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# Scleroderma

## New Zealand support group

## Autumn 2022

Greetings to you all.

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

We hope everyone is well and keeping safe.



We hope everyone has had a good Christmas, a happy New Year and restful time over the holiday period.

We are into the start of 2022 and we already have a big challenge ahead of us, a challenge to keep safe from the Covid virus Omicron. Take care everyone and be careful when you go out, remember to wear your mask.

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 **Marie McLellan**, a long-time member of the Wellington Scleroderma group. Marie was always so happy and cheerful when she came to our meetings. We will miss you greatly Marie.

We have stories to share from our members **Amy, Erena** and from our own president **Jenny**. We have a few articles from Scleroderma News.com regarding Covid-19 vaccine safety for people with Systemic Sclerosis (SSc) and Eating well with SSc.

We have an interesting article on the link between Raynaud's and Scleroderma, as well as some very interesting **YouTube video links** from the Scleroderma & Raynaud's UK (SRUK) website. Those of us who suffer from Raynaud's may want to note that this website has also produced an app called **STAR** for use on your mobile phone to record times when you have a Raynaud's attack.

We have our regular Covid-19 updates, plus Members News from our different support groups, including a notice that the Southland Seminar has been postponed. We also have a small section talking about our calendar fundraiser.

Be Safe and take care everyone.  
Warmest regards,  
**Tina and Jenny**



# Presidents Report:

## Autumn 2022



Happy New Year to you all. Amazing that we are in March already. By all accounts the whole country seems to have had a lovely summer.

A big welcome to all our new members. It has been wonderful talking to and at times meeting

some new members. It's good to know that we are out there enough for people to be able to get in touch with us. We have most hospitals passing on our information but there are still a few who have slipped through the cracks. I am working on making sure our information is at each DHB. Not pushing the issue too much at the moment as DHB's are going through a lot at the moment.

The country sadly is breaking records for positive covid cases each day and heading up towards the peak at the moment. If you do end up catching it hopefully our vaccines will do their job and keep us out of the hospital. Remember to wear your masks while you are out and about and you know your body better than any-one else so keep an eye on any changes to how you are feeling.

Unfortunately, the Southland Group have had to postpone our seminar that was to be held on the 26<sup>th</sup> of March. We held off as long as we could but with Covid creeping its way down here it was really the only decision we could make. The safety of our members is paramount. Covid has reached a lot of us in one way or the other and personally for me I have my son locked down in Dunedin with a positive result but his vaccine is doing its job and he has been asymptomatic.

We have heard from our wonderful Secretary Jane Sainsbury that she will be leaving NZ this month and heading back to the U.S after having 20 odd years in Hawkes Bay. We will miss Jane here and I am sure she has left her group in great hands. Jane has very kindly agreed to stay on as our committee secretary from the States. Thank you so much Jane. Look forward to hearing your news from afar.

A lot of our groups have stopped having in person meetings at the moment just until things settle down a tad, during this time there will be zoom meetings you can attend to keep in touch. Information on these will be in the pages that follow. If you are feeling lonely and need to talk then get in touch with someone from your group if you are not part of a group then I am always just a phone call away and can put you in touch with someone.

I have personally had a great start to the year with a road trip with my daughter to Auckland to shift her for her new job. We took 10 days travelling up the country and saw some beautiful spots. Caught up with family and friends of both of ours, we got to catch up with a few Scleroderma friends along the way and I was lucky enough to meet some lovely ladies in Mount Maunganui at their first Bay of Plenty Meeting. A huge thank you to Jane Puckey for opening your home to us. Some more on my travels with some pics further through the newsletter.

Feeling saddened by all the happenings at Parliament in recent weeks. Jeff and I were there exactly a year ago and it was such a warm welcoming environment. My heart goes out to Wellingtonians and to the NZ Police and their families who were so affected by this. It certainly felt like we were watching scenes from overseas, rather than from our own beautiful country. Stay safe out there and fingers crossed covid will peak very soon and we can see things beginning to improve.

All the best  
Jenny





# Memorial for Marie McLellan

Scleroderma New Zealand Member

**Marie McLellan**



McLELLAN, Marie Paule (née Barrett):

21 January 1943 - 14 January 2022

In her 79th year. Dearly loved daughter of Robert and Emilienne Barrett, sister of Ann, Raymond, Bobby and Les, wife of Andy McLellan, mother of Andrew and Elizabeth, grandmother of Rose, Grace and Kellan, and great-grandmother of Willow.

**Source:** [Marie MCLELLAN Obituary \(2022\) - The Dominion Post \(dompost.co.nz\)](https://www.dominionpost.co.nz/obituaries/2022/01/21/marie-mcLellan-obituary/)

It is with great sadness that we bring you the news of Marie McLellan passing. Liz her daughter said that she went peacefully with no pain so that is a real blessing.

Marie and Liz have been with us pretty much from the beginning of our group. For those of you who didn't get to meet Marie, she was a real sweetie, and was a real battler with Scleroderma and showed a lot of strength. Marie will be sadly missed by our group, but I hope Liz will keep coming along when she can.



Maree and her daughter Liz started coming to the Wellington support group very early on, soon after we got started. Maree came all the way down from Foxton which is a bit of a trip of approx. 2hrs, it was a great effort and we really appreciated seeing them both.

Maree was always a real sweetie to us all, and always very happy to share her experiences with us, which helped others too.

We will sadly miss Maree but we will always remember her in our hearts.

Our love to Liz and all the family.

**Dianne Purdie**



# Members Stories:

## Amy Thompson – “Guarding her life saving gift!”

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After resigning herself to start planning her own funeral, Amy was given a second chance at life with a lung transplant— only to face a new challenge – keeping herself safe and alive during COVID-19.

In 2006, Amy was diagnosed with Scleroderma - a rare, chronic autoimmune disease that scars the skin and internal organs. Her condition worsened over time and she was placed on the active lung transplant list.

In September 2018, while having dinner with her family, Amy got the life-saving phone call from the transplant service that a suitable donor had been found.

The news couldn't have come soon enough for Amy who by then was relying on oxygen 24/7 and describes small things like getting dressed, eating, and showering as “mammoth tasks.”

“I guard these precious lungs as they were donated when my donor family were going through a time of devastation yet had the heart to make such a selfless gesture. I do what I need to, to protect them.

“I take a lot of medications now especially ones to suppress my immune system to prevent rejection and this makes me susceptible to any infectious diseases.

“Getting COVID-19 could be so devastating for me and others like me. It's scary because people can be asymptomatic with COVID so it's hard to know who has it or not.”

Amy is one of our patients and also a valued staff member of 19 years. Before COVID-19, she was based at Middlemore Hospital as a Clinical Quality Specialty Nurse for the Surgery, Anaesthesia and Perioperative Services (SAPS) for Counties Manukau Health.

Being a ‘high risk vulnerable worker’, means Amy now has to work from home to protect herself.

“I am so grateful for the support of my managers to work at home. My colleagues and friends check in on me and keep in contact which is comforting to know they still think of me and care.”

“I miss going out meeting up with friends, eating out, seeing my colleagues, having a laugh and just seeing

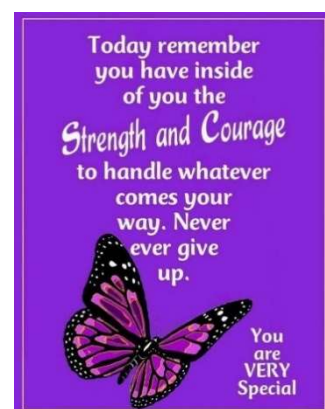
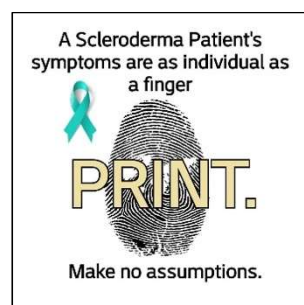
other people in general but I do what I have to do to guard my precious gift.”

