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Scleroderma

New Zealand support group

SUMMER 2022

Greetings to you all.

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



We hope everyone is well and looking after themselves. As we move towards the end of the year we hope everyone takes the time to relax and take a break to look after yourselves and recharge.

We hope everyone has a wonderful Christmas and a safe and Happy New Year for 2023.

Summer is finally here and we hope the weather improves and everyone is able to get out and enjoy the warmer days.

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 in our Scleroderma community around New Zealand.

We have stories to share from our members and we also have some interesting articles, including Scleroderma & Reynaud's UK links to some useful educational videos about Scleroderma related issues.

We have our regular Members News from our different support groups, information on our Scleroderma NZ Inc. Fundraising cards, Give a Little page and the Rewardhub retail site.

Be safe and take care everyone.

Warmest regards,

Tina and Jenny



Presidents Report:

Summer 2022



Merry Christmas everyone. I hope you are all surrounded by your family and friends and take the time to stop and enjoy the moment. A big welcome to all our new members. I wish you all the very best in your journey with Scleroderma. Please see further through the newsletter with our support group information as there may be one near you. My

condolences go out to anyone who has lost loved ones in the past couple of months. Never an easy time and it seems so much worse at this time of year.

2022 was a year of ups and downs. With us still dealing with Covid throughout the world, the war in Ukraine, the passing of Queen Elizabeth II and the failing health of many of our members. On the up side we had an awesome showing at the Commonwealth Games in Birmingham. Then just look at those amazing Black Ferns who did us so proud. We welcomed a King for the first time in 7 decades and we are continuing to be Scleroderma Warriors and appreciating the good days.

A very, very big thank you to Tina. Tina has worked so hard researching and bringing us such great information in the pages that follow. We are very lucky to have her on board. Also thank you to the wonderful committee members. I am very grateful for all the work you do in the background. Thank you so much to the support group leaders, Facebook coordinators, website administrator and especially thank you to all of our members who are out there trying their best, always with a smile on your faces. Keep being you!!

I was very happy with the response we received from you all for our fundraising cards. Thank you so much for the support and it is so great to see some many talented members among us with their fantastic art work. We even had to get more printed as the orders flowed in, so we do have some left for anyone who missed out on the first print. Please get in touch with me and I can get them out to you.

During the crazy time that can be Christmas please remember to be kind to yourselves. Remember to take some time out, and you can say NO. I heard the other day that... No. is a full sentence. That is such great advice. If you are making food for Christmas, try making something that you can make in advance so you can do it when you feel up to it and not when your body and mind are struggling. It is ok to ask for help.

If you are going to be outside, please put on your hat and sunblock. Look after that skin of yours. Sometimes we forget ourselves if we are busy protecting the ones we love. Don't forget you. Be safe while travelling around the country and allow plenty of time to get places.

Make those lists; I have been able to tick off my Christmas cake, most presents are bought and wrapped. Christmas tree is up (undecorated at this stage) and food has been decided on for one of our three different Christmas events. About 27 years ago I was given a Christmas Cake recipe from a friend. It is the same cake I have baked every year since, except one. I find it very yummy so thought I would share it here with you all. Wishing you all a very Merry Christmas and a happy and healthy 2023.

Jenny xx

Christmas Cake recipe

500 grams sultanas	200 grams raisins
200 grams dried figs (opt)	150 grams currants
150 grams mixed peel	150 grams cherries
2Tb marmalade	½ cup Rum/Brandy

Stand over night or for up to 4 days

Line tin well with at least 2 layers.

250 grams butter 1 cup sugar

Beat until really light;

Add

1 tsp vanilla essence

1 tsp almond essence

MIX

Then add 5 eggs,

stir into fruit mixture,

fold in dry ingredients of

100 grams blanched almonds

1 ¾ cup flour

½ tsp baking powder

1 tsp mixed spice

½ tsp ground nutmeg

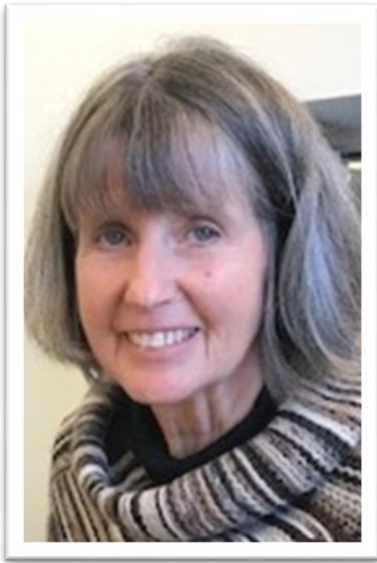
Bake at 100 degrees Celsius for as long as it takes. About 4 hours. You can place a magazine under the bottom so as not to burn it.

(I now use a big square roaster so I double it and cut it into 4 and give away ¼ of it to family. I just buy 2kgs of fruit mix. I don't have to line my pan or put it on a magazine as it is such a thick pan, I also use Brandy for soaking the fruit in). Yummy ☺



Members Stories:

Dianne Purdie



*“Plenty
of
Lovely
Flowers
to
Enjoy.”*

Gordon and I have been isolating since January due to a new diagnosis on top of

Scleroderma called **ANCA Vasculitis** (Anti-Neutrophilic Cytoplasmic Autoantibody). With the treatments that are given to me, it means that my immune system is vulnerable, so staying home with no visitors has been our experience except for going off to the hospital, Drs and Chemist visits.

You learn quickly to appreciate what you have around you and make the most of it. Catching up with the scleroderma friends on line last week was great, and I have been doing some other courses with SPIN (Scleroderma Patient Intervention Network) and Edx and of course plenty of reading gardening, keeping fit by walking and I have only just started Nordic walking to improve the strength in my back. We are lucky here to have a nice big bush section.

Gordon has been building tracks which we use every day except on really wet days like today. There is such a lot to do, plenty of hobbies and enjoying our natural environment. Gordon has been doing all the heavy work in the garden and keeping the tree trimmed back, and it has worked out well with him being retired as things could have been quite difficult otherwise, I am very lucky to have his full support.

