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Scleroderma

New Zealand support group

Christmas 2021

Greetings to you all.

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

We hope everyone is well and keeping safe.



As we come towards the end of the year, and Christmas celebrations is upon us, we wish everyone a Merry Christmas, a safe and restful time over the holiday period and a Happy New year for 2022.

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 members stories from both Chris Carlyon, Linda Bell and Jane Puckey. Chris sharing her special

birthday with us, Linda introducing her beautiful Great Granddaughter to us and Jane sharing her journey with hook worms. It was fantastic seeing Jane on a segment on the Sunday Program.

We have our Covid update, and an article from Arthritis NZ regarding vaccines. Then members news from our different support groups.

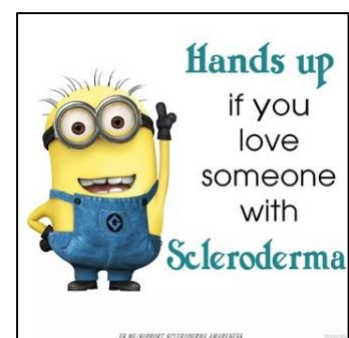
There is a registration section for Southland's Seminar coming up, and we have a small section talking about our calendar fundraiser.

In pet corner we see Linda's sleepy cat Strawberry.

Be Safe during the festive season and enjoy being able to be around family and friends.

Warmest regards,

Tina and Jenny



Presidents Report:

Christmas 2021



Merry Christmas to you all. Thank you for joining us on our last newsletter for 2021. And what a year it has been. Full of ups and downs, highs and lows and plenty of uncertainty.



So, I wish to make a huge shout out to all those in the Auckland and Waikato areas who have had such a tough time of it this year. Looking in from the outside we are fully aware of the sacrifices you have made for the rest of the country. Surely 2022 will be a better year for all of us. Please take care of yourselves during the Christmas period and stay safe. Unfortunately, we will be living a new normal so will have to adjust accordingly.

I would like to thank all those who supported us in the Calendar fundraiser. We had 200 made and the sales were awesome. We couldn't have done it without the amazing work put in by Carolyn Barkhausen and the awesome team she works for. Thank you BNS Design & Print Ltd. They turned out rather eye catching, with gorgeous bright pictures. It is so nice to see the artwork and photography by our members. This could possibly be our annual fundraiser, so to all those budding artist and photographers get your artistic juices flowing ready for next year. It helps if all work submitted could be in landscape, and of high resolution. Looking forward to seeing what you can do. ☺



Southland Scleroderma Support group are still planning on holding the National Seminar on 26th March 2022. We have been able to move it

to larger premises which means we can have the numbers we want but also allow for social distancing. All attendees will need to be double vaccinated and show their vaccine certificate on entry as per the request of the venue. Should things change, which is very possible with the country opening up during the Christmas New year period then we can reassess but at this stage we are all systems go. Registration is open and you will find a page further through the newsletter on how to do this. It has been a while since anyone has been able to have a seminar held so it will be great to catch up on our fellow scleroderma members. Very excited about the speakers we have attending who will be full of knowledge to share and answer any questions you might have.

We have a new group starting in Tauranga in January so that will be exciting to meet you all. Thank you, Jane, for opening your home for this.

My heartfelt condolences to all those who have lost someone special in their lives this year, whether a scleroderma member or a wonderful support person, or that loved friend or family member. My thoughts go out to you all and wishing the memories you have of them will give you comfort in the days, months and years ahead.

Wishing each and every one of you a very, very Merry Christmas and happy holidays. Remember to take some time to really appreciate those around us.

All the best
Jenny



Members Stories:

Chris Carlyon – “Celebrating my 65th birthday”

What a beautiful majestic country we live in.

The Clay Cliffs just out of Omarama, in the South Island is one of the places I visited and spent some magical time with lifelong friends as these three photos will show.

Note the APPARITION in the cliff of first photo. !!!

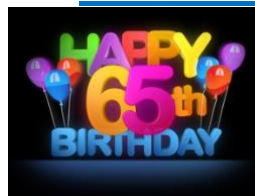
If friends are crazy enough to dare, impossible things happen.

A unique challenge (photo 2).....The question is, did I make it?

They said, best view, comes after the hardest climb....!!!

Humm.... what goes on tour stays on tour. But I will say.....

Plenty of laughs and great memories were made, as I celebrated my special birthday with friends who match my level of crazy.



