor or nurse make a note of previous treatments
- Keep a note of symptoms between appointments
- If you have a complex history there may not be time to go through everything – summarise key points
- Complete any pre-consultation paperwork. Be aware these may come through online tools or Personal Health Records

How To Get The Most Out Of Your Appointments

- If you need particular provisions, for example an interpreter, let your doctor or nurse know before the appointment
- If you have a strong preference for a particular type of consultation, ask for it
- Decide if you would like to have someone with you

## Preparing for a virtual appointment

- Try to find a quiet comfortable area where you will not be disturbed
- If you are having a phone conversation, be aware it may appear as 'no caller ID on your phone'
- If you are having a video appointment try to choose an area with good lighting – particularly important if you need to show a physical change.
- You may wish to take photographs which can have better clarity than video.
- If you feel you need a face-to-face consultation ask

## During your appointment

- Set a clear agenda in collaboration with your doctor or nurse
- Be honest and descriptive about how you are feeling
- Do not be afraid to ask questions
- Listen to what is being said
- Ask for clarification if you are unsure of the answers
- Make notes or ask to record the conversation
- Take your time – if you need to take a minute to process information you have been given say so

- Appointments tend to focus on the physical, do not be afraid to raise any issues you are having with your mental health and wellbeing
- Check for additional information sources
- Ask for contact details

Your doctor or nurse should summarise key points and tell you what will happen next.

## After the appointment

- You should receive confirmation of any follow-up appointments, tests or treatment dates
- If you think of additional questions do not be afraid to get back in touch with your doctor or nurse
- Use reliable, evidence-based information to help you make decisions about what happens next
- Be aware letters may not be sent in chronological order. If anything is unclear, seek clarification
- Information may appear in your Personal Health Record


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## Top tips

- Prepare for appointments in advance
- Ask questions
- Look for reliable, evidence-based information
- Try to work as a team with your doctors and nurses

**Remember you have a right to information so you can make informed decisions about your care.**

If you do not understand something it is because it has not been explained properly. It is not your job to make sense of complex information.

 SCLERODERMA & RAYNAUD'S UK



# YouTube Video Clips on Scleroderma

From the SRUK – Scleroderma & Raynaud's UK website

SRUK – Scleroderma Raynaud's UK website has put together some very informative and interesting YouTube videos on Scleroderma related issues. I found these video presentations are very helpful and informative. I have provided the YouTube links below for members to see:

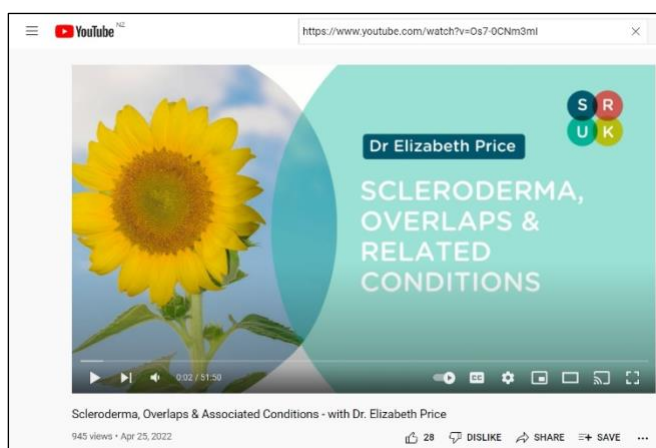
## Dry Eyes: Causes & Management



<https://www.youtube.com/watch?v=FyUgrdWybOY>

Ever wondered why your eyes feel so dry? Dr. Elizabeth Price goes over the mechanics of how eyes stay lubricated, and what you can do to help them along the way.

## Scleroderma, Overlaps & Associated Conditions - with Dr. Elizabeth Price - YouTube



<https://www.youtube.com/watch?v=Os7-OCNm3ml>

Dr. Elizabeth Price goes over some of the overlapping and associated conditions associated with scleroderma, including Sjogren's, lupus, and thyroid disease.

## Gut Instinct: SSc and the GI Tract - YouTube

### Systemic Sclerosis-Related Gastrointestinal Involvement: Diagnosis and Treatment Options with Dr Elizabeth Volkmann



[https://www.youtube.com/watch?v=cr1kR677\\_h0](https://www.youtube.com/watch?v=cr1kR677_h0)

## Diet & Disaster: The Role of Nutrition in Systemic Sclerosis with Dr Volkmann – YouTube



<https://www.youtube.com/watch?v=7xY9nORxsw8>

Dr Elizabeth Volkmann, director of the UCLA Scleroderma Program, discusses gastrointestinal involvement in Systemic Sclerosis and how diet can affect your wellbeing.





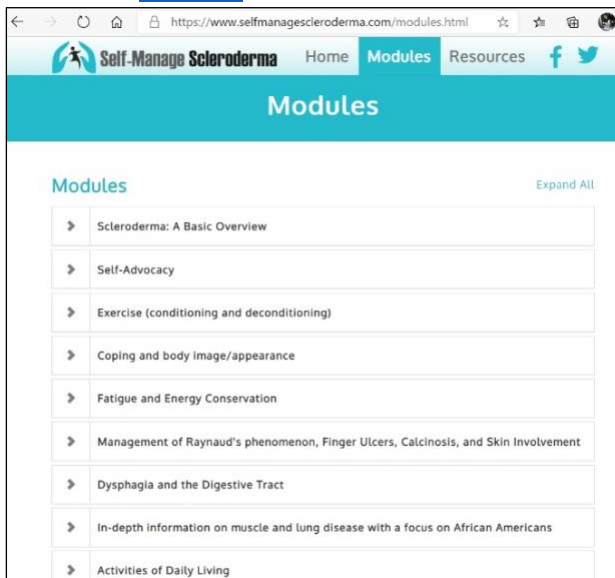
# Taking Charge of Systemic Sclerosis (TOSS)