Amy loves her job of caring for others and she continues to do so when she herself needs care. Her inspiring story is a reminder to care for our vulnerable, especially in these COVID-19 times.

*Amy Thompson*



Source: Counties Manukau Health News  
<https://www.countiesmanukau.health.nz/news/guarding-her-life-saving-gift/>



# Members Stories:

**Erena Bruce** – “Kia Ora, Talofa lava, Malo, fellow Scleroderma peoples” ....



Kia Ora, Talofa lava, Malo, fellow Scleroderma peoples, Summer has been a goody.

We have been able to travel in and out of the Waikato, able to do activities, have time by the sea, a pleasure to reflect on the beauty

and bounty we have here in Aotearoa/NZ. Sports were able to be played albeit managed differently at Club level, then opening up to Regional level in February, fantastic thing, Sport. To top it off with the Winter Olympics going ahead recently just awesome.

Our group have had to manage their personal and family worries, with lingering virus like influenza symptoms prolonging. Much of it hit grandchildren therefore Grandies were going to naturally pick it up! So when our boarder opened it was such a relief to spread wings to open spaces. We (as a whaanau) managed to get to the Hokianga, Hastings and Mount Maunganui. All three destinations we had different reasons to do and all we had good bonding time, rest and relaxation with some competition cricket also. Its times like this that I reflect on where I was a year ago, and lets just say 2022 I am able to participate more.

As a family we lost my dad in August last year right on lock down it was a challenge and gratefully to a large extent we were prepared. We managed to get through the borders (back up to the Hokianga (Northland West Coast) early hours in the morning to lay dad to rest. Letting go of dad was a little more manageable as dads Kidney failure was progressive, we had time to farewell, but its the afterwards the time family and friends would usually come to visit or stay that is tough cause they couldn't come. We couldn't grieve together. Phone calls, skype, zoom fill a gap but as a people its the contact, that affection, a touch that can say a thousand words. Now every time we meet family again its like opening up a very sad time again, quite draining really. I am sure you folk have experienced or

maybe now going through this very process and to you all a great big arm length hug and blessings. Grief needs its time in our lives, if we take time to see it through all the feelings it evokes then it does not fester and cause harm. Can I suggest you make that call to someone, send that card, send that personal text or have that outing.....in the long run it just helps!

Here in the Mighty Waikato we have had the perfect weather for our big big gardens. Harvests have been superb and with the price of vegetables, well timed. Fruit trees have been abundant yummy bottled plums, pickles, jams just great. I still find gardening a real chore, mind you anything bending too often and certainly getting on floor is a no go. So glad flaxseed oils are kicking in again, not sure why I stopped but huge difference going back on. Also have shared a product called MOVE with my group a spray on or cream smells like liniment, works treat overnight. Oils and heat go well on joints.

Folks do take care as we are now in Autumn enjoy the days (wrap up in the mornings) take those special moments in your day to smile, laugh and keep them to the front of your mind

Nga manakitanga (with great respect)  
Erena Bruce





# Members Stories:

## Jenny Andrews – “Road Trip; Winton – Auckland”....

In January I travelled from Winton to Auckland with my daughter Maddy in her little Honda Fit car. We loaded all her belongings into her car and set off.



Maddy at Rabbit Island

Our first stop was Christchurch where we had a couple of nights, joined by hubby and son, we attended our nephews engagement party. I was able to pop in and see Carolyn Barkhausen at her work and see where our booklets, calendars etc have all been printed. Then a



Me in Greytown

quiet trip through to Nelson, stopping in at Hanmer Springs. We spent 2 nights in Nelson with my Mum's cousin. We were so looked after it was amazing. Maddy had a swim at Rabbit Island and we enjoyed fresh fruit ice creams. Taking the ferry to Wellington went pretty quickly as we shared my ear pods and watched a movie together. Arriving in Wellington was a little scary as I

have only driven there once and for a very short time. We stayed a couple of nights there and visited Te Papa, did some shopping and ate ice cream at Duck Island. Yummy. Maddy drove us through to Napier, stopping in at Martinborough, Greytown, and the sunflower field.



Flying Gannet



Me and Maddy at the Gannets



Sunflower Field- Tararua



Maddy & Mum's Cousin in Napier





We spent 2 nights there with another cousin of my Mum's which was wonderful. We took the tour to the Gannet colony. This was amazing, 3 hours of wicked countryside and thousands of Gannets going about their day looking after their babies. We travelled on to Taupo and visited the Craters of the Moon walk and visited Huka Falls. Then on to Mount Maunganui. Stopping at the Redwoods Treetop walk. Such a great attraction. Went straight to Jane's house for the first Bay of Plenty Meeting. We had a lovely afternoon and Jane was a superb host. Mary & Alumie attended and Mary has taken on organising the next one in March. Fish N Chips on the beach watching the sun set was how our day ended with Maddy and her two friends. It was just stunning. Our next night was spent in Whitianga then on to Auckland via Coromandel Town. Hubby flew up and we found our way to the airport to pick him up. The next week was spent organising bedroom furniture, and everything she needed for her flat. Maddy had her 22<sup>nd</sup> birthday while we were there and we fitted in a visit to the zoo. Then we could go home knowing she was all ready to start work and begin the next stage in her life.



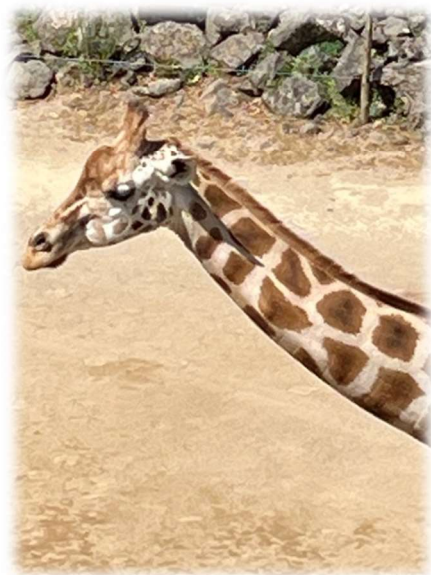
*Maddy and her friends Mount Maunganui*



*Enjoying the peace while working around the Mount*



*At lookout on the Napier – Taupo road*

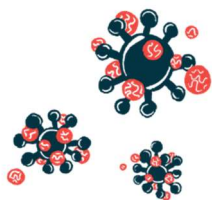


*My favourite animal – Auckland Zoo*



# COVID-19 Vaccines Safe in SSc, With Few Reported Flares, Survey Finds:

by [Patricia Inacio PhD](#) | February 3, 2022



People with systemic sclerosis (SSc) vaccinated for COVID-19 fare well, with no

serious adverse events and a low rate of reported flares, according to an international survey.

“To our knowledge, this is the first large study that details experiences with COVID-19 vaccines in systemic sclerosis. Vaccination was safe in this group,” the researchers wrote.

The survey results were reported in “Systemic sclerosis and COVID-19 vaccines: a SPIN Cohort study,” published in the journal *The Lancet Rheumatology*.

Several vaccines have been developed against SARS-CoV-2, the virus that causes COVID-19. Initial clinical trials supporting the use of these vaccines enrolled only healthy individuals and so there is little information regarding their safety among people with autoimmune rheumatic disorders, such as SSc, also known as scleroderma. This may contribute to patients’ hesitancy in being vaccinated.

In fact, a prior study, published in mid-2021, suggested that SSc patients might be more hesitant to get a COVID-19 vaccine than those with other rheumatic diseases.

To learn more, an international team led by researchers from the department of rheumatology at the Hospital for Special Surgery, in New York, evaluated the proportion of SSc patients enrolled in the Scleroderma Patient-centered Intervention Network, called SPIN, who were vaccinated against COVID-19. SPIN is an organization of researchers, healthcare providers, and people with SSc from around the world, which aims to develop strategies to help scleroderma patients better cope with and manage their condition.