Members Stories:

Jane Puckey – “My Scleroderma Helminth Journey”

AT THE START

I have systemic scleroderma, myositis with Creatine Kinase (CK) around 500, Raynaud's, poly arthritis and gastric reflux. The first thing I noticed at the beginning stages of scleroderma was a blue little finger and feeling more tired than usual. From there I developed a red rash on my face, carpal tunnel in both hands and felt exhausted all the time.

After the carpal tunnel release there was swelling in my hands which simply didn't go away. From there I was then diagnosed, this was in 2010. I have been pretty lucky to escape the worst outcomes and kept quite well.

I have had some hardened skin over the back of my hands and chest with a skin score of 16 (out of 50). Arthritis never worried me until 2018 with mild burning in the knees and shoulders.

Myositis causes me the most problems with weak muscles in the quads and biceps. I had severe fatigue along with the weakness, for which I needed prednisone, and took 7.5 mg daily.

I had regular flares of muscle weakness which sometimes meant I couldn't get up our stairs without one or two rests. It meant I increased my dose to 30 mg of Prednisone a day. I would then wean down to 5 mg in continuous cycles of flares every 3 months.

I had severe Raynaud's which made the cold unbearable. I also had calcinosis on my fingertips which caused painful ulcers.

I have been trialled on methotrexate which did help and many others which caused side effects. I used to call mercaptopurine my vomit pills lol. Intragram P which did help. I do believe that immune suppression helped my disease stay mild. The type of scleroderma I have can result in very severe disease such as lung fibrosis and renal failure.

But for one reason or another the doctors had to stop them. Many of the immune suppressing medications have horrible side effects and don't actually reverse disease rather they help stop it progressing or help with symptoms..

I worked 20 hours per week and danced although I needed a nap in the afternoon if I wanted to go out dancing.

TAKING THE PLUNGE WITH HELMINTHS

This is from my journal: Today (July 2018) I applied 10 Necator Americanus (NA). Which is the human hookworm. I began feeling a stinging itchy feeling 10 minutes after the patch was applied. So hopeful this is them burrowing and not my over excited and hopeful imagination.

26 March 2019 from Journal

9 month update: I thought I would let everyone know my progress. I have been taking NA between 5 and now 8 every 3 months. I had an early positive response with skin softening and increased energy and muscle strength.

I have had continued skin softening which is noticeable on my hands and face. I can drink from a drink bottle and suck through a straw which is fabulous (scleroderma makes the skin thick and tight and the mouth cavity gets smaller). My Rosacea is totally gone. Finger nails are strong for the first time in my life.

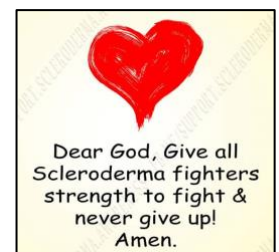
As for muscle strength/weakness (myositis), it's difficult to know because I still get periods of weakness. I haven't had to use high dose prednisone in the 9 months hosting which is a big change, usually I need to go up to 30mg every few months. I have got down to 5 mg a day but when I tried to reduce further I had a return of symptoms.

I'm not climbing any mountains right now but am working and walking on the flat. And dancing without sneaking extra prednisone. Unfortunately I haven't coped with an increase in workload and being on my feet for 5 hour a day. So... all and all it's a cautious win on the myositis front. As for Raynaud's, I can definitely claim a big improvement.

The temperature has dropped here in NZ and I am not getting much: a faint blush of blue fingertips occasionally but I previously had a severe reaction to a faint breeze, so subjectively I think its 80% better.

NOW 3 YEARS IN

I'm now 3 years along my hookworm journey (4 September 2021). I'm trying to think of the good, bad and the ugly of this journey so that you get a realistic idea of how things progressed for me.



Members Stories:

Jane Puckey – “My Scleroderma Helminth Journey” continued.....

I have continued with the improvements described above. The only time my muscles flare now is if I have taken antibiotics. Usually I am quite fatigued for a month to 6 weeks following ABs.

I haven't needed to take increased doses of Prednisone in the 3 years of being on NA. Actually, I did take a one off dose during an antibiotic induced myositis flare about a year ago. I want to be entirely honest about my journey! My CK, which measures muscle damage, is in the normal range under 220 and has been for 2 years now despite weaning Prednisone. I'm also on medication for reflux and other symptoms of scleroderma but no immunosuppressant

I have managed to get down to 2 mg Prednisone daily which is amazing after 10 or more years on it! I have done this slowly over the last 18 months, but without very much effort or effect on my life. I like to live each day and keep up my dancing so have limited tolerance for putting up with too much weakness!