I am still the secretary of the Hutt Valley Horticultural Society and help manage the three shows we have, working from home, it's been a shame that we can't get to the show and show our plants, but it's nice to help others enjoy, themselves, it's something to gain a lot of pleasure.

Gordon and I entered the Great Southern Bioblitz a few weeks ago and managed to cover 115 different species that are native to NZ. We were not allowed to use cultivated plants. We lodged insects, birds, spiders, snails, moths and the many plants, including trees, shrubs, ferns fungi and lichens etc. We were 3rd in Wellington for the number of species and 6th in NZ and 201 in the Southern hemisphere out of 6217 entries and we didn't need to leave home :-). It has been an interesting experience and has certainly made us look at our environment and we see different fungi daily currently.

Bioblitz from all of the NZ observations

<https://inaturalist.nz/projects/great-southern-bioblitz-2022-aotearoa-new-zealand?tab=observations>

Bioblitz observations from Gordon and Dianne

https://inaturalist.nz/observations?place_id=any&project_id=great-southern-bioblitz-2022-umbrella&user_id=dianne_and_gordon_purdie&verifiable=any

I'm on a new mission now, helping to get a medication called Avacopan into NZ. It is targeted therapy for the ANCA Vasculitis. It is FDA approved and used in many other countries. It is used instead of Prednisone, and targets the white cells called neutrophils before they attacked the small blood vessels. The Rare Disorders Group is helping which is great. Avacopan has less side effects than Prednisone, and those of you who have been on Prednisone at high doses for a long period of time will know how hard it is to deal with. So fingers crossed it could take a while yet.

One in 500 people with Scleroderma can get ANCA Vasculitis, so I certainly hit lotto when it arrived. It came on suddenly for me and was aggressive, causing 75% loss of kidney function, which is a silent misfortune. My lungs have been affected as well, so lots of hill walking to keep the function working well, and yoga to help with stiffness. I used to worry about kidney involvement with Scleroderma and things were going so well for eighteen years on that front. It's always best to check the kidney function with your regular check-up blood tests, My kidney function was ok 3 months prior to ANCA vasculitis. I can say that Scleroderma saved my life..... as it was at my six minute walk test for Scleroderma which showed up a problem, as they couldn't find a reason for the blood that I was coughing up after CT, Bronchoscopy etc.



Members Stories:

Continued....

Dianne Purdie

It was the high heart rate, then they found that it was anaemia which fronted me into hospital urgently. I thought I was feeling tired from the lack of exercise, then the testing went on from there. There might be one other person with Scleroderma in NZ with ANCA Vasculitis, although this is variable of course.

Here some of our flowers that we can share with you all, we hope you enjoy them. Take Care, and keep up with your monitoring :-)

Dianne Purdie

"Flowers from Dianne and Gordon's beautiful garden."



Members Stories:

The life and times of Perry...

Are you in the game or are you watching from the side-lines...

Health Update #10

November 14, 2022 by [Perry](#)



Yet again, I find myself in familiar surroundings at Hutt Hospital's Medical Day Stay Department hooked up for another infusion.

In my [last health update](#) I mentioned that since my 1st course of Rituximab (back at the beginning of June) I'd started to see some improvements to my SpO2 levels and that overall my weekly average had improved to consistently be over 95.

Unfortunately, those levels didn't last as long as I and my Respiratory Specialist would have liked. As I weaned off of Prednisone my SpO2 levels started to drop off and my general health and well-being started to be affected. The crackling in my lungs started to return and the breathlessness returned when walking short distances, as well as when I was walking and talking, which can be extremely frustrating.

It had been envisaged that the effect of Rituximab in my system would have lasted a good six months, or possibly even lasting as long as 12 months. However, it seems that this is not the case and I am now required to have regular **four** monthly infusions.

One of the things that my specialist has found quite beneficial is my diligent recording of my SpO2 and heart rate readings, which I do morning and night to gauge how I am going and I also note how I'm feeling.



These initially showed an improvement, which was great and I was feeling a lot better.

But as I stepped down a milligram of Prednisone, every three weeks initially (then monthly) each drop in medications saw a corresponding increase in breathlessness and subsequent decrease in my SpO2 readings.

Both the Respiratory and Rheumatology Specialists obviously don't want me on Prednisone long-term as it can have a detrimental effect on a person: They can experience an increased risk of infections, especially with common bacterial, viral and fungal microorganisms; thinning of the bones (osteoporosis) and fractures; and severe fatigue, loss of appetite, nausea and muscle weakness.

The other concern in these days is the increasing amount of Covid in the community and other viruses and respiratory illnesses that are circulating. Therefore, over the next couple of months I'll need to continue being extremely vigilant and careful about being out and about in the community, in effect isolating and working from home until the beginning of February.

In March we'll start the whole process of organising the next round of Rituximab for April as we continue trying to come to grips with what my body needs and strike the right balance of medications so that I can carry on.

This obviously comes with many challenges; as we juggle doctors and specialist appointments, as well as any further tests that are required from time to time, and ensuring that prescriptions and medications are ordered and arrive on time for my hospital appointments.


Also add into the mix the need to ensure that we have the funds to cover these expenses and work out if we are entitled to any supports along the way. Also, balancing expectations around work. All of which can be quite taxing and from time to time leave one feeling frustrated and wondering how we are going to get through at all.



Continued...

Are you in the game or are you watching from the side-lines...

Palliative Care



I CAME SO
THAT YOU
MAY HAVE
LIFE AND
LIVE IT MORE
ABUNDANTLY.

JOHN 10:10

Members Stories:

Continued....

Betty Wilson — “The 12 days of shearing”

Betty shares something that many of us will be able to relate to in some way or another....

On the first day of shearing, my true love said to me: The Shearers are going to bring their own food this year, Darling. So your time will be free.