In addition, the team investigated whether medications were altered before vaccination, as well as adverse reactions. The degree of vaccine hesitancy, and

patients’ perceptions on vaccination, also were evaluated.

Participants in the SPIN group were invited to complete the COVID-19 vaccine survey, delivered by email. Responses were linked with their clinical and sociodemographic data.

A total of 932 (66%) of the 1,410 patients actively enrolled in SPIN completed the full survey and were included in the analyses. These patients, who had a mean age of 60, were mostly from the U.S., France, Canada, and the U.K., and 89% were women.

Results showed that 699 patients (75%) received at least one vaccine dose and 358 (38%) two vaccine doses.

Most received the Pfizer/BioNTech vaccine, followed by the vaccine from Moderna, and then the one from the University of Oxford/AstraZeneca. Other vaccines brands — Novavax, Johnson & Johnson, Sputnik V, and Convidicea (Ad5-nCoV) — were less commonly used. The vast majority of respondents had been vaccinated by mid-May of last year, or intended to be vaccinated.

Changes in medication among vaccinated patients were rare, occurring only in 42 patients (6%) before their first dose and in 28 patients (8%) before their second dose.

Source: <https://sclerodermanews.com/2022/02/03/covid-19-vaccines-safe-ssc-patients-survey/>

## RECOMMENDED READING

January 5, 2022  
[Columns](#)

by [Amy Gietzen](#)



[Scleroderma Brings Both Endings and Beginnings](#)





# COVID-19 Vaccines Safe in SSc, With Few Reported Flares, Survey Finds: *continued...*

Adverse reactions following the first dose of the vaccine were reported by 270 patients (39%) and, after the second dose, by 209 participants (58%). The most common reaction was a sore arm, as reported by 30% of participants after the first dose and 45% after the second dose. Other common reactions were fatigue, as noted by 22% after the first dose and 40% after the second, and muscle ache — 9% first dose; 22% second dose. No severe reactions were reported.

Worsening of at least one SSc-related symptom was reported by 6% of participants after the first dose and 8% after the second.

After the first dose, factors linked with an adverse reaction — other than a sore arm — included age, being male, a history of COVID-19 infection, and taking the Oxford/AstraZeneca vaccine. The factors linked with adverse reactions after the second dose also included age and being male, as well as non-white race or ethnicity, being French, use of immunosuppressants, and having had the Moderna vaccine. The researchers noted that, for the second dose, only 21 patients received the Oxford/AstraZeneca vaccine.

A total of 90 patients (10%) were classified as vaccine-hesitant. Being hesitant was linked with younger age — a mean age of 55 versus 60 for people vaccinated or willing to be vaccinated — as well as a history of COVID-19 infection (21%), and with being a current smoker (25%). Patients from France showed the highest hesitancy (16%), while those from the U.K had the lowest (3%).

The reasons for the hesitancy included doubts regarding vaccine effectiveness, the potential for adverse reactions, the development process of the vaccines, and the overall need for COVID-19 vaccination.

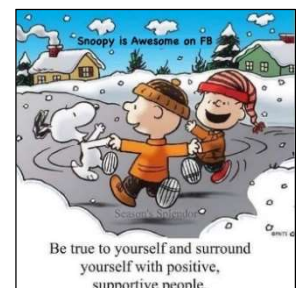
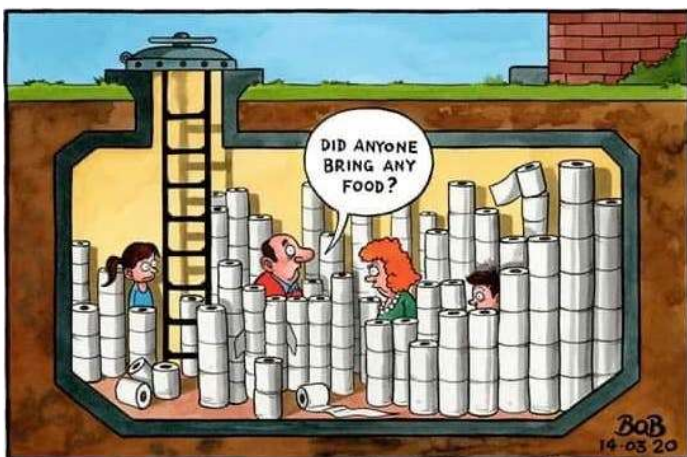
Compared with vaccine-hesitant patients, significantly more individuals who were vaccinated or were willing to be considered the vaccine a civic duty (74% vs. 13%). This group also rated information sources as important or very important — namely, recommendations by their doctors (80% vs. 50%) and the ability to discuss concerns with their doctor (74% vs. 62%) — more often than the vaccine-hesitant group.

In addition, vaccine-hesitant patients gave higher importance to having time to assess the long-term negative effects of the vaccine (80% vs. 59%) and to knowing the experiences of other SSc vaccinated people (64% vs 51%), as compared with those who were vaccinated or were willing to be.

“There is little information on the safety of COVID-19 vaccines in patients with autoimmune rheumatic diseases, and patient concerns about possible adverse outcomes in these diseases contribute to vaccine hesitancy,” the researchers wrote, adding that this survey suggests that the vaccine is “safe in this group.”

There were “no serious adverse events, a side-effect profile similar to that seen in other populations, and a low rate of reported systemic sclerosis flare,” they concluded.

Source: [COVID-19 Vaccines Safe in SSc, With Few Reported Flares, Survey Finds \(sclerodermanews.com\)](https://www.sclerodermanews.com)



# 6 Recommendations For Eating Well With Scleroderma:

by [Marta Ribeiro](#) | November 9, 2017



According to the Scleroderma Foundation, what we eat ends up affecting our body and our health in many ways. Fruits and vegetables are beneficial foods since they provide our bodies with energy and essential nutrients.

On the other hand, processed junk foods are devoid of nutrients and when consumed in large quantities can potentially be harmful to our bodies regardless of our age or current health. We've listed some general recommendations on how to organize your meals and what to eat to improve your health.

## 1. Eat less, more frequently

Aim to eat small meals every three to four hours. However, if you are carrying an excessive amount of weight or can only eat small amounts at a time, try to eat even smaller meals every two hours to maximize nutrient intake.

## 2. Eat fresh and natural foods

Choose whole, fresh, unprocessed foods without any preservatives, artificial ingredients or hydrogenated oils. Choose products with a short ingredient list. If you spot any "chemical" sounding names in the ingredient list, try to avoid it.

**MORE:** Seven tips for new caregivers for scleroderma patients

## 3. Add herbs and spices

Add anti-inflammatory and antioxidant rich spices and herbs, like rosemary, basil, oregano, ginger, cinnamon, cayenne, paprika, turmeric and curry powder to foods.

## 4. Cut down on added sugars

Unless it causes you some GI distress, the natural sugars found in milk, yogurt and fruit are not a concern.

However, keep an eye on ingredient lists for stealthy terms indicating added sugar such as sucrose, fructose, evaporated cane juice, brown rice syrup, agave nectar, honey, molasses, corn syrup, and maple syrup.

## 5. Multivitamin or mineral supplement

Consider taking multivitamins or mineral supplements. If specific nutrient deficiencies have been identified, extra supplementation may be required.

## 6. Water, water, and more water

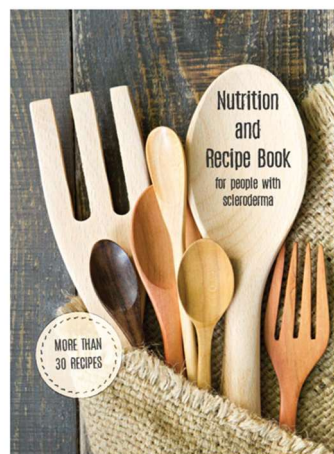
Don't forget to drink fresh, filtered water — preferably water that's never been exposed to plastic. Drink only from stainless steel or glass containers and use a water filtration system at home.