My lungs whilst never too bad, have improved from borderline low to normal range in terms of lung function tests.

I don't nap in the day as much. I still work 20 hours a week. I walk 4 km a few times a week.

My Raynaud's is still improving and muscle strength is pretty good consistently. Although I still can't go far uphill! My big issue now is calcinosis in my ligaments around my joints. This started prior to hookworm but it has got worse and I have pretty stiff joints now. I am also 58 years old so maybe I expect too much! Currently no calcinosis or ulcers on my fingertips even though we have just been through winter. (I still get this occasionally and have had some surgery).

I am about to add HDC (another species) to the NA for the first time this week (September 2021) My goal is to come off the last 2 mg of Prednisone, completely resolve Raynaud's, reduce joint stiffness and walk up big hills. Also soften the skin on my index fingers which are still tight and prevent me making a complete fist. Wish me luck! I'll keep you all updated!

25/11/21 update, I'm well and feel good on two species of helminth. I'm down to 1 mg Prednisone and have halved my dose of Omeprazole. Previous attempts at this have failed due to severe Gerd.

I'm not getting Raynaud's at the moment or maybe a faint blush, but it's quite warm here in Tauranga so time will tell. Continuing meds are Sildenafil 25 mg twice a day, candesartan 4 mg, 1 mg Prednisone, 20 mg Omeprazole. I also take a probiotic.

Hope this helps and I recommend joining the Facebook group, Helminthic therapy support group. They have an amazing data base of research and information. They give good advice and support and well as helminth provider details.

In answer to a few other questions our members had.

I do keep in regular contact with a specialist. She is not interested in helminth at all. She tolerates my decision. I go for annual lung function (stable, slight improvement in DSCO and 2 yearly cardiac echo (stable) tests. As well as 3 monthly bloods.

My GP is warmly supportive and has referred people to me who are interested.

No I cannot feel the worms inside me other than the wee scratch of them entering.

In regards to keeping the population down, they do not multiply inside the body as when they lay eggs these are removed in the faeces. The life cycle needs to be incubated in soil for 2 weeks, so it is **impossible** to multiply in the body. They don't travel outside your gut.

It has had no effect on my insurance. Hookworms are not available in NZ. These are an experimental treatment so you need to be aware that the responsibilities has to be yours alone. If you want them to be verified and go through official steps then it will be a matter of waiting for NZ to become verified and get lab tested ones. There is a Rat Whip worm (HDC) which I have been using which is having good results, that comes from an authorised verified Lab in the UK. I had to get an import licence to bring these into the country. Some people may experience tummy upset, but I have not. My condition has stabilised and I haven't had a flare up while using the worms. I have been able to wean off the steroids that I was on. If you are really serious about proceeding with trying this then you are welcome to private message me.

Joining the Facebook page would be a fantastic place to start also. This will answer all your questions.

Helminthic Therapy Support Group.

All the best
Jane Puckey



Members Stories:

Linda Bell — Introducing my Great Granddaughter

Introducing beautiful Nila Jay, my new Great Granddaughter. Born in lockdown, premature and we were unable to visit, a most distressing time.

So please have the vaccine so we can all get back to a normal life.

I have had to cancel coffee group and the seminar this month. Our Christmas Luncheon on 4th December at Matte Black St Andrew's Golf Course was lovely great you see everyone.

Our coffee group will be in February 2022 hopefully.

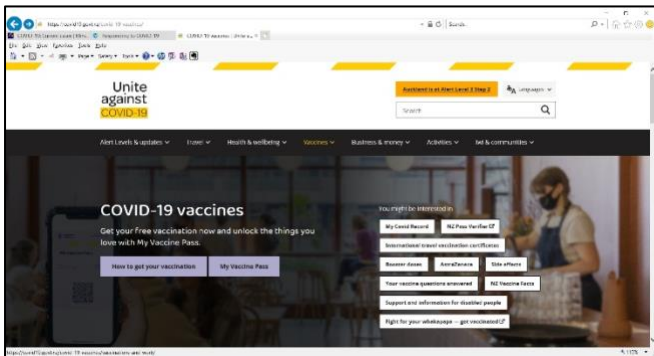
I would like to wish everyone a Merry Christmas stay safe and well happy New Year too.