On the second day of shearing, it became apparent by degree, that with the children busy in the shed, all the household tasks like chopping the wood, collecting the eggs, feeding the animals and mowing the lawns, would now be up to me.

On the third day of shearing, my true love said to me, “a seal on the hydraulic press has blown? Could you dash the motor into town, get it fixed, then rush it back here urgently?”

On the fourth day of shearing, my true love said to me “coz of the press, we’re behind in the mustering? Could you rush out on the motorbike to the North boundary paddock and bring back the two tooth wethers, then take the ewe weaners that’ve just been shorn home to their paddock very carefully.”

On the fifth day of shearing, my true love said to me: “Some of the bellies on those wethers are damp? Could you get the four old wire shearers’ stretchers down from the hayshed loft, put them up in the garage and spread all the wool out on them to dry by half past three.”

On the sixth day of shearing, the board boy cut his knee, so guess who was asked to drive him into town and look after him at the hospital and hold his hand while he had it stitched up in casualty?

On the seventh day of shearing, my true love said to me: “The wool room’s jammed with bales and I can’t get away ‘cos now I’m on the board? Could you take a load to In’gill this morning in the truck and while you’re there go to Wrightson’s and bring home 80 bags of superphosphate and don’t worry ‘cos they’ll probably help you load them – if they’re free.....”

On the eight day of shearing, my true love called on the CV. “I’ve bogged the bloody ute in the north

fattening paddock? Could you get the tractor out of the shed, find the drag chain and get on out here as fast as you can and rescue me?”

On the ninth day of shearing, my true love yelled: “A limb’s fallen over the fence between the spring and the tall tree? Could you dash out with the chain saw and the wire strainers and fix it up, then saddle the horse and drive the steers out of the wheat crop – instantly.”

On the tenth day of shearing my true love roared at me: “Have you got the tax stamps ready, calculated the travelling, been to the bank, prepared the tally sheets and estimated the classer’s fee?”

On the last day of shearing, my true love beamed at me: “If all goes well, my darling, we’ll cut out by arvo tea? And aren’t you glad this year we didn’t need you at all – Hon-ey?”



Travelling with Sunflower Lanyard

In our last Winter newsletter, Helen Parsons gave us information about the Hidden Disabilities Sunflower Lanyard from Auckland Airport.

I did a little bit of research on the **Hidden Disabilities** website and found out that travelling with Sunflower Lanyard is recognised across several countries as shown below from their website:

AMERICAS	EUROPE	OCEANIA	MIDDLE EAST	
Canada USA	Belgium Denmark Finland Greenland Iceland Ireland Netherlands Norway Sweden	Australia New Zealand	UAE - English	Other countries

Source: <https://hiddendisabilitiesstore.com/>

Scleroderma is one of the many hidden disabilities that is listed on their website. It has good information on Scleroderma and the hidden disabilities that are associated with having Scleroderma. It makes a very handy print out to give to an employer or those you work with, if you want them to be more aware of what Scleroderma is.

Source: <https://hiddendisabilitiesstore.com/insights/post/scleroderma>

Hidden Disabilities Sunflower lanyard



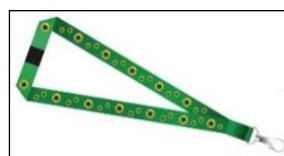
If you or someone you're travelling with has a hidden disability, you can wear a Hidden Disability lanyard which indicates to our staff that you may like some extra assistance or care.

We understand that living with a hidden disability, such as autism, anxiety, vision or hearing impairments, chronic pain or dementia, can make travel more challenging.

The Hidden Disabilities sunflower scheme is an international approach which is recognised by Air New Zealand staff and a growing number of

airports, tourism attractions and accommodation providers.

If you're travelling with a disability that is not immediately obvious, you may wish to wear a sunflower lanyard, pin or bracelet to discreetly signal to our crew that you may need additional understanding, time and support. Our staff are trained in how to approach, support and guide you through your journey.



The lanyards, which are bright green in colour and decorated with an easily recognisable sunflower design, are entirely voluntary and indicate to staff that a passenger may:

- Need more time to process information or more time to prepare themselves at check-in, boarding or disembarking
- Need clearer verbal instructions, as it can be difficult to understand facial expressions and/or body language
- Need help reading departure boards or signs
- Always need to stay with family or friends
- Benefit from more information on what to expect before, during and after their flight

Please keep in mind that a sunflower lanyard won't help you get through queues faster or provide a personal escort or wheelchair through your airport journey.

How to get a Hidden Disability Sunflower lanyard

If you're travelling throughout New Zealand, the airports at [Auckland](#), [Wellington](#), [New Plymouth](#), [Christchurch](#) and [Queenstown](#) have adopted the Hidden Disabilities Sunflower. Prior to your travel, you can request a free lanyard from the airport company, which you can collect at the airport to keep and use on future trips.

If you're departing from other international airports, or would like to know more, visit the [Hidden Disabilities website](#).

Source: <https://www.airnewzealand.co.nz/hidden-disabilities-sunflower>





Looking after yourself

From SRUK – Scleroderma & Raynaud's UK website

There may not be a cure for scleroderma yet, but it can be treated and managed well, meaning that you can continue to live as normally as possible. Here is some simple, straightforward advice on treating the most common symptoms of scleroderma.

Need more detailed information on treatments for specific organs or parts of the body? Please visit [Scleroderma and your body](#). One of the symptoms of scleroderma is Raynaud's, also view [Raynaud's treatments](#).

Look after your skin

The skin becomes thickened in scleroderma, meaning it can become dry, cracked, swollen and less flexible. You can protect your skin from becoming too uncomfortable with creams, ointments and emollients:

- Creams are water-based so offer short-term protection, ointments are oil-based and give longer term protection.
- If your hands are severely dry, apply cream at night then cover them with [cotton gloves](#).
- Use emollients in the bath, but take care not to slip.
- Treat itchy skin with Eurax or antihistamines.
- Avoid the midday sun, protect car windows on hot days, and use UVA and UVB-rated sun creams.
- Keep nails trimmed and filed and cover areas of calcinosis.
- Use aqueous cream instead of soap.
- Use gloves when you're washing up, or get someone else to do it.