Aim to drink at least 50 percent of your body weight in ounces of water each day. For example, a 150-pound person should drink at least 75 ounces of water daily.

**MORE:** Seven common misconceptions about scleroderma

Source: [6 Recommendations For Eating Well With Scleroderma - Scleroderma News](#)

***Dianne has kindly given us a link to a Scleroderma Cookbook. ☺***



Click on the below link to check it out

[https://sclerodermie.ca/wp-content/uploads/2020/01/GuideAlimentairV2020\\_ang\\_br.pdf](https://sclerodermie.ca/wp-content/uploads/2020/01/GuideAlimentairV2020_ang_br.pdf)





# The link between Raynaud's and Scleroderma:

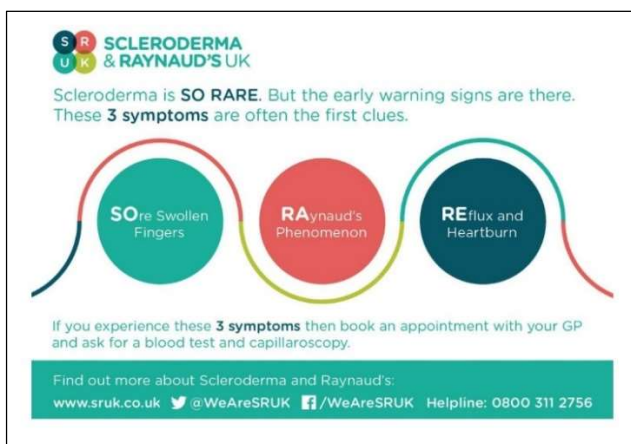
From the SRUK – Scleroderma & Raynaud's UK website

## The link between Raynaud's and Scleroderma

Most people diagnosed with Raynaud's will not develop scleroderma, which only affects 0.1% of everyone who has Raynaud's. This is because the majority of people who are living with Raynaud's will have the primary form, with symptoms of cold hands and feet and painful attacks with changes in temperature. In primary Raynaud's however, there is no link to any other disease, including scleroderma.

Secondary Raynaud's can be a sign of scleroderma, and is caused by another, potentially serious health condition, including lupus or vasculitis as well as scleroderma. It is often the first noticeable sign of scleroderma, for example 95% of people diagnosed reported that Raynaud's was their first symptom. If you do have Raynaud's, it is important to get tested to establish whether you have the primary or secondary form, and this can be arranged by your doctor.

Although we often talk about people with scleroderma having 'Raynaud's symptoms', primary and secondary Raynaud's are actually very different, with important distinctions in the disease processes of each condition.



[ If I had known about this diagram above, I would have been able to recognise Scleroderma straight away – Tina]

## How Raynaud's is different for people with scleroderma

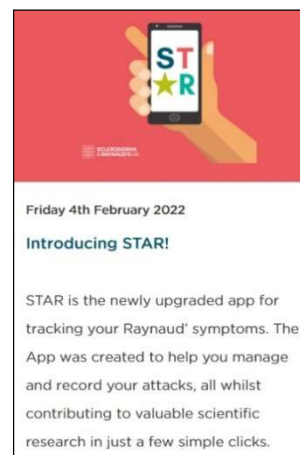
Unlike primary Raynaud's phenomenon where the blood vessels narrow and then return to normal size, in cases of scleroderma, the small blood vessels in the skin gradually change in size, becoming increasingly smaller and sometimes even disappearing over time.

Blood vessels lose the ability to return to their normal size in between attacks, and this reduces the supply of oxygen and nutrients to the skin. If the skin does not receive enough nutrients, it can become dry and cracked, and small ulcers sometimes form on the tips of the fingers or thumbs, with gangrene developing in severe cases.

In people with scleroderma, problems with the blood vessels can spread into other parts of the body and internal organs. This never happens in primary Raynaud's. So although the effects on the fingers and toes initially appear to be the same, the ways in which the two conditions develop are very different.

Source: <https://www.sruk.co.uk/raynauds/link-between-raynauds-and-scleroderma/>

## Introducing STAR!



This January, **SRUK** released the updated and upgraded version of the 'Raynaud's ResearchApp,' renamed STAR (short for Symptom Tracking App for Raynaud's). Star is the result of 12 months' hard work in collaboration with the SRUK community and leading rheumatologists researching Raynaud's, in order to build the best possible next version of our symptom tracking app.

Complete with over 20 trackers, including validated measures such as the 'Raynaud's Condition Score' and many lifestyle trackers such as sleep, caffeine intake and exercise, STAR generates charts and graphs designed to help you spot trends and patterns in your own Raynaud's and identify the best ways to self-manage your condition.

Source: <https://www.sruk.co.uk/about-us/news/introducing-star/>

## YouTube Video Clips from SRUK:

### Raynaud's Symptoms and Classification

[https://www.youtube.com/watch?v=BSu4lv1Dv\\_w](https://www.youtube.com/watch?v=BSu4lv1Dv_w)

### Dr John Pauling presents on the impact of Systemic Scleroderma

<https://www.youtube.com/watch?v=VL94mZVbTRE>

### Diet Nutrition in Systemic Sclerosis

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



# Understanding Gastrointestinal Involvement in Systemic Sclerosis: The Role of Nutrition:

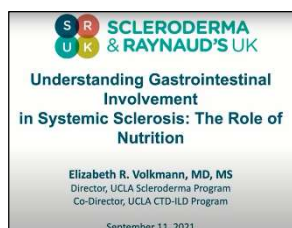
Presented by Elizabeth R. Volkmann, MD, MS

The video clip from SRUK (Scleroderma & Raynaud's UK) is very interesting about the role of Nutrition in people with Systemic Sclerosis. I suggest watching their clip for those who are having problems with their digestive system.

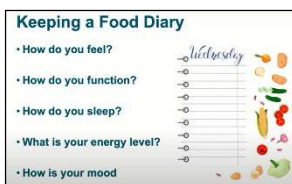
Title and link to the video clip below:

## [Diet & Disaster: The Role of Nutrition in Systemic Sclerosis - YouTube](#)

### Understanding Gastrointestinal Involvement in Systemic Sclerosis: The Role of Nutrition



I have found that the tips Elizabeth has presented in her video clips are very helpful and I have summarised some of those tips below: -



**Keeping a Food Diary**, over the course for 2 -3 weeks is good to see patterns. What foods are problematic and what may nourish you.

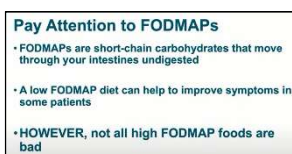


When it gets confusing, try an **Elimination** diet, do this with the guidance of a Health Professional i.e. Nutritionist or Dietician.

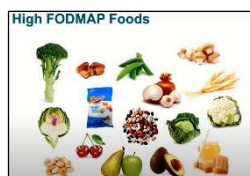


**Mindful Re-Introduction** of Foods. Stop eating foods that are causing problems for 2 – 3 weeks, and then re-introduce, one at a time.