*Loving the Sunflower wrap Linda.
Thank you for sharing your
beautiful Great Granddaughter with
us. xx*



Covid-19 update:

COVID-19 Vaccines



My Vaccine Pass is now available

Requesting your pass only takes a few minutes and will be emailed to you within 24 hours. The quickest way to get your pass is through your **My Covid Record**, but if you cannot access this service you can call **0800 222 478** — have your NHI number ready.

[Learn more about My Vaccine Pass](#)

Get vaccinated now to enjoy greater freedoms

To enjoy the full life everyone in New Zealand deserves, get vaccinated today.

If you are already vaccinated, do your best to help your friends and family get their vaccinations so we can all enjoy life within the new system sooner.

[Book My Vaccine \(external link\)](#)

Check your COVID-19 vaccination records

If you have had your first or second dose of the vaccine, now is the time to make sure your vaccination details are accurate

Go to My Covid Record now to confirm your vaccination information is correct.

[My COVID Record \(external link\)](#)

Tracking the vaccination rate in your community

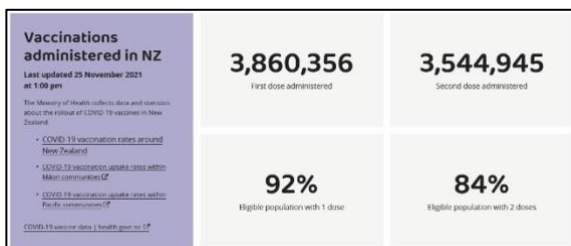
Our interactive vaccination map allows you to keep track of the vaccination rates across New Zealand.

You can see the proportion of people who have received their first or second dose, and compare your area or DHB with others in New Zealand.

Search your address or check the map to find your area or DHB.

[Vaccination rates around New Zealand](#)

Vaccinations administered in NZ:



Source: <https://covid19.govt.nz/covid-19-vaccines/>

Arthritis New Zealand article

UPDATED November 2021

People with rheumatic disease should get vaccinated against COVID-19, and observe all public health measures (such as mask-wearing and handwashing) as recommended by the New Zealand Ministry of Health.

Studies published to date have shown that the use of oral disease-modifying anti-rheumatic drugs (DMARDs) and most biological therapies for arthritis **do not** increase the risk of infection, hospitalization or mortality caused by SARS-CoV-2 (the novel coronavirus).

Use of rituximab and prednisone greater than 10 mg per day was, however, associated with an increased risk of severe illness due to COVID-19. Studies have also shown that people with poorly controlled inflammatory disease are at increased risk of severe illness due to COVID-19.

It is therefore recommended that people with inflammatory arthritis continue to take their arthritis medications during the pandemic, and try to minimize the use of corticosteroids such as prednisone.

COVID-19 vaccination can be given safely to people on DMARDs and is strongly recommended for all eligible people with rheumatic disease.

Patients on rituximab, cyclophosphamide, and most oral DMARDs (including methotrexate, leflunomide, azathioprine, mycophenolate, tacrolimus, and cyclosporin) are now eligible for a third primary dose eight weeks after the second dose, in accordance with the Ministry of Health guidance ([version 3](#)). Patients on long-term prednisone $\geq 10\text{mg}$ daily are also eligible for a third primary dose. A booster vaccine dose should also be given six months after the third primary vaccine.

After the third primary vaccine dose and the booster dose, oral DMARDs (but not prednisone) should be withheld for 1-2 weeks, if disease activity allows. This recommendation is to increase the effectiveness of the vaccine rather than due to concerns about safety.

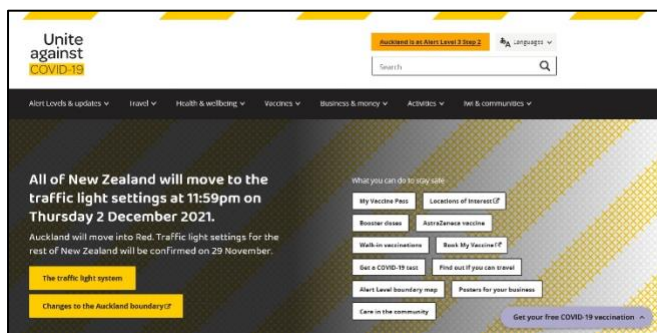
For any questions regarding this statement, please phone us at **0800 663 463** or email info@arthritis.org.nz.