An internet self-management program from Self-Manage Scleroderma website

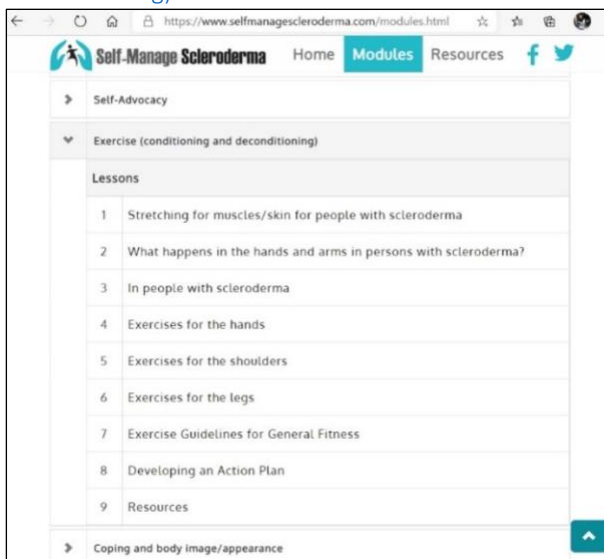


Self-Manage Scleroderma is a very informative and practical website, especially for those who have been recently diagnosed with Scleroderma. The website is a very useful tool for managing some of the common effects of Scleroderma. Even though I have had Scleroderma since 2004, I still find that this website very helpful because you can use it to manage the different aspects of Scleroderma over time as you need to. You can dip into any of the modules as you require or if you need to check on specific parts of Scleroderma that affect you. I have taken some screen shots from the site, to give you an idea of what the modules are.

Some of the [Modules](#) listed below:

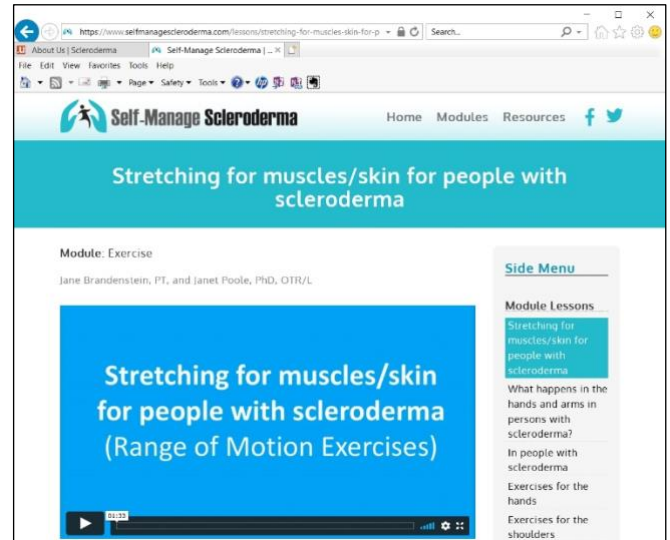


Example of one of the [Modules: Exercise](#) (conditioning and deconditioning)



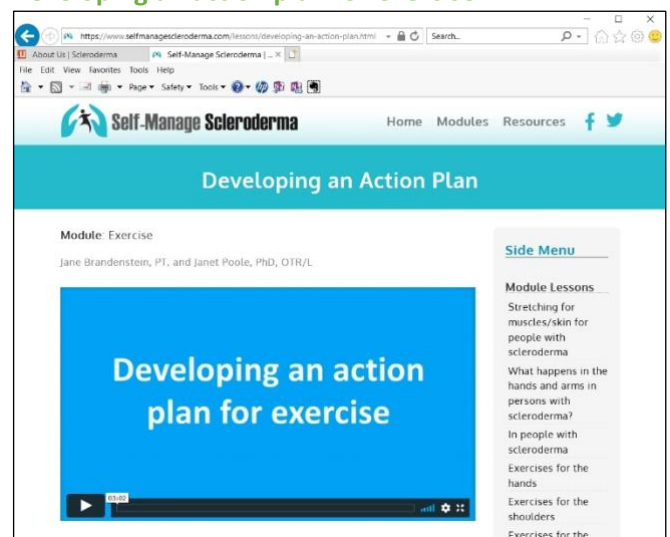
A Lesson in one of the [Modules: Exercise](#) –

## Stretching for muscles/skin for people with Scleroderma (Range of Motion Exercises)



A Lesson in one of the [Modules: Exercise](#) –

## Developing an action plan for exercise:



I have done some of the Exercise Lessons and found them very helpful and beneficial.

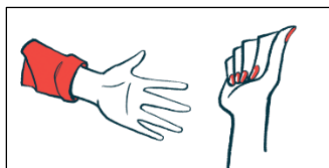
Source: <https://www.selfmanagescleroderma.com/modules.html>



# Ultrasound Plus Manual Therapy Helps in Healing Digital Ulcers:

From Sclerodermanews.com website

By Steve Bryson PhD | March 29, 2022



A combination of ultrasound and therapy that includes joint manipulation and massage improved hand function and ulcer wound healing in

a small group of systemic sclerosis (SSc) patients with skin involvement, a study reported.

“Therapeutic [ultrasound] combined with manual therapy should be used as additional intervention to manage [digital ulcers] in SSc patients,” the researchers wrote.

The study, “Rehabilitative interventions for ischaemic digital ulcers, pain, and hand functioning in systemic sclerosis: a prospective before-after study,” was published in the journal *BMC Musculoskeletal Disorders*.