### Pay Attention to FODMAP's.



### High FODMAP Foods



**Consider How You Combine Foods.** Also consider how you cook these food.

### Strategies to Improve Bacterial Balance:

- Avoid ultra-processed foods
- Increase whole food consumption
- Avoid added sugars

**Tip:** Look at the back of packets, if it has more than "5 ingredients" it is highly processed.



### Dangers of Food Additives

Food Additives	Effect on Microbiota	Effect on Host Physiology
CMC	Bacterial overgrowth	Intestinal inflammation
P-80	Microbiota encroachment, altered species composition, increased pro-inflammatory potential	Intestinal inflammation, obesity, liver dysfunction
GML	Gut microbiota dysbiosis	Metabolic syndrome, systemic low-grade inflammation
Sucralose	Increased expression of bacterial pro-inflammatory mediators	Elevated pro-inflammatory gene expression in the liver
NAS	Compositional and functional alterations of microbiota associated with obesity	Glucose intolerance
Saccharin	Increased pro-inflammatory potential	Liver inflammation
Aspartame	Compositional alterations of microbiota	Glucose intolerance

### Increase Natural Probiotic Consumption e.g.

Yogurt (dairy & non- dairy)  
Dairy products (milk)  
Fermented Foods  
These food have higher Natural Probiotics rather

than supplements. **Increase Natural Prebiotic Consumption** (e.g. Onions, Garlics, Leaks, asparagus, acacia powder, artichokes).

### Dietary Suggestions for Specific GI Symptoms

#### Acid Reflux: Dietary Recommendations:

Acid Reflux: Dietary Recommendations
<b>Avoid</b>
Fried food
Poor quality vegetable oils
Red meat
Coffee
Hot spices (chili, mustard, pepper)
Alcohol
Citrus fruit, Tomatoes
Vinegar

#### Foods to Avoid

#### Foods to Increase (if tolerated)

Increase (if tolerated)
Soups
Gluten free oats
Yogurts (non-dairy if cannot consume dairy products)
Avocado
Spinach
Cucumber
Liquid chlorophyll
Chamomile tea

### Bloating: Dietary Recommendations

Bloating: Dietary Recommendations
• Make sure you are drinking enough water
• Avoid white foods (white bread, white rice, white sugar)
• Avoid harmful food combination (heavy fat/protein + simple carbs like fruits)
• Avoid excessive fiber intake (especially fiber supplements with additives)



### Bloating : Herbal Remedies

Bloating: Herbal Remedies
• Try an herbal tea
• Ginger tea- before meals
• Chamomile tea- after meals
• Lemon balm- between meals
• Add organic aloe vera juice to your morning ritual
• Always consult your doctor before starting a supplement or herbs for your safety



### Diarrhoea: Dietary

### Recommendations

### Summary of Suggestions

Summary of Suggestions
• How you eat can have a tremendous effect on how you feel when you have SSC
• An individualized approach to your nutrition is best
• Developing a relationship with your body will help you understand what foods nourish you the most

Summary of Suggestions
• Eat when you feel warm and relaxed
• Avoid processed foods and added sugars
• Limit raw food, especially if you have bloating or diarrhea
• Consider a plant-based diet

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





# Covid-19: Our response to Omicron

Omicron is in our community. There are 3 phases to our response. We are in Phase 3: - Find out what this means for you.

## Latest update — 24 February 2022

From 11:59pm tonight, we will move to **Phase 3** of the Omicron response.

At Phase 3, the focus is on safely managing COVID-19 at home. This means we can keep our hospital beds free for people who are vulnerable and need medical treatment.

## About Phase 3

### Getting tested for COVID-19

You should only get a COVID-19 test if:

- you have symptoms, or
- you are a Household Contact

At Phase 3, PCR tests will be used for people who need it most, and rapid antigen tests (RATs) will become more widely available. When you go for a test, the testing centre will let you know which test — RATs or PCR is best for you. Positive RAT results do not need to be confirmed with a PCR test unless advised.

Critical workers who are Household Contacts will still be able to use RATs tests to return to work, if they are fully vaccinated and do not have any COVID-19 symptoms. They will need to return a negative RAT before they go to work.

[When you should get a test](#)

[More information about rapid antigen tests](#)

[Find out if you are a Critical worker](#)

[Close Contact exemption scheme | business.govt.nz\(external link\)](#)

### If you test positive for COVID-19

If you test positive for COVID-19, you will need to isolate for **10 days**. You will be sent a link to complete an online form, which will help identify locations you have visited and people you have come into close contact with.

If you do not have access to a mobile, you will be contacted by a contact tracer, or a primary care, Māori, iwi or Pacific health provider.

You can leave isolation after 10 days — you do not need a negative test.

[What to expect if you test positive for COVID-19](#)

[If you test positive for COVID-19 | Health Hub\(external link\)](#)

### Close Contacts

At Phase 3, Close Contacts no longer need to isolate. If you get a notification from your workplace, school or through the NZ COVID Tracer app that you are a Close Contact, you should monitor your symptoms for 10 days. If you develop symptoms get a test, and you should isolate until you get your result.

If you live with someone who has tested positive for COVID-19, you are considered a Household Contact and will need to isolate for **10 days**. You must get a test on Day 3 and Day 10 of your isolation. If you develop symptoms you should get a test sooner. If you are a Household Contact and you test positive, you will need to isolate for 10 days.

From Friday 25 February, if you are currently a Close Contact and are part way through your isolation, you do not need to complete your 10 days isolation and you will be permitted to leave. You do not need to get a negative COVID-19 test.

[Close Contacts](#)

[If you are a household close contact | Health Hub\(external link\)](#)

### Contact tracing and locations of interest

Locations of interest will not be published during Phase 3. Contact tracing will focus on identifying high risk contacts of cases. If you test positive for COVID-19, you will be supported to notify people you may have spent time with while infectious that you have tested positive.

Contact tracers will focus on helping people who do not have access or are not confident using technology.

It is important to continue scanning in using the NZ COVID Tracer app. If you have scanned in, you can upload your digital diary to the online contact tracing form. This will make it easier for you to identify people you may have been in contact with.

### 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.

[Get support if you have COVID-19 or are self isolating](#)

[Financial support if you are self-isolating](#)

Source: [Our response to Omicron | Unite against COVID-19 \(covid19.govt.nz\)](#)



# Covid-19 update: About the Omicron variant

Omicron, also known as the B.1.1.529 strain, was first identified in mid-November 2021. The World Health Organization rapidly classified Omicron as a variant of concern due to the large number of mutations it contains, with at least 30 located in the spike protein.

*Last updated: 14 February 2022*

The Omicron variant has spread worldwide rapidly and is now the major variant in many countries. Omicron is much more transmissible than previous variants of the COVID-19 virus, including Delta. However, as the Omicron variant is so new, more data is needed to understand how Omicron has spread so rapidly across the world.

It is important to remember that Omicron was only declared a Variant of Concern at the end of November 2021. The rapid emergence of Omicron will require yet another change in the way New Zealand manages COVID-19.

New Zealand has a very effective system in place for identifying new variants. The ongoing emergence of new variants such as Omicron underline why it is so important that we continue to perform whole genome sequencing on cases from overseas and those not linked to a cluster in New Zealand.

## What New Zealanders can do now:

- if you are eligible to have your COVID-19 vaccine booster shot, please make a [booking here](#). 5–11 year old's are also now able to receive the pediatric Pfizer vaccine
- prepare a kit for your home and make a plan if you or someone in your household becomes a positive COVID-19 case. [Prepare and stay safe](#)
- continue to follow good hygiene practices and wherever you go: [Mask, Scan and Pass](#)
- if travelling around the country over summer, have a plan in place if you become unwell or test positive. See [advice here](#).

## How Omicron is different from earlier variants

Although Omicron is a very new variant, there is already much that we have learned about this variant. Most of this information has come from overseas, so it is important to understand that all countries are different, so the information needs to be carefully analysed to see how it will apply to New Zealand.

### Infectiousness

- Omicron is more transmissible – case numbers may double every 2 to 4 days

### Vaccines

- People who are fully vaccinated have less protection against transmission of Omicron than for Delta.
- Protection against infection with either Delta or Omicron decreases over time. A booster dose at 3 months after the end of the first course will improve protection against Omicron, particularly for protection against severe disease, such as hospitalisation.

### Symptoms

- Omicron probably causes similar symptoms to other variants, such as Delta. However, in a country that has most people vaccinated, many people may not have any

symptoms at all, but still be able to pass on the virus to other people.