Protecting Your Joints

Joint protection means protecting swollen and painful joints from stresses and strains that can make them hurt more. Lifting or carrying heavy objects for example can strain and hurt your joints.

Joint protection includes learning to perform daily activities in ways that will help your joints rather than strain them. Physical and occupational therapists can show you new ways to do activities such as opening doors and drawers getting out of chairs carrying packages ironing clothes and brushing teeth.

Joint protection may also include resting individual joints in removable lightweight splints to help control inflammation. Splints should be well padded to avoid pressure on any areas of the skin.

There are many devices that reduce stress on painful joints which you can purchase or make at home.

Keep Raynaud's attacks under control

The majority of people with scleroderma also have Raynaud's phenomenon, where the small blood vessels in the extremities are over-sensitive to changes in temperature.

There's lots of information on our [Managing Raynaud's](#) page, but here are some basic tips on keeping attacks at bay:

- Keep warm, [wear gloves and use hand warmers](#).
- Maintain a stable temperature if you possibly can.
- Keep stress to a minimum.
- Speak to your doctor about medication – vasodilators can help.

Take action to prevent and treat ulcers

Dryness, calcinosis and digital pitting scars can lead to ulcers on the skin. It's important to try to prevent these, and to take action quickly if they appear, as they can become infected and take a long time to heal:

- Look after your skin and cover any broken areas with a clean plaster, iodine or Mepilex.
- Keep warm with [extra warm blankets](#).
- Keep an eye out for signs of infection in broken skin – yellow discharge, redness, swelling, pain and failure to heal.
- If you see any of these signs, contact your GP or local rheumatology team immediately.
- Keep a diary of where your ulcers appear – this will help your doctor to monitor and treat the problem.

Keep eyes and mouth from becoming dry

Many people with scleroderma have 'sicca' symptoms, meaning they have problems resulting from decreased tears and saliva production. These can cause pain and infections, but they can be treated.





For dry eyes:

- Avoid dry atmospheres.
- Humidify rooms.
- Wear glasses with side arms.
- Speak to your chemist about tear replacement drops, or your doctor about antibiotic eye drops if you have an infection

For a dry mouth:

- Take sips of water rather than glugs.
- Avoid sugary drinks.
- Chew sugarless gum.
- Speak to your chemist or doctor about saliva replacement products and saliva stimulation tablets.
- Take a spoonful of sugarless Greek yogurt before bed.
- Speak to your doctor about the medications you are on, as some can worsen dry mouth symptoms.

Take care of your gut and bowels

Problems with eating, reflux, and a sluggish gut and bowel are common symptoms of scleroderma. Here are some symptoms to look out for, and ways to manage to them.

For pain when swallowing:

- Avoid foods that 'stick' like white bread, steak and chips, and speak to your doctor if it becomes unmanageable.

For reflux:

- Avoid eating for two to three hours before bedtime.
- Avoid drinking for an hour and a half before bedtime.
- If you are smoker, try to quit.
- If you are overweight, try to diet.
- Elevate the head of your bed and sleep propped up.
- Avoid fat, chocolate, caffeine and alcohol, and acidic foods like citrus fruits.
- Eat small meals often rather than three large meals a day.

For a sluggish bowel:

- Follow a well-balanced diet and avoid fatty, spicy, rich or dry foods
- Speak to your doctor about swelling, pain, diarrhoea or constipation.

- Try a probiotic drink or supplement.
- Keep up a good fluid intake.

Listen to your body

Because the symptoms of scleroderma are so diverse, it's important to look out for changes in your body and the way you feel. If anything is troubling you, it's worth taking the time to speak to your doctor about it.

Many people with scleroderma suffer from fatigue and feel overwhelmed by the condition at times, so it's important to take a rest when you need to, too.

- Look out for times and situations when you become more fatigued, and plan for them.
- Make sure you're getting enough sleep, and ask for help from your doctor if not.
- Notice any changes in your body and the way you feel, like breathlessness, palpitations or persistent coughs. Report anything unusual to your doctor.
- Try to maintain a positive outlook and to make time to do the things you enjoy. That's not always easy, we know.

Source: <https://www.sruk.co.uk/scleroderma/managing-scleroderma/treatments/>





SRUK Educational YouTube video's

From SRUK – Scleroderma & Raynaud's UK website

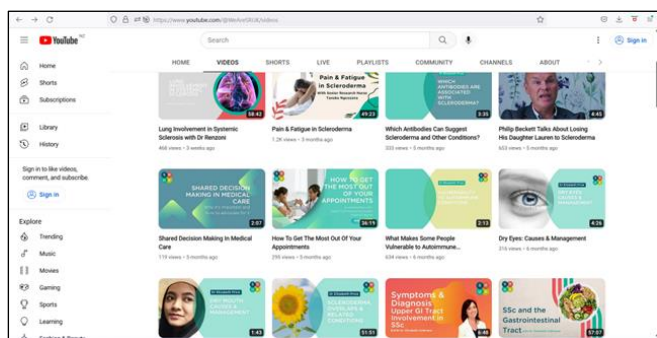
A question was asked at our zoom meeting. Where do we find educational videos from.

Scleroderma & Raynaud's UK has some very educational videos on all sorts of things.

From personal stories, to their conferences and information about the GI tract, lung involvement, pain and fatigue, Dry eyes and management, Dry mouth and management, diet, exercises, nutrition, itchy skin, you name it they have got it.