Hear from Professor Nicola Dalbeth in the link below:

<https://youtu.be/6OoofqvOnMY>



Covid-19 update: The Traffic Light System



About the new system

Elimination and the alert levels have served New Zealand well. They delivered the lowest number of cases, hospitalisations and deaths in the OECD, gave us sustained periods of days without restrictions and a strong economy that sees GDP rising and unemployment falling to historic low levels. But it was never intended as a forever strategy.

We now have the unique advantage of moving to the next phase of managing COVID-19 in our community with a highly vaccinated population.

The traffic light system (also known as the COVID-19 Protection Framework) brings us a world where we are freer to move and live with less disruption and offers the stability businesses need to plan for the future. It introduces a new traffic light system to manage COVID-19 in the community:

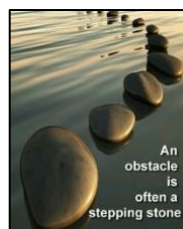
- Green
- Orange
- Red

The framework is more flexible than the current Alert Level system because we know that businesses that only open to vaccinated customers pose a lower risk. We can move up levels when needed to control an outbreak.

- [COVID-19 Protection Framework \[PDF, 84 KB\]](#)
- [COVID-19 Protection Framework — Large Print \[DOCX, 546 KB\]](#)
- [COVID-19 Protection Framework — Audio \[MP3, 15 MB\]](#)
- [COVID-19 Protection Framework — Easy Read \[PDF, 3.6 MB\]](#)

Green	<p>Green is when there are some COVID-19 cases in the community, and sporadic imported cases. Community transmission will be limited and COVID-19 hospitalisations will be at a manageable level. The health system will be ready to respond, including primary care, public health, and hospitals.</p> <p>How we stay safe at Green</p> <ul style="list-style-type: none"> Record keeping and scanning will be required. Face coverings are mandatory on flights and encouraged indoors. <p>Where we can go at Green</p> <ul style="list-style-type: none"> Public facilities. Retail. Workplaces. ECCEs, schools, kura and tertiary providers. Specified outdoor community events. Regional boundary restrictions will not apply.
Orange	<p>At Orange, there will be increasing community transmission that is putting pressure on our health system. The whole of health system will focus its resources, but can continue to manage primary care, public health, and hospitals. There may also be an increasing risk for at-risk people.</p> <p>How we stay safe at Orange</p> <ul style="list-style-type: none"> Record keeping and scanning will be required. Face coverings will be mandatory on flights, public transport, in taxis, retail, public venues, and encouraged elsewhere. <p>Where we can go at Orange</p> <ul style="list-style-type: none"> Public facilities will be open with capacity limits based on 1 metre distancing. Retail will be open with capacity limits based on 1 metre distancing. ECCEs, schools, kura and tertiary providers, with public health measures in place. Workplaces. Specified outdoor community events. Regional boundary restrictions will not apply.
Red	<p>At Red, action will need to be taken to protect both at-risk people and protect our health system from an unsustainable number of hospitalisations.</p> <p>How we stay safe at Red</p> <ul style="list-style-type: none"> Record keeping and scanning will be required. Face coverings will be mandatory on flights, public transport, in taxis, retail, public venues, and recommended whenever leaving the house. <p>Where we can go at Red</p> <ul style="list-style-type: none"> Public facilities — open with up to 100 people, based on 1 metre distancing. Retail — open with capacity limits based on 1 metre distancing. Workplaces — working from home encouraged. ECCEs, schools, kura and tertiary, with public health measures in place. Specified outdoor community events — allowed with capacity limits. Regional boundary restrictions may apply.

Source: <https://covid19.govt.nz/alert-levels-and-updates/traffic-light-system/>



Anxiety Over Public Restrooms Is Real...

Article from Sclerodermanews.com

By Lisa Weber

November 12, 2021

I take immunosuppressants to stop my body from fighting itself and reduce the symptoms of scleroderma. But that also prevents my body from defending against bacteria and viruses.

This makes me think of everything in a new way. After the first few months of taking immunosuppressants, I learned that I'll catch everything going around and it will last months. Even the common cold can turn into a house guest that overstays its welcome. The last snuffle and cough I contracted lasted nine weeks!

So, imagine me in public restrooms.

It typically starts with me wondering if it's possible to pile enough paper on top of the toilet to create a barrier strong enough to protect my immune-compromised bottom. Toilet paper in public restrooms is thin, and there's never enough time to build a nest thick enough to make me feel safe from the layers of germs I envision on the seat. When I have to go, it's urgent!