### Severity

- Omicron does not appear to result in as many people being hospitalised. However, because Omicron can cause so many infections over a short period of time the number of people going to hospital each week has risen steadily in many countries.
- Omicron can still cause severe illness and even death, especially in people who are at risk of severe outcomes, but a smaller proportion of people who are infected with Omicron need to go to hospital compared to people infected with Delta.

Please also see the latest information about Omicron in our [Variants Update on the COVID-19: Science news page](#).

## How we can protect ourselves: vaccine effectiveness and health measures

Globally, and here in New Zealand, it is so important to stamp out any community outbreaks as quickly as possible and to ensure very high rates of vaccination. This will provide important time to get as many people vaccinated and make the changes that are necessary to deal with Omicron.

The same measures which kept us safe against Delta are effective against Omicron.

Vaccination and boosters help to reduce transmission of the virus. Remember, that if you don't get the virus, you can't give it to someone else. Taking other precautions also remains important to continue to protect our communities against Omicron. As well as vaccination, early detection of cases and swift contact tracing, and isolation of cases and contacts, is critical.

It will also be important to continue to protect ourselves and our whānau and stop the transmission of the disease by following health habits such as:

- Keep indoor rooms well ventilated (e.g. by opening windows and doors) where possible
- [Wearing masks and face coverings](#) is one way of keeping yourself safe and protecting others from COVID-19, especially when physical distancing is not possible. Wear masks in confined or crowded environments.
- Physical distancing of 2m where possible
- If you feel unwell or show any symptoms, stay home. Call Healthline and get a COVID-19 test
- Use your My Vaccine Pass to scan into venues and events. MVP is a record of your COVID vaccination status
- Keep a record of where you've been or scan in wherever you go using the COVID Tracer app and turn Bluetooth on your phone so you can be contacted if you have been near a case.

Source: <https://www.health.govt.nz/covid-19-novel-coronavirus/covid-19-health-advice-public/about-covid-19/covid-19-about-omicron-variant>





# Update on COVID-19 cases : from 11<sup>th</sup> March 2022

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

## Today's COVID-19 numbers

- 20,989 new community cases
- 23 new cases identified at the border
- 856 cases in hospital
- 4,614 total PCR tests in the last 24 hours
- 7,863 booster doses administered yesterday

11 Mar 2022

Watch the latest update on our response to COVID-19 at 1pm.

The COVID-19 media conference starts at 1pm.

## Speakers:

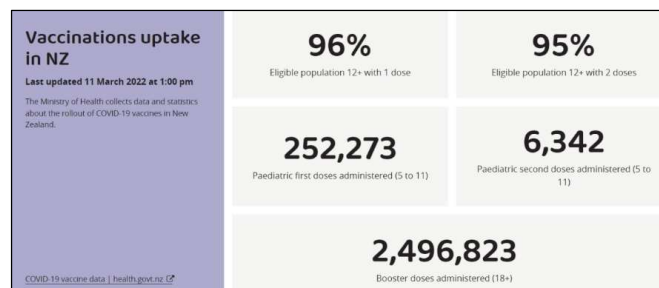
- Chief Clinical Officer for the Northern Region Health Coordination Centre, Andrew Old
- Associate Chief Clinical Officer and Clinical Lead for the Vaccination Programme, Dr Anthony Jordan
- GP and co-clinical lead for the home isolation programme at Whānau HQ, Dr Christine McIntosh

Read the latest update from the Ministry of Health

Source: <https://covid19.govt.nz/news-and-data/latest-news/covid-19-media-conference-11-march-2022/>

## COVID-19 data and statistics – 11<sup>th</sup> March 2022

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



Source: <https://covid19.govt.nz/news-and-data/covid-19-data-and-statistics/>

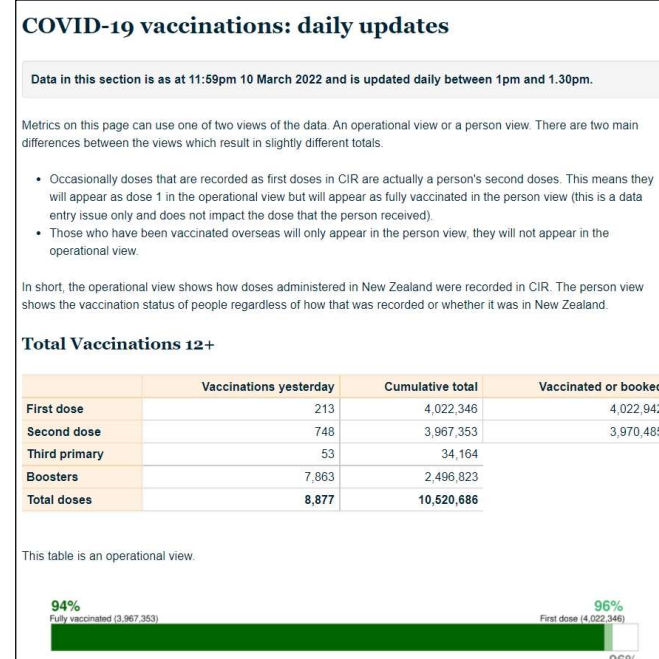
## COVID-19 data and statistics – 11<sup>th</sup> March 2022



Source: <https://covid19.govt.nz/news-and-data/covid-19-data-and-statistics/>

## COVID-19: Vaccine data

Data and statistics about the rollout of COVID-19 vaccines in New Zealand



Source: <https://www.health.govt.nz/covid-19-novel-coronavirus/covid-19-data-and-statistics/covid-19-vaccine-data>



# Update on COVID-19: Rapid Antigen Tests

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

## Update from the Ministry of Health (from 24 Feb 2022)

Increasing numbers of cases and hospitalisations are another reminder that vaccination is our best defence against the virus.

There is growing evidence that three doses of Pfizer is protective against infection and symptomatic infection for Omicron.

We are strongly encouraging people to get a booster dose if it has been more than three months since their second dose.

There were 24,632 booster doses administered across the motu yesterday and overall, around 68.2% of the eligible population have received a booster dose.

## Positive rapid antigen test reporting

The total number of cases reported will now include those identified from both RATs and PCR tests. A breakdown gives how many cases were identified using PCR and how many through RATs.

Today's figure will include cases identified with RATs in the same midnight-to-midnight reporting period used for reporting positive PCR tests.

The Omicron public health response during Phase Two and Three operates on more devolved model to ensure health resources are focused on those who need it most. It is very important to the overall response that people self-report positive results for RATs, so we understand the size of the outbreak.

We'd like to thank the thousands of people who have already self-reported positive RAT results.

Based on overseas experiences, the Ministry of Health has been expecting the true number of community cases to be higher than the cases reported each day and this has been factored into our Omicron planning.

When assessing the outbreak, health officials typically review trends in the 7-day rolling average of community cases to understand the spread of the virus, as well as hospitalisations to understand severe COVID-19 illness and related impacts on the health system. Because we focus on the actual trend, any potential 'undercount' doesn't significantly impact our assessment of the trend, and subsequent public health advice and decision-making.

Further information on RATs will be reported in coming days.

## Rapid antigen testing update

From Monday morning, rapid antigen tests (RATs) will be made available at all Auckland testing sites to those who fit

the appropriate clinical criteria. The site will determine which test (PCR or a RAT) is best for you

Access to RATs will be expanded further during the coming week.

As the outbreak grows more people will have COVID-19 and there will be more close contacts we need to test. As planned we will now increase the use of RATs in Phase 2 and Phase 3 of our response in order to relieve pressure on the PCR testing and reserve it for those most likely to have COVID-19.

Only those with symptoms or who have been identified as close contacts of a case, or directed by a health professional to get tested should be turning up at testing sites.