Thick and hardened skin caused by excessive collagen production, the main protein component of scar tissue, is the hallmark of systemic sclerosis (SSc), also known as scleroderma. Scar tissue can also accumulate in organs, including the heart, blood vessels, kidneys, and lungs, and cause damage.

Excessive scar tissue is known to narrow blood vessels and restrict blood flow, resulting in ischaemic digital ulcers (IDUs). These chronic and painful lesions are found equally on patients’ hands and feet, and can lead to tissue death and bone degeneration.

Although several medicinal treatments for IDUs have been investigated, few studies focus on rehabilitation approaches such as exercise, manual therapy, and other physical applications.

This study, conducted by scientists in Italy, aimed to evaluate the effectiveness of a standardized rehabilitation regimen using a combination of ultrasound and exercise therapy for ulcers, pain, and hand function in people with IDUs associated with SSc.

“Although few studies support rehabilitative interventions for patients with SSc, these approaches are widely used in clinical practice,” the researchers noted.

It enrolled 20 SSc patients (14 women and six men), with a mean age of 61 and a mean of two digital ulcers. Four have taken immunosuppressants or immunomodulators due to disease-related lung complications. The others had no SSc manifestations except for skin involvement.

Patients were treated with ultrasound using an I-Tech medical device that involved immersing their hands in a container of body-temperature water for 15 minutes.

Manual therapy included 40 minutes of McMennel joint manipulation, a stretching technique used to ease joint stiffness, 15 minutes of pompage — applying rhythmic and

regular movements involving traction and release to the fascia, or fibrous bands, of the hands — and 30 minutes of connective tissue massage, which aimed to preserve the smoothness of skin by promoting blood circulation.

This 100-minute rehabilitation regimen consisted of 10 daily weekday sessions for two consecutive weeks.

After those weeks, patients reported a significant reduction in pain, as assessed by a numerical rating scale (NRS) ranking pain from 0 (no pain) to 10 (extreme pain). Before treatment, half of these people reported an NRS value between 5.5 and 7 (median of 5.5, indicative of moderate pain), while after treatment, half reported an NRS of between 3 and 5 (median of 3, indicating mild pain).

Better NRS scores were reported by all but two people, with most patients reporting a two-point decrease and three a five-point drop. All but one had better hand function.

Scores on the Duruoz Hand Index (DHI), a self-reported questionnaire of hand impairment, and the Pressure Sore Status Tool (PSST) scores, a wound assessment, also significantly declined after treatment, indicating clinical improvements. The median DHI score dropped from 25 to 19, while the median PSST score fell from 23 to 16.

Each of five PSST items — wound depth, size, edges, wound repair, and skin colour — showed significant benefits in some participants.

Wound size either reduced or was maintained in all patients, while a lessening in wound depth was evident for 11 patients. Further improvements were seen in wound edges, with better measures of wound healing found in nine people. Skin colour surrounding wounds also improved after treatment for 15 patients.

“The strength of the study is the originality of the proposed treatment, as the combination of therapeutic US [ultrasound] and of manual therapy has never been studied in patients with SSc-related IDUs [ischaemic digital ulcers],” the researchers wrote.

“Based on our data, we demonstrated the effectiveness of therapeutic [ultrasound] combined with manual therapy in reducing ulcer depth and margins, improving perilesional skin colour and fullness, and in improving hand function in SSc patients with IDUs,” they concluded.

“In the future, we would improve the study design to carry out a more reliable investigation including the comparison of treatment effects with a control group.”

Source: [https://sclerodermanews.com/2022/03/29/ultrasound-manual-therapy-helps-heal-hand-ulcers-small-study/?fbclid=IwAR0Af2Py22zkY-Zu2\\_BbmazdMCBWeYaz0SbBcCSwURXSns6sOyKLOxfnObk](https://sclerodermanews.com/2022/03/29/ultrasound-manual-therapy-helps-heal-hand-ulcers-small-study/?fbclid=IwAR0Af2Py22zkY-Zu2_BbmazdMCBWeYaz0SbBcCSwURXSns6sOyKLOxfnObk)



# Rituximab May Ease Arthritis in Long-time SSc, Small Study Finds:

From Sclerodermanews.com website  
by Margarida Maia PhD | June 7, 2022



The immunosuppressant Rituximab may ease arthritis — an inflammation of the joints — in patients with long-standing systemic sclerosis

(SSc), a small Turkish study found.

Moreover, in some patients, skin and lung symptoms either remained stable or eased, the researchers also observed.

“The factors and markers affecting the treatment response in rituximab responders may be the subject of new studies,” the investigators wrote, noting both that the therapy “appears to be effective in SSc-associated arthritis” and that “the success rate of [Rituximab] seems to be higher in the mild severity/extent of lung involvement and early stage of skin involvement.”

The study, “Rituximab on lung, skin, and joint involvement in patients with systemic sclerosis: A case series study and review of the literature,” was published in the International Journal of Rheumatic Diseases.

Rituximab is a medication that decreases the number of B-cells, a type of immune cell, by causing their death. The medication is marketed as Rituxan in the U.S., and as MabThera in Europe, and also is available as a range of biosimilars.

Its use is approved for certain blood cancers and autoimmune diseases in which the immune system turns against the body’s own cells, attacking them and causing inflammation. One such disease is rheumatoid arthritis, an inflammation that causes swelling, pain, and damage to the joints, most commonly including those of the hands and feet.

In some cases, rituximab has been used off-label to treat patients with lung damage from scleroderma. While some studies have looked at the effects of rituximab on skin and lung symptoms, less is known about its effects on arthritis in patients with SSc.

To learn more, researchers now drew on data from the medical records of eight patients — five women and three men — with SSc who were treated with rituximab.