I always end up deciding to squat like a sumo wrestler — close enough to keep my clothes dry, but far enough from the dangers lurking beneath.

The last time I tried this strategy, I realized how weak scleroderma has made me. Trying to squat was excruciating; my leg muscles began shaking and my joints felt like they'd been set on fire. The lower half of my body shook like an earthquake. I kept imagining my legs giving out and me falling backward into the disease-infested seat, bare-bottomed.

Like the scleroderma warrior I am, I wasn't going to give up. I curled my toes inward and clenched my teeth, bracing myself with every ounce of strength I had left.

Then I realized I had been holding my breath. What was I thinking? I have a lung disease! Withholding even a moment's breath could have resulted in a hyperventilation episode, in which I breathe rapidly while feeling like I'm suffocating. Passing out would have been the end. The only thing worse than the toilet was the years of build-up on the tile grout.

My anxiety really goes into high gear when the motion sensor flusher knows I've moved away! The bowl begins to erupt, and I try to get out of the stall fast, but because the stall door opens inwardly, I can't leave without moving closer to the very water cyclone I'm trying to get away from! All I can do is close my eyes and pray, "Please don't let anything wet hit me!"

It used to be so nice, before immunosuppressants, being able to use public restrooms without having germ anxiety.

I wish the healthy population understood challenges like these. Using immunosuppressants means worrying about germs wherever I am. Having to sterilize everything when I'm in public invites snarky looks and rude glares. I want to shout, "Do you think I want to wipe down the table, menus, and condiments in my fancy dress? While celebrating my own birthday?" But instead, I bashfully lower my head and pretend I don't see them.

I was once on the other end of such naive judgments, and I know it's simply a matter of being uneducated about chronic illness. I spent 36 glorious years of my life blissfully unaware that disabilities can look very different from one person to the next.

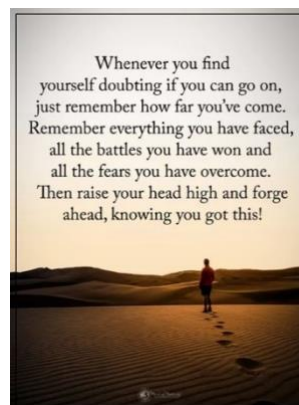
Being chronically ill can certainly make life a bit more challenging. I would like to see everybody show more compassion when they don't understand what other people are living with. I promise to work on my empathy, too. I'll also start working on my thigh muscles with some extra squats, because wearing a diaper doesn't pair well with my skinny jeans.

SOURCE:



sclerodermanews.com/2021/11/12/anxiety-over-public-bathrooms-is-real

Note: Scleroderma News is strictly a news and information website about the disease. It does not provide medical advice, diagnosis, or treatment. This content is not intended to be a substitute for professional medical advice, diagnosis, or treatment. Always seek the advice of your physician or other qualified health provider with any questions you may have regarding a medical condition. Never disregard professional medical advice or delay in seeking it because of something you have read on this website. The opinions expressed in this column are not those of Scleroderma News or its parent company, BioNews, and are intended to spark discussion about issues pertaining to scleroderma.



Members News:



Southland Scleroderma Group

Heather Milligan bring us up-to-date with happenings from down in Southland...

Thanks so much to Jenny and Jeff who opened their home for our last Scleroderma meeting for the year, a superb location on an equally superb Southland day to meet up with friends in the 'Scleroderma family' again and eat the delicious delights we brought for afternoon tea.

We were pleased to welcome a 'slightly shell shocked' Judy who had just been diagnosed with Scleroderma and her daughter Melanie.

An enchanting end to a very strange 2021.
Heather



Graham, Linda & Lorraine enjoying the shade



Jenny, as you can see in the photo, seized the moment for those who were wanting to do their 'Covid Pass', got on her laptop and got it done!!!!



Kimberley looking good in her Highlanders jersey and looking cool on a hot day.

She later showed us her beautifully framed diamond paintings and sparkly key rings, amazing, the work is so intricate. I was so stunned I forgot to take photos..... next time Kimberley.



Judy, Melanie, Betty and Ian



Jenny made sure our amazing calendar was on display to purchase



Members News continued:



Christchurch Scleroderma Group

It was great catching up with everyone, we hadn't seen each other for four months. There was lots of talking, hearing how everyone had been. A few of our members had been very unwell, but are on the mend Roll on the summer weather and warmer days.

There were lots of lovely comments about the Scleroderma Calendar! Well done to all those contributors.