The link is: <https://www.youtube.com/@WeAreSRUK/videos>

Fantastic information well worth the time looking.
Just a few sampled below:



Some examples of the Topics and the links are:-

[Lung Involvement in Systemic Sclerosis with Dr Renzoni](https://www.youtube.com/watch?v=FTuifTuyLys)

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

[Pain & Fatigue in Scleroderma](https://www.youtube.com/watch?v=uryH87HL4Uo)

<https://www.youtube.com/watch?v=uryH87HL4Uo>

[Shared Decision Making In Medical Care](https://www.youtube.com/watch?v=cetTkiBwsHU)

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

[How To Get The Most Out Of Your Appointments](https://www.youtube.com/watch?v=xOjb74y84BU)

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

[Dry Eyes: Causes & Management](https://www.youtube.com/watch?v=FyUgrdWyBOY)

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

[Dry Mouth: Causes & Management](https://www.youtube.com/watch?v=OzBn9_Y1c3U)

https://www.youtube.com/watch?v=OzBn9_Y1c3U

[Scleroderma, Overlaps & Associated Conditions - with Dr. Elizabeth Price](https://www.youtube.com/watch?v=Os7-OCNm3mI)

<https://www.youtube.com/watch?v=Os7-OCNm3mI>

[Symptoms & Diagnosis: Upper GI Tract in SSc](https://www.youtube.com/watch?v=-El3bGz0nMw)

<https://www.youtube.com/watch?v=-El3bGz0nMw>

[Gut Instinct: SSc and the GI Tract](https://www.youtube.com/watch?v=cr1kR677_h0)

https://www.youtube.com/watch?v=cr1kR677_h0

[Acid Reflux, Bloating & Diarrhoea in Scleroderma: What To Eat & What To](https://www.youtube.com/watch?v=9gDL8JJyi1Q)

<https://www.youtube.com/watch?v=9gDL8JJyi1Q>

[What Makes Some People Vulnerable to Autoimmune Conditions?](https://www.youtube.com/watch?v=XlduOX41Ocw)

<https://www.youtube.com/watch?v=XlduOX41Ocw>

Rare Disease Day 2023



The team at Rare Disorders NZ are well underway with planning for Rare Disease Day 2023 (28 February). They are excited to share that the plan for the campaign includes extending Rare Disease Day out into a whole month, to allow them more time to get our messages out into the public and increase influence on decision makers. Keep your eyes open for updates.

More information on Rare Disorders NZ can be found on their website link below:-

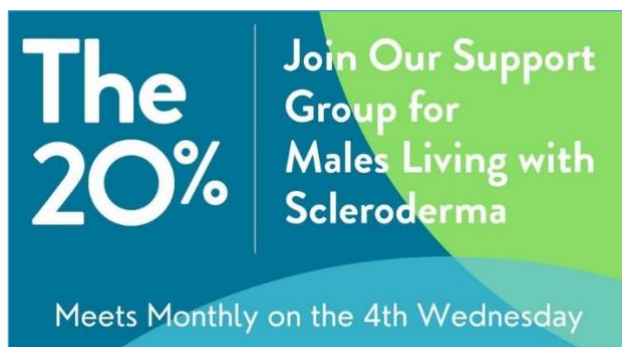
<https://www.raredisorders.org.nz/>



The 20%: A Virtual Support Group for Males Living with Scleroderma

From National Scleroderma Foundation website..

The **National Scleroderma Foundation** has organised a virtual support group for Males living with Scleroderma.



See below for the details or visit the website to register:

Date: Wed, November 23, 2022
Time: 7:00 PM - 8:00 PM

Repeat on the fourth **Wednesday** of the month until **12/31/2023**

Location: **Virtual**

Scleroderma diagnoses are less common amongst men. In fact, only 20% of the patient population is made up of males. We've designed a support group especially for males with scleroderma. In it, you'll learn scleroderma tips and resources and find support from others in your position. Each meeting, we'll focus on a different topic; from mental health to intimacy and so much more.

Meets the fourth Wednesday of the month (with some exceptions) from 7 p.m. to 8 p.m.

[Click here to register:](#)

https://national.scleroderma.org/site/Calendar/1418856142?view=Detail&id=112032&fbclid=IwAR3XDSZWUPtVC3sgPOiRnr6HWP-NEZcv_CqpZR5A43wYdVAD5qVYlePgT9Y

This event does not require an RSVP. Registered users can request event reminders.

Source: [National Scleroderma Foundation](#)



Five Ways to Maintain Muscle Mass as You Age

By Landmarkhealth.org

View fun ideas for resistance training in the cartoon below.



Age-related muscle loss, also known as sarcopenia, is a common part of aging, but there are ways to limit it. According to Harvard Health Publishing, after age 30, you lose as much as 3% to 5% of your muscle mass per decade. It's important to start developing healthy habits as early as possible to limit your loss of muscle mass.

Here are five ways to maintain muscle mass as you age:

1. Eat protein. The body breaks down protein-rich foods into amino acids, which it uses to build muscle. Protein sources such as chicken, turkey, fish, eggs, red meat, yogurt and beans are good sources of protein to build muscle.
2. Resistance train. A consistent strength training routine builds muscle mass. Aim for two to three 30-minute sessions per week. (Always consult your doctor before you get started.)
3. Increase Your Omega-3s. Omega-3s, found in salmon, walnuts and flaxseeds, are anti-inflammatory and can easily be added to your diet. Inflammation causes muscles to break down, so by consuming anti-inflammatory omega-3s, you can improve the rate of muscle protein synthesis.
4. Check your vitamin D levels. Vitamin D helps with muscle protein synthesis, which helps build muscle strength. Sun exposure is a source of vitamin D, but it takes four times as long for people over age 60 to receive vitamin D through sun exposure. A vitamin D supplement can be

used, but always consult with your physician before starting a new supplement.

5. Walk. Walking increases your mobility and enhances blood flow. Aerobic exercise is beneficial to your body's response to insulin, which helps with muscle repair. Taking 10-minute walking breaks throughout the day can help you maintain muscle mass.

To learn more about healthy habits, visit www.landmarkhealth.org

Some advice from Heather on a skin product...