Five patients had diffuse scleroderma, a subtype of the chronic disease that’s marked by extensive skin scarring over large areas of the body and damage to the internal organs. The remaining three patients had limited scleroderma, another subtype of scleroderma that is generally milder than the diffuse form.

The mean age of the patients was 62.4, and the mean disease duration was 16.7 years. All but one of the patients (seven, or 87.5%) were started on rituximab because they had treatment-resistant arthritis. The other patient (12.5%) had progressive skin symptoms.

Each received three cycles of rituximab, spaced every six months. The cycles each included an intravenous (into-the-

vein) infusion of 1 gram of rituximab, followed by a second infusion 15 days later.

Methylprednisolone, a corticosteroid, was used prior to each infusion to prevent infusion-induced reactions, which are commonly reported among patients on such therapy. All of the individuals were allowed to continue with their usual medication regimens, including other immunosuppressants and corticosteroids.

Two patients with pulmonary arterial hypertension, which is caused by a narrowing of the blood vessels that supply the lungs, died after the first rituximab cycle. Both had sudden cardiac death, or loss of heart function.

Of the six patients who survived, five had arthritis. When the researchers watched for changes in disease activity between before and one year after rituximab treatment, they found it had significantly improved.

The median DAS28-CRP score — used to monitor disease activity and how well patients with arthritis are responding to treatment — decreased from 4.97 to 3.95 points. The median Clinical Disease Activity Index (CDAI), another measure of disease activity, decreased from 39 to 16 points.

Next, the researchers looked at skin thickening using the modified Rodnan Skin Score (mRSS). While the median mRSS did not improve significantly after rituximab treatment, among the five patients with diffuse scleroderma, mRSS did not worsen by more than five points. That’s minimal clinically significant difference reported for people with dcSSc. Moreover, in one patient, that score decreased by 10 points. Five patients had interstitial lung disease, or lung disorders in which the tissue in and around the lung air sacs becomes inflamed and scarred. When the researchers watched for changes in forced vital capacity (FVC), a measure of lung function, they found that it had improved in two, worsened in one, and remained stable in two patients at one year after rituximab treatment.

“The effect of [rituximab] on lung and skin involvement was in favour of stabilization or improvement,” the researchers wrote. However, the median FVC did not improve significantly with rituximab treatment, nor did the diffusing capacity for carbon monoxide (DLCO). The DLCO is a measure of the ability of gas to transfer from the tiny airways to the red blood cells.

While the patients were few and used other immunosuppressants, the findings suggest that rituximab may be effective to treat arthritis in patients with SSc, the researchers concluded.

Source: [https://sclerodermanews.com/2022/06/07/rituximab-treatment-may-ease-arthritis-longtime-scleroderma-study/?utm\\_source=SCL&utm\\_campaign=5a746649e4-US&utm\\_medium=email&utm\\_term=0\\_8741067e1d-5a746649e4-71439821](https://sclerodermanews.com/2022/06/07/rituximab-treatment-may-ease-arthritis-longtime-scleroderma-study/?utm_source=SCL&utm_campaign=5a746649e4-US&utm_medium=email&utm_term=0_8741067e1d-5a746649e4-71439821)





# Covid-19: Update

Omicron is in our community, we are in Orange Light, latest update on Covid-19 cases..

Unite  
against  
COVID-19

All of NZ is at Orange

Languages

Search

News & data
Traffic lights
Prepare & stay safe
Vaccines
Testing & tracing
Isolation & care
International travel

Home / Traffic lights / Life at Orange

## Life at Orange

At Orange, there is community transmission of COVID-19, with increasing risks to vulnerable communities, and pressure on the health system. Learn what we all need to do.

What to do at Orange:

- Gatherings
- Hospitality
- Businesses and workplaces
- Events
- Early learning and schools
- Shopping and services
- Travel and accommodation
- Sport and recreation

Wearing a face mask at Orange
If you have COVID-19

### Key points

- At Orange, you can continue to do everyday activities, but we need to protect our vulnerable communities.
- You must wear a face mask in many indoor locations. You do not need to wear a face mask outdoors.
- You can visit cafes and bars, attend gatherings and events, and go to the hairdresser and gym. There are no capacity limits or distancing requirements at venues.
- Workplaces and schools can open.
- To protect yourself, your whānau and your community, keep up healthy habits.

17 Jun 2022

Read today's update on COVID-19 cases from the Ministry of Health.

## Today's COVID-19 numbers

- 4,869 new community cases
- 370 cases in hospital
- 36,712 active community cases
- 11,764 total RATs reported
- 3,095 total PCR tests

Home / News and data / Data and statistics

## COVID-19 data and statistics

The Government collects and publishes a range of data and statistics about COVID-19 in New Zealand. Access the latest data.

Data and statistics available:

- COVID-19 cases
- Vaccine data
- COVID-19 data portal
- COVID-19 modelling reports
- Resources for more data

### Vaccinations uptake in NZ

Last updated 17 June 2022 at 1:00 pm

The Ministry of Health collects data and statistics about the rollout of COVID-19 vaccines in New Zealand.

96%
Eligible population 12+ with 1 dose

95%
Eligible population 12+ with 2 doses

263,616
Paediatric first doses administered (5 to 11)

128,980
Paediatric second doses administered (5 to 11)

2,671,847
Booster doses administered (16+)

COVID-19 vaccine data | health.govt.nz

### COVID-19 cases

Last updated 17 June 2022 at 1:00 pm

The Ministry of Health collects data about cases of COVID-19 and testing in New Zealand. This includes:

- Current COVID-19 cases
- COVID-19 case demographics
- Source of COVID-19 cases
- Testing for COVID-19

We update this data every weekday. For weekend case numbers, visit the Ministry of Health website.