We have another new member who has joined, and we look forward to meeting her in January.

We look forward to meeting up again in 2022. Merry Christmas to all our Scleroderma family throughout New Zealand. If any of you are in Christchurch when we have our meetings, we'd love you to join us.



Hawkes Bay Scleroderma Group

The Hawkes Bay Group met at The Figgery Café outside Havelock North on November 26 for coffee. Unfortunately a couple of the group were unable to make it, but those of us who went had a lovely catch up. We were able to be outside so we were comfortable. We try and meet every 2-3 months for a catch up at a café in the mornings. Please give Jane Sainsbury a ring and join us if you can. We would love to hear from you.... Next time I will get a photo of our wee group.



Waikato Scleroderma Group

Sadly due to Covid and lockdowns Waikato Coffee Group had to cancel both a coffee group and seminar in November.

Our Christmas Luncheon on 4th December at Matte Black St Andrew's Golf Course was lovely great you see everyone.

Our next coffee group will be in February 2022 hopefully.



New Plymouth Scleroderma Group

This is our first main catch up here for the Scleroderma Support group taken at Little Fed Café in New Plymouth.

This will become a regular thing for the New Plymouth area. If you want to join in with them, feel free to get in touch with Elle.



Barbara Rankin, Elle Bray, Wendy Broad and Judy Monk



Members News continued:



Wellington Scleroderma Group

The Palmerston North group and the Wellington group had a lovely get together for a combined end of year Christmas lunch at the George Café in Levin.

It was a lovely opportunity for the Wellington group to drive up to Levin and meet familiar faces from the Palmerston North group.

We all had a wonderful time catching up with each other and had a lovely lunch.

Thank you to everyone who could attend and a big thanks to Chris & Martine for organising this wonderful get together. Thank you also to Cushla for taking all the beautiful photos to capture the moments.



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:

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

To register please email the following
details to 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:

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

One of our members has been recommended to
have a bone infusion. **Has anyone, or do you know
of any person with scleroderma that has had the
bone infusion done for osteoporosis bone decline?**
Drips into the veins for about 10 minutes.
Bisphosphonates infusion. Helps strengthen the
bones. If so please get in touch with either Tina or
Jenny so they can pass on the information to our
member.

Thank you

Joke of the day:



Scleroderma NZ Inc. Fundraising

2022 Calendar

We had a very successful fundraiser for
Scleroderma NZ Inc. with our 2022 Calendars for
sale. We have almost completely sold out with only
a couple left. Now is the time to get yours before
they are all sold out.

They are \$20 each and if we have to post them
there will be a small charge of \$4.50 postage.

Thank you so much for supporting this awesome
fundraiser as the funds raised will be going into the
cost of printing our updated booklets
"Understanding and Managing Scleroderma".

To order your copy please email: Jenny Andrews at
jennyred@xtra.co.nz

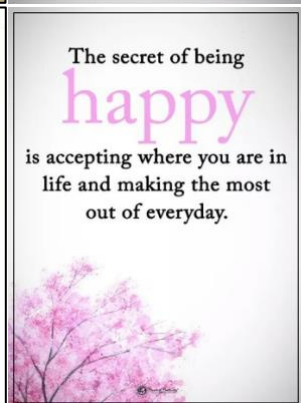
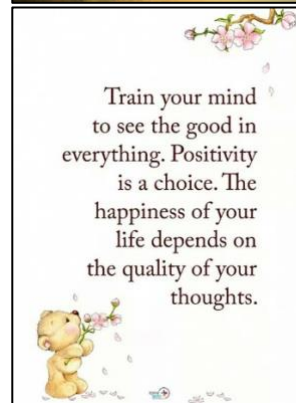
Here is a wee preview of our fundraising
calendar. Thank you to all those who submitted
work for it. I am guessing it could be an annual
event so think about what you would like to submit
for next year's one.



Pet Corner:

Linda Bell – Strawberry

My cat Strawberry saying “you are not ironing, I am sleeping”



Recipes:

The 8 Best Teas for Inflammation

1. **Ginger Teas.** **Ginger** is a popular ingredient in many herbal and caffeinated teas, and is well-known for its powerful anti-inflammatory effects. ...
2. **Turmeric Teas.** ...
3. Chamomile Teas. ...
4. Rose Petal and **Rosehip** Teas. ...
5. Black Teas. ...
6. **Green Teas.** ...
7. **White Teas.** ...
8. Rooibos Teas.