## Some important points for the public to be aware of are:

- People who are directed to have a RAT will be given advice on what to do if they have a positive result. At the current time, they will likely be advised that they need to have a PCR test to confirm the positive result.
- RATs are not as accurate as PCR tests at identifying someone early in their illness so if you have a negative rapid antigen test result and symptoms start to develop, you may need to have another test.
- This is also why it is so important that if you are unwell, you must stay home regardless of the test result, which will also help reduce the spread of other viruses.
- RATs will initially be available in Auckland, as we continue to widen access in other high-demand centres around New Zealand. We will provide updates on this rollout over the coming week.
- We have good stocks of RATs (7.3 million) to support the public health response, with a continual supply arriving by airfreight

Testing continues to be one of our best defences against COVID-19. Understandably as case numbers grow, so too does demand on COVID-19 testing sites.

That's why it's important to reiterate once again that people do not need to get tested, unless they are unwell with cold or flu symptoms, have been identified as a close contact of a case or have been instructed to do so by health officials.

As this demand has grown, some COVID-19 test results for Auckland and Waikato are currently taking longer to process at laboratories. The use of rapid antigen testing, alongside PCR testing, will improve this process at a time of exceptional demand in Phase 2, provided the testing centre queues are freely available for those who really need a test.

[Update on today's COVID-19 cases | health.govt.nz \(external link\)](https://health.govt.nz/news-and-data/latest-news/update-on-covid-19-cases-20-february-2022/)

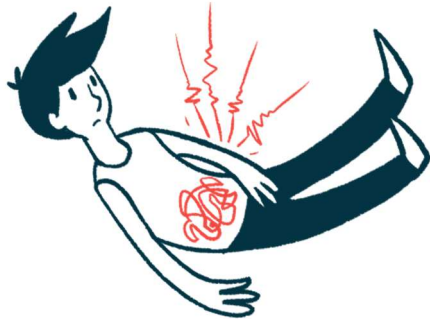
<https://covid19.govt.nz/news-and-data/latest-news/update-on-covid-19-cases-20-february-2022/>





# Study Links GI Symptoms to Low Muscle Mass in Systemic Sclerosis (SSc) :

By Lindsey Shapiro PhD, February 24, 2022



Low muscle mass is associated with gastrointestinal (GI) bloating in patients with systemic sclerosis (SSc), a recent study revealed.

Disease duration, severity, and activity, as well as skin thickening, also were higher in patients with low muscle mass.

“At the best of our knowledge, this is the first study assessing an association between symptoms related to GIT [gastrointestinal tract] involvement ... and reduced skeletal muscle mass,” the researchers wrote. “In SSc, low [muscularity] is associated with symptoms related to GIT involvement, in particular with distension/bloating.”

The study, “Symptoms related to gastrointestinal tract involvement and low muscularity in systemic sclerosis,” was published in the journal Clinical Rheumatology.

Approximately 90% of SSc patients experience GI symptoms, and it is thought that GI dysfunction may contribute to the changes in nutritional status, including malnutrition, that sometimes are observed in SSc.

SSc patients often show loss of muscle mass, which could be related to GI and nutritional changes, although the association is poorly understood.

To explore this relationship, an Italian research team examined muscle tone and GI symptoms in 69 adult SSc patients (nine men) from their scleroderma unit.

Thirty-three people (47.8%) had diffuse SSc and 36 (52.2%) had limited SSc.

Muscle tone was measured using a bioelectrical impedance analysis, which calculated a fat free mass index (FFMI) for each patient. Muscularity was considered low at an FFMI of less than 15 kilograms per square meter for women, or 17 for men.

According to these criteria, 16 patients (23.2%), 15 of whom were women, had low muscularity.

In patients with low muscularity, greater disease severity and activity, and increased skin thickening were observed, supporting previous observations that greater disease severity is a risk for low muscle mass. Longer disease duration also correlated with lower FFMI scores.

According to the University of California, Los Angeles Scleroderma Clinical Trials Consortium Gastrointestinal Scale (UCLA SCTC GIT), nine patients had overall severe GI symptoms (13%).

By individual severe symptom, 20 patients (28.9%) had reflux, 24 (34.7%) had bloating, six (8.6%) had diarrhoea, and 15 (21.7%) had faecal soilage.

In addition, 10 patients (14.4%) had severe problems in emotional well-being and 13 (18.8%) were significantly limited in social function as a result of GI problems.

Total UCLA scores, which combine all symptoms, showed a significant, yet weak, negative correlation with FFMI, according to the researchers, meaning that patients with lower muscularity showed overall greater GI dysfunction.

Among individual GI symptoms, only bloating was associated significantly with low muscularity.

Changes to gut bacteria in SSc may underlie the relationship between bloating and muscle loss, the team hypothesized.



# Study Links GI Symptoms to

## Low Muscle Mass in Systemic Sclerosis: continued

Recently, a “gut-muscle axis” was proposed, in which greater gut permeability to microbial products promotes inflammation and subsequent muscle loss in older adults. This process could be similar in SSc patients, who have some of the same gut bacteria changes that are seen in the elderly.

Of note, low muscularity did not correlate with either of the two measurements of inflammation — erythrocyte sedimentation rate or C-reactive protein levels — that were assessed in this study.

Malnutrition was diagnosed using two criteria — the European Society of Clinical Nutrition and Metabolism (ESPEN) and the Global Leadership Initiative on Malnutrition (GLIM) scales. Using ESPEN, eight patients (11.6%) were diagnosed with malnutrition, whereas 16 (23.2%) patients were malnourished according to GLIM.

Neither of the malnutrition scales were associated significantly with GI symptoms.

“The mechanisms underlying loss of muscle mass in SSc might be at least partially independent of nutritional factors,” the researchers wrote.

According to the scientists, even though inflammatory markers were not significantly different in the low and normal muscularity groups, body-wide inflammation is a driver of muscle loss in acute and chronic disorders. “Evaluation of the relationships between inflammatory response and body composition in SSc patients would be of undoubted interest,” they wrote.

Future studies should further probe the mechanisms underlying reduced muscularity in SSc in larger groups of patients, the team noted.

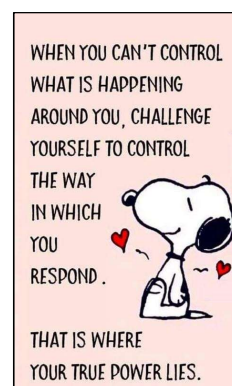
“In conclusion, the present study confirms that low muscularity is a common feature in SSc patients,” the researchers wrote. “The involvement of the gastrointestinal tract may negatively impact on muscularity through different mechanisms, the individual role of which deserves further investigation.”

**Source:** [GI Symptoms Associated With Low Muscle Mass in Systemic Sclerosis \(sclerodermanews.com\)](http://sclerodermanews.com)

## Some light Humour:

*Readers you are welcome to submit any jokes or suggestions and hints here...*

*“Sometimes I’m sure there are days like this we face”*





# Members News

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## Hawkes Bay Scleroderma Group

The Hawkes Bay group recently met at Jane's house. They will be meeting once a month going forward. Gail Neilson will be their new contact now that Jane is heading back to the U.S. Thank you Jane for all your support and we wish you well in your new venture. Thank you Gail for stepping up to lead your group.



*Jane Sainsbury, Gail Neilson, Anastasia Paxie & Frances Todd with Maximus on her lap. Stella joining in also*



## Christchurch Scleroderma Group

No news from the Christchurch group as they have not been meeting lately.



## Waikato Scleroderma Group

There have been no coffee groups in Waikato lately and unfortunately this will continue for the moment.



## New Plymouth Scleroderma Group

We have had two catch ups scheduled this year that have been canceled due to various reasons. We will keep trying. Barbara will take over the organizing of the group for the time being.