Latest news | health.govt.nz

COVID-19 data and statistics | health.govt.nz

370
Cases in hospital

4,869
New community cases

64
Cases recently arrived from overseas

36,712
Active community cases

### COVID-19 deaths

Last updated 17 June 2022 at 1:00 pm

The Ministry of Health reports on how many people have died of COVID-19 and COVID-19 related deaths.

COVID-19 related deaths include:

- people whose cause of death was not COVID-19 but they had COVID-19 when they died
- people whose cause of death is still under investigation.

COVID-19 current cases data | health.govt.nz

7
COVID-19 related deaths reported in the last 24 hours

1,315
People who have died within 28 days of testing positive for COVID-19

1,390
Total number of publicly reported COVID-19 related deaths

### Testing for COVID-19

Last updated 17 June 2022 at 1:00 pm

The Ministry of Health collects information on testing rates around New Zealand.

Testing for COVID-19 | health.govt.nz

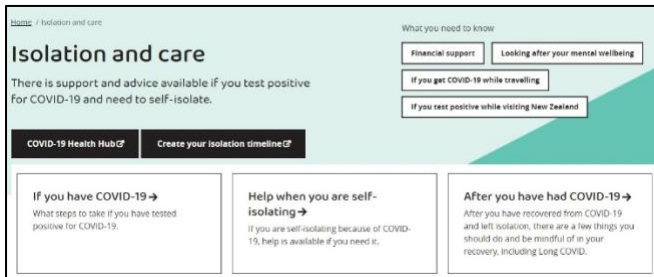
11,764
RATs reported in last 24 hours

3,095
PCR tests in last 24 hours



# Help when you are self-isolating

From Covid 19 website: Isolation and Care...



## Support for people in self-isolation

If you are self-isolating at home, you can access help if you need essential supplies like food or medicine. If your symptoms worsen, call your doctor or Healthline for advice. They will tell you what you need to do next. Vulnerable people will have access to clinical care to help them self-isolate safely.

Source: <https://covid19.govt.nz/isolation-and-care/>

## Help when you are self-isolating

If you are self-isolating because of COVID-19, help is available if you need it.

### On this page

- [Requesting help](#)
- [Keep in touch](#)
- [Financial support](#)
- [Wellbeing helplines and support](#)

## Requesting help

Most people will be able to manage self-isolation with help from whānau and friends, but there is help available for you and your household if you need it.

You may be able to get:

- money to pay for urgent and essential costs, like food, medicine and some bills
- support from community groups, iwi and Pacific groups in your area, or supplies delivered to you.

Anyone can request help — you do not need to be getting a benefit.

Work and Income have an online form where you can request support from a community organisation for your household, or to apply for money for urgent costs.

[Request help](#) | [workandincome.govt.nz](https://workandincome.govt.nz)(external link)

If you prefer, you can call Work and Income's COVID-19 Welfare line for free on [0800 512 337](tel:0800512337). It is open 8am to 5pm Monday to Friday, and 8am to 1pm Saturday, Sunday and public holidays.

If it is an emergency and you need urgent medical help or cannot breathe properly, call emergency services on [111](tel:111). If you have COVID-19, tell them when you call.

## Keep in touch

Keep in touch with your friends and whānau, your healthcare provider, and any community groups you are in contact with. They can:

- check how you are feeling
- monitor your health
- check if you need basic supplies like food or medicines.

It is important you answer your phone while you are self-isolating.

## Financial support

There is financial support for people who need to stay at home due to COVID-19.

[If your income has been affected](#)

[Money to help with urgent costs | workandincome.govt.nz\(external link\)](#)

## Wellbeing helplines and support

If you feel you are not coping, or you have concerns for others, it is important to talk with a health professional.

[Find helplines to get support](#)

Find services for when you need help, support, advice or information about COVID-19.

[COVID-19 support](#)

Source: <https://covid19.govt.nz/isolation-and-care/help-when-you-are-self-isolating/>



# If your support worker or carer gets COVID-19

From Covid 19 website: Support and information for disabled people...

If your regular support worker or carer gets COVID-19, they will need to stay home and isolate. This means you may need to have someone else support you with your care.

## On this page

- [If your support worker has COVID-19](#)
- [If your carer has COVID-19](#)
- [Make a plan for emergency care](#)

## If your support worker has COVID-19

If your support worker gets COVID-19, the disability support organisation they are from is responsible for finding a replacement.

In some cases, they may only be able to provide essential services while your regular support worker recovers. Your support provider will check in with you about any changes.

If you would prefer that a family member or friend support you instead, discuss this with your disability support organisation.

## If your carer has COVID-19

If you usually get support from a family member or friend, or you individually contract support people, make a plan for alternate support in case they get COVID-19.

### Options could include:

- another family member or friend providing care for you over this time
- a paid carer to be arranged through a care support agency
- contacting your local Needs Assessment Service Co-ordination service (NASC). If you receive disability funded support, they will put you in contact with a disability support provider.

[Needs Assessment and Service Coordination services | health.govt.nz](#)

If you live in the same home as your carer, and they are well enough to continue providing care, they can do so. They will need appropriate infection prevention control and personal protective equipment.

[Infection prevention and control recommendations for health and disability care workers | health.govt.nz](#)

## Make a plan for emergency care

If you receive support in your home, it is important to have a support plan. This should include your important health information and care routines.

If your regular carer becomes unwell and you need emergency care, this plan can be shared with the new carer. This means your care and support can continue safely.

Your disability support provider can help you create a plan. You can also use the emergency care planning tools available on the Carers New Zealand website.

[Emergency care planning tools | carers.net.nz](#)

There are a few things to consider, specific to COVID-19:

- tolerance with medication
- tolerance around needles, etc.
- tolerance around masks and nasal prongs
- anticipated staffing/supervision requirements.