I struggle with calcinosis on my fingers. I think the main problem is that my skin is so tight it really pulls on the lumps and my fingers get quite sore and don't bend. I looked at my fingers from time to time and thought if only I could get something that would plump up the skin around the lumps.

While lurking in the chemist, waiting for a prescription to be filled I saw this Neutrogena Hydra. at about \$30, I paused, thinking that might work. Bought some and it did take a few weeks but I certainly have noticed that the skin has plumped up, there are even some wee wrinkles! and my fingers can move a wee bit better, as the skin is not so tight. I have rubbed it in night and morning around my mouth also, thinking maybe that will plump the skin up and I will be able to shut my mouth better and not wake up in the night with a dry mouth, it did work, just a wee bit.

This may or may not work for you but it certainly does help the tight skin on my hands and around my mouth.

Heather Milligan



Learning to Say No Can Save the Holiday Season:

From Scleroderma News website

Sometimes we push ourselves so hard we lose sight of what's important

by [Lisa Weber](#) | November 25, 2022



All the bedroom doors were closed and everyone was tucked in under their warm comforters. Except for me. I had taken on the 2013 holiday season like it was another full-time job. Without enough daylight hours to squeeze it all in, I was working the graveyard shift and bleeding myself dry.

For a long time, I evaluated my value based on how much I could accomplish for myself and others. Acts of service, checked boxes on task lists ... but there's a trap to this method of pleasing people.

I didn't want to say no! I accepted every invitation. I committed to every cookie party, holiday light festival, and gift exchange. I didn't want my kids to miss out, and I certainly didn't want to let down friends and family.

With a packed schedule, I was up in the middle of the night bedazzling silly Christmas shirts for Ugly Sweater parties and scrolling Pinterest for drink concoctions to wow party guests. The more I took on, the less I enjoyed the things that mattered the most to me.

Doing too much and living less

Saying yes to everyone was like a paper cut: Tolerating one is doable, but after 10 or 20, they have an impact on your physical and emotional state. I was neglecting my basic needs and suffering an enormous price.

I worried my little girls would miss out on things, until I realized I was causing them to miss out on me. I had become an employee that worked in the house, baking, sewing, and prepping. Then I would be their taxi driver, shuttling them from activity to activity. The worst part? I justified it as being a great mom that gave them the best experiences.

I neglected to see the negative impact it was having on me and my relationships. Working so many side hustles left me exhausted, stressed out, and anxious. I knew I was angry and tired, but I had no clue that I was the one responsible for it. So I continued to complain about having too much to do and blaming others for whatever I could.

Regret

The 2013 holiday season was the last I had as a healthy, disease-free Lisa. And I spent it on edge while doing chores. I

kept myself so busy that I missed out on enjoying the moments.

I can still hear myself telling my daughter Chloe, "I'm sorry, honey, I can't jump on the trampoline with you. I have to finish making your fancy dress." And I can still feel the strain in my voice when I told my then-7-year-old, Kylie, "You're old enough to ride your bike alone if you stay on the sidewalk. I have to finish making these cookies for the party tomorrow."

That was the last year I could jump on a trampoline or ride a bike without losing my breath or going into a coughing fit. And I let those carefree moments pass me by, replacing them instead with things I could check off a list. I don't remember what those cookies looked or tasted like. And the dress is packed away inside a box now. All that's left are the memories of moments I let slip away.

Things will steal moments no longer

I wish I could rewind time and experience my healthy life again yet retain the lessons I learned from living with scleroderma. I would embrace the wisdom that know no one will remember the perfectly decorated cookies, but they will remember the family snowball fight.

Learning to say no is difficult but powerful. At first, the guilt will feel too heavy to carry, but it goes away after time. It will eventually be replaced with a holiday season filled with less stress and more moments of happiness.

It's more than OK to choose a couple parties and say no to others, or show up to the dessert happy hour with store-bought cookies — especially when living with an autoimmune disorder like scleroderma. Stress is a trigger, and scleroderma certainly doesn't need extra help or encouragement!

It's not how much we do or how well we do it that counts. It's about being present and free from everything that weighs us down. We're not guaranteed another holiday season. Use the power of no and free yourself to make memories that count.

Happy holidays to all of you reading this column!

Source: [Learning to Say No Can Save the Holiday Season | Scleroderma News](#)

About the Author



Lisa Weber Lisa is the married mother of two beautiful girls. She holds a master's degree and currently teaches third grade. She is extremely passionate about overcoming challenges while living with a rare autoimmune disease called scleroderma. This systemic disease attacks her entire body inside and out. Still, she manages to continue doing the things she loves: cooking (poorly), building furniture, jogging (slowly), and making clothes. She will tell you everything she does is perfectly imperfect! One of her life goals is to help raise awareness for rare diseases and to continue her personal fight to survive and thrive until a cure is found.



Members News



Bay of Plenty Scleroderma Group

Bay of plenty group

We had a small but cosy catch-up on a Saturday morning at Nourish. So lovely to get together to share issues and ideas. I certainly went home with some contacts and more questions to ask my specialists. Thanks so much to Barb for organising and also to Vicki and Mary for listening and being supportive - so much good help and advice from the group!

We made a group decision that we liked Nourish so much we will meet there again. Hope to see you again then. I'll send out a reminder nearer the time. 'Til then, take care and stay warm!

Cheers,
Millie



Hawkes Bay Scleroderma Group

We had a lovely catch up. It was a warm day so we were able to sit outside. Talked about if anyone dies what to do. The rest just talking about our sclero, knitting and other things. Lovely morning.



New Plymouth Scleroderma Group

The New Plymouth group continue to meet regularly and are meeting again on Friday. See page 20 for details.



Waikato Scleroderma Group

The Waikato Group met up for their Christmas lunch organised by our wonderful Linda. They had a lovely time together for friendship and catch up over lunch.