## Southland Scleroderma Group

No news from Southland Group as we had to cancel our last meeting as Covid arrived in our area. It will be a quieter time for us with also having to postpone our seminar. Do not worry though. It will happen one day 😊



# Members News continued..



## Bay of Plenty Scleroderma Group

The Bay of Plenty group had their first meeting on January 30<sup>th</sup> 2022. Jane very kindly opened her home to us on a fabulously sunny day so we were able to sit outside and enjoy it. With excellent company, yummy nibbles and a cuppa it was a perfect way to spend the afternoon. It was my first time meeting the ladies and they were just lovely. See our noticeboard page for the next dates.



*Jenny, Mary, Jane & Alumie at Jane's house*



## Wellington Scleroderma Group

No news from Wellington, as we have not been meeting due to COVID.

**Wellington Branch will host a national zoom meeting on Saturday the 19th of March 2022 at 1:30pm - 3pm**

**People can attend at any time during this time, if you need to go early or come a bit later that is ok.**

### Zoom Link :-

**Time: Mar 19, 2022 01:30 PM** Auckland, Wellington  
Join from PC, Mac, iOS or Android

<https://otago.zoom.us/j/93059198700?pwd=SjJuR001anozYjRCUW5FMkI5d2dNZz09>

**Password: 696006**

This meeting will be a general get together to see how we are all getting along during this pandemic, some of us will be isolating so having a chat is always a big help.

The newly diagnosed people with Scleroderma and the more experienced people are welcome to come and ask questions for any help they might need. Everyone will do their best to help encourage you and keep you positive and point you in the right direction to the professional health care you may need.

It is not an easy time to land yourself with a new diagnosis during this pandemic especially, some support should help you along.

Look forward to seeing you there.

Kind Regards

Dianne and Gordon





# Southland Scleroderma NZ Seminar:

Southland Scleroderma Support Group presents

## Scleroderma Seminar 2022

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

Saturday March 26, 2022

The Corinthian Centre @ IWMC  
154 Esk St, Invercargill

Opens 8.30am - Presentations from 9.00am  
\$25 pp - registration and vaccine pass required

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:

- Dr. Paddy O'Connor, Gut health
- Dr. Miranda Buhler, Hand Therapy
- Prof. Simon Stebbings, Fatigue
- Dr. Sarah Jordan, Lung issues
- Dr. Katey Jenks, Skin health



**Scleroderma  
New Zealand Inc**

For more info or to register before March 10th please  
contact Jenny: jennyred@extra.co.nz / 027 316 6124





# Southland Seminar Registration:

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Registration is open for the Southland  
Scleroderma NZ Seminar to be held  
26<sup>th</sup> March 2022

To register please email the following  
details to [jennyred@xtra.co.nz](mailto:jennyred@xtra.co.nz)

NAME:

ADDRESS:

PHONE:

VACINATION STATUS:

SPECIAL DIETARY REQUIREMENTS:

*On registration the bank account number  
will be given to you to pay the \$25 into.*

## Information wanted:

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*Readers you are welcome to submit your questions or  
suggestions and useful hints here...*



# Scleroderma NZ Inc. Fundraising

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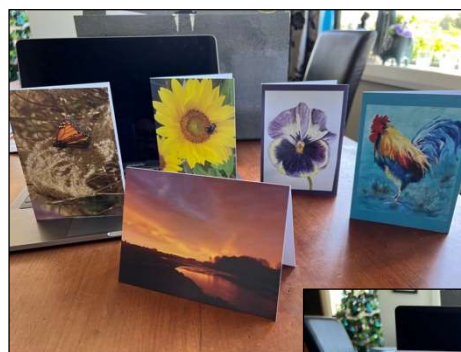
## 2023 Cards

We had a very successful fundraiser for Scleroderma NZ Inc. with our 2022 Calendars for sale. With all the calendars now paid for we have been able to pay for the whole printing of the "Understanding and Managing Scleroderma" booklet and also the printing of the calendars and came out about \$6 down so a fantastic result. Thank you so much to all of you who bought a calendar.

The fundraiser for this year will be gift cards. (A5 folded) They will come in a pack with envelopes. We would like to welcome anyone who is into photography or art to submit their own artwork for this please. It can be either landscape or portrait, but please send it to me in as large a format as you can.

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

Here is a wee preview of an example of our fundraising cards. So all we need now is some new artwork and we can get them underway. Happy painting ☺



# Noticeboard:

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## ALL ATTENDEES MUST HAVE VACCINE PASS

### 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 26th March 2022, 2:00pm to 4:00pm  
Saturday 28th May 2022, 2:00pm to 4:00pm  
Saturday 30th July 2022 - lunch : venue to be advised  
nearer the time  
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 re venues for Christchurch meetings for 2022. With Covid it will not be possible to have our meetings at Burwood Hospital until further notice.*  
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:

We will try again to have a catch up.  
Sunday June 26<sup>th</sup>, 2022, 12pm lunch  
**Venue:** Gore, TBA  
Please contact Heather or Jenny 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. 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:

Our group of 5 are looking to meet Tuesday 22nd March for lunch.  
**Venue:** To be confirmed in Cambridge, picnic or cafe depends closer to the date on weather.  
All welcome, in case of changes please contact Erena Bruce, Mobile: 021 186 9680.

### Palmerston North support group:

If you wish to join in with the Palmerston North Group please get in contact with Martine Fremaux [curios@xtra.co.nz](mailto:curios@xtra.co.nz), 027 242 4939

### New Plymouth support group meets:

To attend the New Plymouth Support Group please get in contact Barbara Rankin [gbrank2@xtra.co.nz](mailto:gbrank2@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 15<sup>th</sup> March 2022, 10.30am  
**Venue:** Café Ahuriri  
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:

Sunday 19<sup>th</sup> March 2022, 10.00am  
**Venue:** Palmers Garden Centre, Bethlehem  
We welcome anyone in the Bay of Plenty area to come along and join us. 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)

## Contacts:

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

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:	Barbara Rankin, Email: <a href="mailto:gbrank2@xtra.co.nz">gbrank2@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>
Southland:	Heather Milligan, Email: <a href="mailto:milliganseeds@xtra.co.nz">milliganseeds@xtra.co.nz</a>
Bay of Plenty:	Alumie Nguyen, Email: <a href="mailto:alumie.uow@gmail.com">alumie.uow@gmail.com</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.

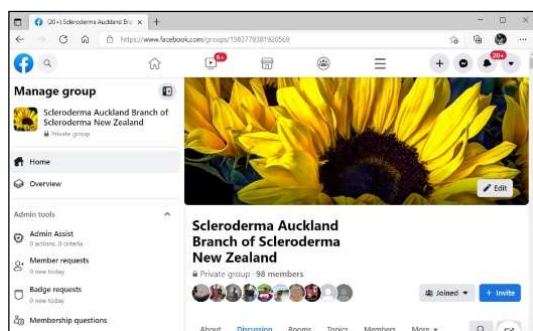
Link to our Website address below: -  
<http://scleroderma.org.nz/>



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



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



## 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>

Wellington Branch will host a national zoom meeting on  
**Saturday the 19th of March 2022 at 1:30pm - 3pm**  
People can attend at any time during this time, if you need to go early or come a bit later that is ok.

**Zoom Link :-**

Time: **Mar 19, 2022 01:30 PM Auckland**, Wellington  
Join from PC, Mac, iOS or Android:

<https://otago.zoom.us/j/93059198700?pwd=SjJuR001anozYjRCUW5FMkI5d2dNZz09>

Password: 696006

This meeting will be a general get together to see how we are all getting along during this pandemic, some of us will be isolating so having a chat is always a big help.

The newly diagnosed people with Scleroderma and the more experienced people are welcome to come and ask questions for any help they might need. Everyone will do their best to help encourage you and keep you positive and point you in the right direction to the professional health care you may need.

It is not an easy time to land yourself with a new diagnosis during this pandemic especially, some support should help you along.

Look forward to seeing you there.  
Kind Regards  
Dianne and Gordon

<http://scleroderma.org.nz/>



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