Source: <https://covid19.govt.nz/prepare-and-stay-safe/iwi-and-communities/information-for-disabled-people/if-your-support-worker-or-carer-gets-covid-19/>





# Emergency Care Planning Tools

From the Carers New Zealand website..



## Be Prepared for Emergencies



Carers often worry about what would happen to the person(s) they support if they were unable to continue providing care for any reason. Having an emergency plan is important if something happens to you.

Although you may be able to contact someone who is willing to cover in an emergency, we know that this isn't always possible. Having a plan in place can stop an emergency turning into a crisis, and can give peace of mind for you and those who you care for.

**Carers New Zealand has created a suite of emergency planning tools to help you in an emergency.**

The tools include:

- Emergency Care Plan
- Important Papers Checklist
- Medications Care Plan
- Emergency Carer ID Card

Download the pack and fill out the information fields. This will make it easier for other people to step in for you. If possible, discuss the 'what ifs' with the person you support, so they have input into arrangements that would affect them if you were suddenly unable to provide support.

You can also place a copy in your home, or your loved one's home in a place where someone can easily find it.

Share the completed tools with anyone who needs to know about your wishes, and the support needs of your friend or family member (if they can't easily communicate these themselves).

Keep this information in an easily located place. Talk about the plan with the person(s) you care for, if possible, and with family and friends whom you would like to nominate as emergency contacts. Let people know where they can find it and make sure that the information is regularly updated.

These tools are also useful for anyone self-managing health or disability support needs.

[Download it here](#)

## Other Resource and Information



Source:

[https://carers.net.nz/info\\_pack\\_item/emergency-care-planning-tools/](https://carers.net.nz/info_pack_item/emergency-care-planning-tools/)



# Members News

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## Hawkes Bay Scleroderma Group

The Hawkes Bay group recently met up. They talked about the weather and all the things that happen. They enjoy the company of each other.



## Southland Scleroderma Group

The Southland Group joined up with the Otago group and had a zoom meeting together. It was nice to meet some new ladies and talk about different things going on in our lives. Thank you to all those who joined in.



## Christchurch Scleroderma Group

Christchurch Group met on the 28<sup>th</sup> May. No report from them, but I'm sure they had a lovely time as always.



## Waikato Scleroderma Group

The Waikato Group met up on May 2<sup>nd</sup> at Chartwell. They had a lovely time together. They hope to have a lunch in June so Linda will be in touch with you all regarding this. Linda had covid and is doing well.



## New Plymouth Scleroderma Group

The New Plymouth group met on the 3<sup>rd</sup> June at Tawa Glen for lunch. They had a lovely catch up and have decided to meet monthly for lunch. Elle has been sharing her love of knitting with the group with making her fingerless gloves and socks. Great idea Elle.



## Wellington Scleroderma Group

The Wellington Scleroderma group has not been meeting due to COVID – If anyone in the Wellington area is struggling and needs to talk to someone, please get in touch with one of your fellow members for support.



## Palmerston North Scleroderma Group

Hi All,  
It's that time again! Time for us to all get together! Come and enjoy some food, beverages, enjoyment and support.

Date: Saturday 16 July 2022

Lunch: 12:30 pm

Where: Caroline's Creative Interiors Cafe, Fitzherbert Road East, Palmerston North

Conversation, support and eating are a complete blend of awesomeness for well-being!

I have discovered a fantastic cafe in the country area of Aokautere. Have been there often. It is very reasonably priced, quick friendly service, large carpark, yummy food that sits well in the tummy! If it is fine weather, there is seating outside - it is placed in a large, beautifully set out garden and surrounded by lush green gardens! (Am I doing a good sell ! LOL), Inside is a large room and I think an open fire, just right for rainy weather.

Hope to hear from you soon

Warm regards

**Martine Fremaux**

Above is an invite from Martine for a get together in Palmerston North and she has included the Wellington group.

Please email Martine if you would like go along at: - [curios@xtra.co.nz](mailto:curios@xtra.co.nz)

Many thanks Martine, for including Wellington.



# Members News continued..



## Bay of Plenty Scleroderma Group

The Bay of Plenty group have been meeting. They have turns organising the get togethers.

Hi everyone,

I'm Alumie Nguyen, in my 30s from Bay of Plenty group in Tauranga.

Moving to Tauranga 6 years ago from Hamilton after a traumatic event, I found it hard to make friends locally as I didn't stay at any social club for long. The connections I have now are my partner's family and work colleagues. I came to the acceptance that I would just cultivate this small network but I always love to see new people.

After my diagnosis in November last year, I have had several months of struggling with my mental health. Luckily I was diagnosed early enough that I think I am relatively okay. However, at the back of my mind, there exists the "what if" of no longer being able to hold my full time job, my mental health has suffered a lot.

It is my pleasure to have the local support available not long after my diagnosis in November last year. Our support group has a good mix of members with a long history of the condition and newbies. Though the manifestation of the condition is different for everyone, being able to share the journey to each other is valuable, heart-warming and for me, reassuring and hopeful.

The support group as well as Scleroderma NZ have been one of the best things to happen to me. I no longer feel so lonely because there are so many people willing to listen to me and give me a push in the right direction.

Our next bi-monthly catch-up will be on Saturday, 2nd July from 10 to 11am at Nourish Cafe, Te Puna. There is a fireplace inside so it will be so toasty!

Anyone stopping by Tauranga is welcome to join us, just let me know via [alumie.uow@gmail.com](mailto:alumie.uow@gmail.com).

Thank you and I will see you at our next catch-up.