Noticeboard:

ALL ATTENDEES MUST HAVE VACCINE PASS

Wellington support group meets:

Wellington meetings are TBA.

For any enquiries please contact Dianne:

diannepurdie@xtra.co.nz,

Christchurch support group meets:

Saturday 29th January 2022, 2:00pm to 4:00pm

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: Café, ground floor at Burwood Hospital

We welcome any new members to come along too.

Please contact Carolyn Barkhausen if you would like to join in; carolynbarkhausen@gmail.com

Southland support group meets:

Sunday February 16th 2022, 12pm lunch

Venue: Croydon Lodge, Gore

Please contact Heather or Jenny if you wish to join us.

milliganseeds@xtra.co.nz

Waikato support group meets:

February 2022 TBA

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

Phone: **07 8535434**

Mobile: **027 548 1214**

Waipa support group:

If you live in Cambridge, Te Awamutu or even Morrinsville you are welcome to come and join us. Let's endeavour to support each other as best we can.

Please contact **Erena Bruce**, all welcome.

Mobile: **021 186 9680**

Palmerston North/Wellington combined support group:

Saturday 12th February 2022, 11.30am

Venue: The George Café, Speldhurst, Levin.

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

New Plymouth support group meets:

Thursday 16th December 2021, Lunch at 11.30am

Venue: Pikopiko Eatery, 532 Mangorei Road, Highlands Park, New Plymouth. To attend the New Plymouth Support Group contact 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:

To join in with the Hawkes Bay Support group get in touch with Jane Sainsbury. They will be meeting again around February 2022.

jsainsbury@xtra.co.nz

Tauranga support group:

We are starting a group in the Tauranga area and will meet for the first time.

Sunday 30th January at 2pm. The address will be emailed out to those interested in joining us. To join in with the Tauranga Support group please get in touch with Jenny Andrews. jennyred@xtra.co.nz

Contacts:

Find a Scleroderma a Support Group near You:

Waikato:	Linda Bell, Email: linda.bell@hotmail.co.nz
Hawkes Bay:	Jane Sainsbury, Email: jsainsbury@xtra.co.nz
Waipa:	Erena Bruce, Email: glenanderena@xtra.co.nz
Palmerston North:	Martine Fremaux, Email: curios@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:	Carolyn Barkhausen, Email: carolynbarkhausen@gmail.com
Southland:	Heather Milligan, Email: milliganseeds@xtra.co.nz
Tauranga:	Jenny Andrews, Email: jennyred@xtra.co.nz



Welcome to Scleroderma New Zealand Inc.

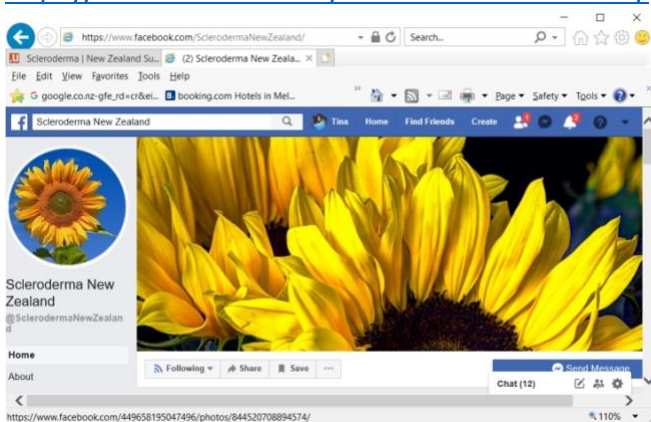
To all our new members, who have recently joined us – Welcome....

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.

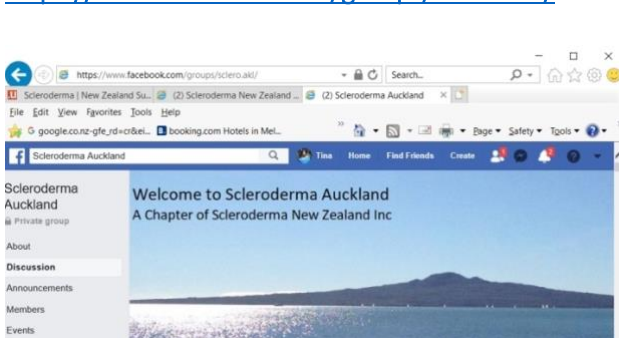
Link to our **Website** address below: -
<http://scleroderma.org.nz/>



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