Christchurch Scleroderma Group

The lovely Christchurch group got together at the Travis Courtyard Cafe at the Burwood Hospital on the 26th of November. It was a great turn out and as you can see by all the lovely smiles that they were enjoying themselves.

They have a new name for their group called the **Sunflowers** :-) and it really suits them too. They were so pleased to see Carolyn and they welcomed their new member Jacqui along. They had a great time chatting with each other and looking forward to the next meeting.



Members News continued...



Wellington Scleroderma Group

Some of our Wellington members including members from Levin, met at the Farm Cafe & Bar at the Lower Hutt Golf club in late October. We had wonderful chat while enjoying a lovely lunch.



Southland Scleroderma Group



Southland November Get together

Thank you so much Jenny for organising our lunch out. It was a delight to have Jenny and Jeff's son Quinn join us, he was heard to say that where there is food you can always find a university student.

We also welcomed Helen and her husband Roger from Auckland, and their daughter Emma. It's so good that they can coordinate their visit to Dunedin to attend our Southland get-togethers.

We also welcomed Raewyn who had just been diagnosed with scleroderma 16 month ago, her partner David, and lovely to meet Raewyn's sister, Gay who also has Scleroderma, and her husband Rowan who joined us from Mosgiel.

We decided to make it a Christmassy theme, so it was delightful to see the hair pieces as you can see in the photos.

Thank you so much to all of you for being there and good to see Kimberly after her being unable to attend previously.



Members News update....

Wellington & Regional Zoom meeting on:

19th November 2022



It was lovely to see the ten of us at the zoom meeting.

We came from Auckland, New Plymouth, Hamilton, Alexandra, Invercargill and Wellington. It was a nice even spread from around the country.

We had a good two hour chat, introducing ourselves and learning about how we cope with scleroderma. There were some helpful tips and experiences shared around. I'm looking forward to the next zoom meeting in **May 2023**, but if anyone would like a catch up before then just let me know and I can organise one.

Dianne



Wellington Scleroderma Support Group Dates:

Wellington Scleroderma Support Group Get Together
January 2023 – July 2023



Date & Time	Venue	Address
Saturday 21st January 2023 12.30pm	Chocolate Fish Cafe	100 Shelly Bay Road, Miramar
Saturday 22nd April 2023 12.30pm	The Farm Cafe & Bar- Boulcott's Farm Heritage Golf Club	33 Military Road, Boulcott, Lower Hutt
Saturday 27 May 2023 1.30pm	Zoom meeting Sharing experiences with managing Scleroderma People from other regions most welcome.	Zoom Link https://otago.zoom.us/j/92333389235?pwd=YnhUZk56ekc5c3BUUnM3WlNnempXUT09
Saturday 22nd July 2023 12.30pm	Chocolate Fish Cafe	100 Shelly Bay Road, Miramar

Wellington meetings have re-started and new dates for the new year of 2023 are published above.

For any enquiries please contact Dianne:

Email to: diannepurdie@xtra.co.nz



Scleroderma NZ Inc.

Fundraising

Note Cards



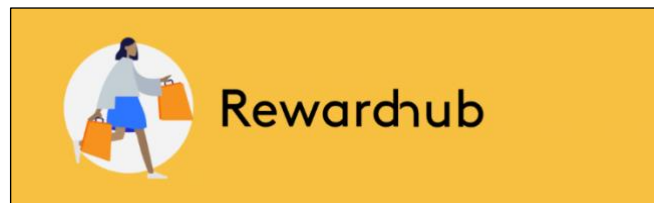
We had an awesome response for our Note Cards. Due to this we did have to do an extra print. So there are about 15 packs left if anyone missed out and still wants to purchase. Thank you so much for supporting Scleroderma NZ.

To order your own card pack, please email:
Jenny Andrews at jennyred@xtra.co.nz



Scleroderma NZ Inc.

Christmas Shopping



REWARDHUB

The thought of Christmas Shopping a little daunting? Why not do it from the comfort of home. Rewardhub is a website where more than 100 leading brands will Reward us with free donations, at no extra cost to you, when you shop online and are signed up to support us.

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

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

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

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



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.





Scleroderma New Zealand Incorporated

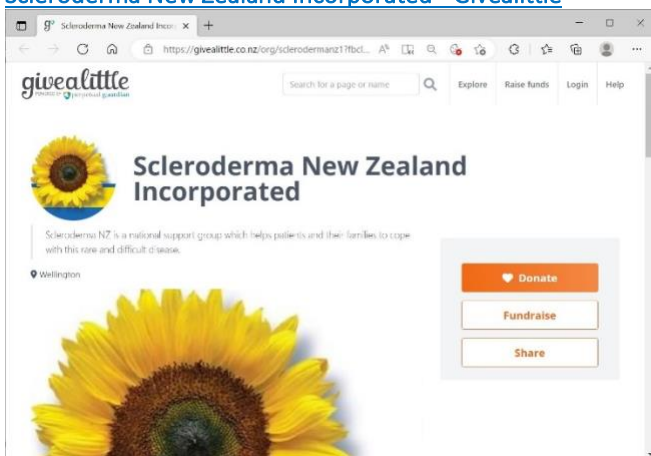
Scleroderma NZ is a national support group which helps patients and their families to cope with this rare and difficult disease.

Scleroderma NZ is a newly incorporated society that became incorporated in 2015. Scleroderma NZ Inc helps support patients and families with this rare and difficult disease. There are approx. 1,000 patients in New Zealand with this condition.

There have been two Scleroderma Give a Little pages established. One was setup from a group in Auckland who are independent to Scleroderma New Zealand Inc.

An example of what our give a little website page is shown below:

[Scleroderma New Zealand Incorporated - Givealittle](#)



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

<https://givealittle.co.nz/org/sclerodermanz1?fbclid=IwAR29Znk701JSOwf9n0Ew-O63nj0FrySOCpV44mBCpIPhtXV7Uff9KlAnAzM>

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

Scleroderma is a chronic, autoimmune, connective tissue disease. It effects patient's skin, major organs like their heart, lungs, kidney, liver, gastrointestinal tract and their vascular system. It can be very disabling in some patients, depending on the severity.