Lots of love,

Alumie



## Waipa Scleroderma Group

Maanawatia o te wa o Matariki

Tata mai ki te wa o Matariki tatou ma 🏠. A time where the turn of the new year for many reflects upon those we have lost, a mindful time of reflection with each of the stars that inherited the energy to nourish our fresh water, sea water, wind and rain, food that grows above and below the ground...and to formulate wishes for forthcoming year. For some it's a connection to our environment a time to reflect about how one personally contributes to the bounty and conservation of our environment.

How is this relevant to SCLERODERMA?

Everything really, it allows us to think about something bigger than us and our day to day ☺ ups and downs. It's so easy to get tied up in SCLERODERMA month and the many published facts on face book. Not a lot of positivity there though!

At least with Matariki we can explore our environment, by visiting, sharing with young people, drawing, singing, performing, donating our time to planting, looking at morning skies, actually feeling the elements.

Keep an eye out folks what's going on in neighbourhood. Our local Cambridge High is having a 5.30am Hautapu ceremony, then night markets in evening, entertainment by the young folk and teachers finished off with spit dinner. A Hamilton Charity Group is putting on week long activities to involve families in Celebrating.

Our Waipa ladies have been a bit absent as two were struck with Covid. Like you may be aware it takes longer to recover, so looking to touch base early July. Any and all welcome to attend a lunch first week July, I thinking Oasis, but ring me as we may have to change.

Blessings for te tau Hou Maaori e!

Na Erena Bruce





# Scleroderma NZ Inc.

## AGM

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We are having our AGM on Wednesday, 22<sup>nd</sup> June at 10am via zoom. Click on the link to join us..

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<https://us02web.zoom.us/j/86226822382?pwd=dzZVU3lVYitBUlI3dThkWWlqcEVXZz09>

This is open to all members of Scleroderma NZ. We are a group of volunteers who wish to make life better for fellow Scleroderma Sufferers. We are on the lookout for new committee members. It is a fun way to meet new people. Don't be shy, get in touch today.  
[jennyred@xtra.co.nz](mailto:jennyred@xtra.co.nz)

## Information wanted:

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*If there is something you have going on, and would like to find someone else who may be experiencing the same thing, get in touch and we can put your question here...*

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*Make sure you rug up warm when going out*

# Scleroderma NZ Inc.

## Fundraising

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### Cards

We have received some wonderful artwork to go on our fundraising cards. Thank you to all of you who have submitted something. If you are still wanting to submit either artwork or photography please get it to me within the next week. The cards are A5 size folded and will have the name of the artist on the back as well at Scleroderma NZ. **It can be in either landscape or portrait, but please send it to me in as large a format as you can.**

To send your artwork in, please email:  
Jenny Andrews at [jennyred@xtra.co.nz](mailto:jennyred@xtra.co.nz)



*Stay warm and cosy indoors*



# Scleroderma NZ Inc. Fundraising



## REWARDHUB

A big thank you to Kelly and Dianne for passing on the information about Rewardhub. 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.

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 most of the brands available to shop with:*

Countdown	My Food Bag	The Good Pet	Simon James	Millenium Hotels
Pet Direct	NZ Sale	Home	Design	Clearly NZ
Trade Tested	Urban Sales	Twisted Thread	Contiki	Spaceships Rentals
Lanocrème	Boody NZ	Linden Leaves	Veronika Maine	Namecheap
Celebration Box	The Market	Wild Poppies	Rusty	Emirates
Life Pharmacy	Hello Fresh	Equipo	Marc's	Blackmores
Dyson	Puma NZ	Bonds	Aliexpress	Banner Buzz
Eco Warehouse	Book Depository	Shaver Shop	Airbnb	Threadless
Ama Balm	Merchant 1948	Michael Kors	Klook	Specsavers
Paper Plus	Rodd & Gunn	Moola	The North Face	Wiggle
Paddock to Pantry	Cue	Vans	Smart Buy Glasses	Tarocash
Manuka Doctor	Lorna Jane	Uggs.com.au	Fishpond	Rockmans
Healthpost	Lego	Slingshot	Wise	Everyday Needs
Hello & Cookie	Bras N Things	Ark Swimwear	Lenovo NZ	Snap Rentals
Essentially Tamara	Hallenstein	Vistaprint	EcosaLuggage.co.	Haka Tours
Ezibuy	Skechers	Wotif	nz	Noni B
Mighty Ape	Baby Bunting	Booking.com	NZGameShop	The Healthy
Expedia	Adairs	Forever New	Platypus NZ	Mummy
Cotton On	Agoda	Restaurant Hub	TreatMe	Lonely Planet
The Iconic	Maverick Surf	Converse	Ticketmaster	Apparel Online
Ace Max	The Well Store	Emma Sleep NZ	City Chic	eBooks.com
The Wild Rose	Rentalot	Bedpost	Microsoft	Simply Wholesale
Bargain Box			Trip.com	



# Noticeboard:

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## Wellington support group meets:

Wellington meetings will not be happening and are TBA.  
For any enquiries please contact Dianne:  
[diannepurdie@xtra.co.nz](mailto:diannepurdie@xtra.co.nz),

## Christchurch support group meets:

Saturday 30th July 2022 - lunch : venue TBA  
Saturday 24th September 2022, 2:00pm to 4:00pm  
Saturday 26th November 2022, 2:00pm to 4:00pm  
**Venue:** Please contact Carolyn on 021 296 1765  
We welcome any new members to come along too.  
Please contact Carolyn Barkhausen if you would like to join in; [carolynbarkhausen@gmail.com](mailto:carolynbarkhausen@gmail.com)

## Southland support group meets:

Sunday July 3rd, 2022, 12pm Pot Luck Finger lunch  
**Venue:** Connected Eastern Southland, 1 Charlton Lane, Gore. Please contact Heather if you wish to join us.  
[milliganseeds@xtra.co.nz](mailto:milliganseeds@xtra.co.nz)

## Waikato support group meets:

**Venue:** Robert Harris Café, Chartwell Hamilton.  
We normally meet every second month. We will be meeting again in June. Linda will be in touch with the details. If you would like to join in with the Waikato Group, please contact Linda Bell. [linda.bell@hotmail.co.nz](mailto:linda.bell@hotmail.co.nz)  
Phone: 07 8535434  
Mobile: 027 548 1214

## Waipa support group:

We are looking to touch base early July. Any and all welcome to attend a lunch first week July, I am thinking Oasis, but ring me as we may have to change.  
All welcome, to find out the details please contact Erena Bruce, Mobile: 021 186 9680.

## Palmerston North support group:

Saturday 16th July 2022, 12.30pm  
**Venue:** Caroline's Creative Interiors Café, Fitzherbert Road East, Palmerston North  
We welcome any new members to come along too.

## New Plymouth support group meets:

We will be meeting in the next few weeks. To attend the New Plymouth Support Group please get in contact Elle Bray [1elle@xtra.co.nz](mailto:1elle@xtra.co.nz)

## Blenheim/Nelson support group:

Jen Soane is organising the Blenheim/Nelson support group so if you would like to attend please get in touch with Jen.  
[jennasoane@gmail.com](mailto:jennasoane@gmail.com)

## Hawkes Bay support group:

Tuesday 28<sup>th</sup> June 2022, 10.30am  
**Venue:** Co-op Café, Pakowhai Road  
To join in with the Hawkes Bay Support group please get in touch with Gail Neilson [gail\\_neilson@hotmail.com](mailto:gail_neilson@hotmail.com)

## Bay of Plenty support group meets:

Saturday 2<sup>nd</sup> July 2022, 10.00am to 11am.  
**Venue:** Nourish Café, Te Puna  
Everyone stopping by Tauranga is welcome to join us, just let someone know. Please contact either:  
Jane: [janepuckey99@gmail.com](mailto:janepuckey99@gmail.com)  
Mary: [marybestrd3@gmail.com](mailto:marybestrd3@gmail.com)  
Alumie: [alumie.uow@gmail.com](mailto:alumie.uow@gmail.com)

## Otago support group:

Sunday July 3rd, 2022, 12pm Pot Luck Finger lunch  
**Venue:** Connected Eastern Southland, 1 Charlton Lane, Gore. Please contact Vanessa if you wish to join us.  
[Nessie332@gmail.com](mailto:Nessie332@gmail.com)

# Contacts:

## Find a Scleroderma a Support Group near You:

Bay of Plenty:	Alumie Nguyen, Email: <a href="mailto:alumie.uow@gmail.com">alumie.uow@gmail.com</a>
Waikato:	Linda Bell, Email: <a href="mailto:linda.bell@hotmail.co.nz">linda.bell@hotmail.co.nz</a>
Hawkes Bay:	Gail Neilson, Email: <a href="mailto:gail_neilson@hotmail.com">gail_neilson@hotmail.com</a>
Waipa:	Erena Bruce, Email: <a href="mailto:glenanderena@xtra.co.nz">glenanderena@xtra.co.nz</a>
Palmerston North:	Martine Fremaux, Email: <a href="mailto:curios@xtra.co.nz">curios@xtra.co.nz</a>
New Plymouth:	Elle Bray, Email: <a href="mailto:1elle@xtra.co.nz">1elle@xtra.co.nz</a>
Wellington:	Dianne Purdie, Email: <a href="mailto:diannepurdie@xtra.co.nz">diannepurdie@xtra.co.nz</a>
Blenheim/Nelson:	Jen Soane, Email: <a href="mailto:jennasoane@gmail.com">jennasoane@gmail.com</a>
Christchurch:	Carolyn Barkhausen , Email: <a href="mailto:carolynbarkhausen@gmail.com">carolynbarkhausen@gmail.com</a>
Otago:	Vanessa Gray, Email: <a href="mailto:Nessie332@gmail.com">Nessie332@gmail.com</a>
Southland:	Heather Milligan, Email: <a href="mailto:milliganseeds@xtra.co.nz">milliganseeds@xtra.co.nz</a>



# Welcome to Scleroderma New Zealand Inc.

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

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

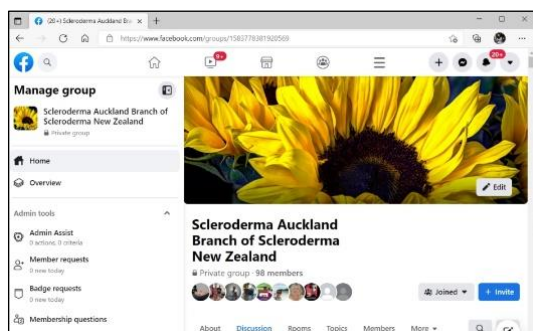
Link to our Website address below: -  
<http://scleroderma.org.nz/>



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



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



## Scleroderma New Zealand

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

### **AGM Meeting**

All welcome  
Meeting via zoom,  
Wednesday 22<sup>nd</sup> June 10am

Click on the Link Below to join  
<https://us02web.zoom.us/j/86226822382?pwd=dzZVU3lVYitBUlI3dThkWWlqcEVXZz09>

If you would like to join us on the committee please put your name in to us or if you have someone you would like to nominate let us know. Contact:  
Jenny Andrews [jennyred@xtra.co.nz](mailto:jennyred@xtra.co.nz)

It is a fantastic way to meet new people and we are all working for the greater good of people with Scleroderma.