The organs become fibrosed and unable to function properly and some people are in considerable pain.

Some patients will require home help, for many tasks around the home. All patients must keep their home environment warm during the winter, as well as keeping their core warm, to help slow progression of this disease. This comes at a considerable cost and may be very difficult for some patients if they are unable to work.

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

We need help with finance for the printing of the booklets, educational speakers for seminars and meetings throughout the country and for aids like warm gloves, hats, special beds if required.

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

More about us

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

We have regular seminars and meetings to help support and educate our members, so that they maintain the best health possible.

Our Group has regional meetings in Auckland, Hamilton, Bay of Plenty, New Plymouth, Hawkes Bay, Wellington, Christchurch and Southland.



Group Meetings:

Wellington support group meets:

Wellington meetings have re-started and new dates for the new year of 2023 are published above on page 17.

For any enquiries please contact Dianne:

diannepurdie@xtra.co.nz

Christchurch support group meets:

Venue: *The Great Escape Café, Burwood Hospital, 300 Burwood Road, Burwood, Christchurch*

Saturday March 25th, 2023, 2.00pm to 4.00pm

Saturday May 27th, 2023, 2:00pm to 4:00pm

Mid-Year lunch Saturday 22nd July 2023, 12pm, **Venue tba**

Saturday September 23rd, 2023, 2:00pm to 4:00pm

Saturday November 25th, 2023, 2:00pm to 4:00pm

We welcome any new members to come along too.

Please contact Dianne Purdie if you would like to join in;

diannepurdie@xtra.co.nz, 04 479 5548

Southland support group meets:

Sunday February 26th, 2023. This will be held in **Gore at the Croydon Lodge, at 12.00pm.**

Sunday April 30th, 2023. **Winton/Hedgehope**

Sunday June 25th, 2023. This will be in **Invercargill**

Sunday September 10th, 2023. This will be in **Gore**

Sunday November 19th, 2023.

Venue: Will decide as a group at the previous meetings

Please contact Heather if you wish to join us.

milliganseeds@xtra.co.nz

Waikato support group meets:

Venue: *Robert Harris Café, Chartwell Hamilton.*

We will be meeting again on 14th February, at 10am. If you would like to join in with the Waikato Group, please contact Linda Bell.

linda.bell@hotmail.co.nz

Phone: **07 8535434**

Mobile: **027 548 1214**

Waipa support group:

All welcome, if you would like to join in with the Waipa Group please contact

Erena Bruce, Mobile: **021 186 9680.**

Palmerston North support group:

See Wellington Dates on page 17.

New Plymouth support group meets:

The New Plymouth group will meet on Friday 9th Nov, at Pukekura Park Kiosk at 1.30pm. To attend the New Plymouth Support Group please get in contact with Elle Bray 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

Hawkes Bay support group:

Friday 9th December, 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

Bay of Plenty support group meets:

We will be meeting either the end January or the beginning of February. Please contact one of us for information.

Jane: janepuckey99@gmail.com

Mary: marybestrd3@gmail.com

Alumie: alumie.uow@gmail.com

Otago support group:

Please contact Vanessa if you wish to join us.

Nessie332@gmail.com





Welcome to Scleroderma New Zealand Inc

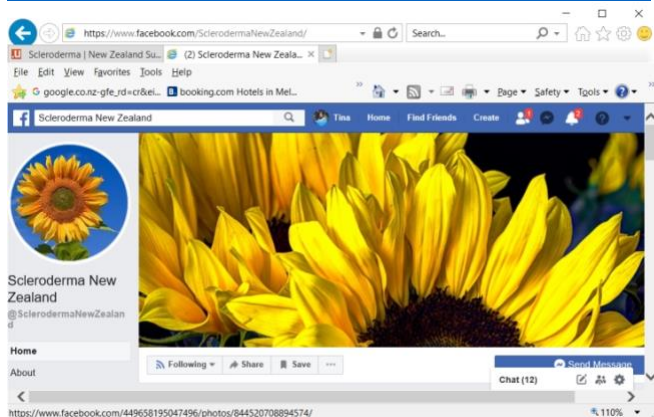
To all our new members, who have recently joined us – Welcome....

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

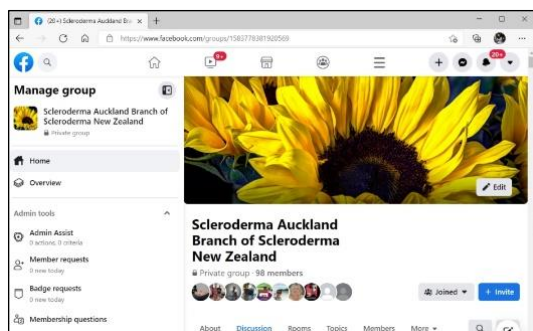
Link to our Website address below: -
<http://scleroderma.org.nz/>



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



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



Scleroderma New Zealand

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

Contacts:

Find a Scleroderma a Support Group near You:

Bay of Plenty:	Alumie Nguyen, Email: alumie.uow@gmail.com
Waikato:	Linda Bell, Email: linda.bell@hotmail.co.nz
Hawkes Bay:	Gail Neilson, Email: gail_neilson@hotmail.com
Waipa:	Erena Bruce, Email: glenanderena@xtra.co.nz
New Plymouth:	Elle Bray, Email: 1elle@xtra.co.nz
Wellington:	Dianne Purdie, Email: diannepurdie@xtra.co.nz
Blenheim/Nelson:	Jen Soane, Email: jennasoane@gmail.com
Christchurch:	Dianne Purdie, Email: diannepurdie@xtra.co.nz
Otago:	Vanessa Gray, Email: Nessie332@gmail.com
Southland:	Heather Milligan, Email: milliganseeds@xtra.co.nz



