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Scleroderma

New Zealand support group

Spring 2026

Greetings to you all...

Welcome to the Spring edition of our Scleroderma Newsletter

We hope everyone is keeping well and taking care of themselves.

We have lots going on in our quarterly newsletter for you! First up, we feature our President's report.

Then Perry has written a piece on oral health which is a common problem for a lot of us.

We have lots of information regarding the upcoming conference in Wellington in April 2027. Dianne has put submitted everything we will need to know. How to get there and what to expect when we are there. Also organising a dinner out afterwards for those who wish to join. Thanks so much Di.

We have the results from our **Scleroderma Health Care Survey 2026**. Thank you to Gordon and Dianne for your hard work putting all this together.

We have a **"Situations Vacant"** notice. Tina and I will be stepping down from producing this newsletter when we find someone to take over the reins. We will offer full support during the transition period and beyond. We have thoroughly enjoyed this role and loved staying in touch with all our group leaders and members, but we

feel it is time for fresh eyes to give the publication a creative revamp!

Please feel free to send us your news, stories, jokes, tips, or anything else you would like to share. Our contact details are listed on the final page.

Remember, this newsletter belongs to you. Sharing your personal experiences and activities can bring immense comfort and connection to other members walking a similar path.

Take care everyone.

Tina and Jenny



Presidents Report:



Hello from Southland

Well the sun is shining, the lambs are frolicking and the dairy farmers are flat out calving. It must be Spring. Such a great time of year with the daffodils and spring flowers all making an appearance.

Also that time of year when we are flat out with meetings and organising the Spring Flowers Shows. The scent inside the hall is amazing. Not so much for those who get hay fever though. It is lovely to see the end of Winter. The country has had a bit of a fickle Winter, also a few too many earthquakes happening around. Not that I have been feeling them which is good.

Our deepest condolences go out to everyone who has lost a loved one over the past few months. You are in our thoughts and hearts.

The committee are still working behind the scenes updating our Understanding and Managing Scleroderma booklet. I am forever thankful to the hard work being put into this, especially to Alumie, Dianne and Gordon. It is good to keep updating it and keeping things relevant.

Our Survey results are here for you to see. Much appreciation goes out to Dianne and Gordon for the time they have put into this.

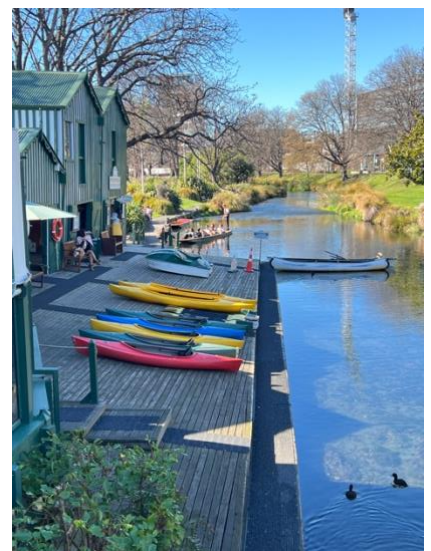
Our 2027 Conference is all go for April. Registrations are open, and you can find full details of the Programme, bio of speakers, accommodation options and how to get there by public transport further along in this newsletter. The event will take place at The Dowse Art Museum in Central Hutt on April 17th. A special thank you to Dianne for her incredible work in organising and finalising these details.

Do be mindful when you venture outside during Spring as it can be very changeable out there. Be

prepared for all temperatures. It is also not too late to get a flu vaccine with a lot of different flu going around this year. Keep yourself safe.

Jeff and I recently had a trip to Christchurch for a car check-up before it came out of its warranty. We were so lucky to have such a great sunny weekend. As shown in the photo. We were given a loan car for the time ours was in the garage. It was the same model as ours but an updated version. Such fun driving around. We went all around Christchurch on full self-drive mode and didn't have to touch the steering wheel or pedals the whole time. We just put the area we wanted to go to and it took us there. I can't believe how relaxed I was having a machine drive me around. It was very courteous, indicating and changing lanes and merging as it should. Because we didn't put a specific address in, it did pull up someone's drive which had us in hysterics. It was fun for the city driving but not needed in Southland, so no we did not update our car. I think I would forget how to drive properly if I had the car doing everything for me. I did feel like we had jumped ahead in time. But it really is a reality. Oh how the last 100 years have progressed.

Take care all.
Jenny



Members Stories:

The life and times of Perry...

How Scleroderma affects the mouth

August 13, 2026 by [Perry](#)



Earlier this month I posted about [Mogil's Mobcast latest episode #126](#) which introduces listeners to Dr. Natalia Trehan.

Natalia's clinical and academic interests centre on oral manifestations of systemic disease, including autoimmune and connective tissue disorders such as Sjögren's disease and systemic sclerosis, as well as other medically complex conditions with oral health implications.

It is an informative podcast that got me thinking about how Scleroderma affects the mouth and my own journey with dental hygiene. Occasionally I get multiple mouth ulcers that seem to take an age to heal and are quite painful, along with reflux.

You see, Scleroderma can significantly affect the mouth and oral health meaning that early recognition and regular dental care are important to help prevent complications and maintain quality of life.

Changes in the skin, connective tissues, salivary glands, muscles, and blood vessels around the mouth may make everyday activities such as eating,

speaking, swallowing, and maintaining oral hygiene more difficult.

A healthy mouth relies on flexible tissues, adequate saliva production, strong teeth, healthy gums, and proper jaw movement. In people with scleroderma, excessive collagen production and tissue fibrosis can reduce the flexibility of the lips, cheeks, and mouth, while changes in the salivary glands and blood vessels may further affect oral health.

One of the most common oral symptoms of scleroderma is microstomia, or a reduced mouth opening. Tightening of the skin and connective tissues around the mouth may make it difficult to open the mouth fully. This can interfere with eating, speaking, yawning, brushing the teeth, flossing, and even routine dental examinations or treatments.

Many people with scleroderma also experience dry mouth (xerostomia).

Reduced saliva production may occur because of involvement of the salivary glands or overlap with conditions such as Sjögren's syndrome. Saliva helps protect the teeth, lubricate the mouth, aid digestion, and prevent infection.

Without enough saliva, individuals may have difficulty chewing, swallowing, or speaking and may be at greater risk for tooth decay, gum disease, mouth sores, and oral infections.

Scleroderma may also affect the gums and teeth. Tight or inflamed gum tissues can make oral hygiene more challenging, allowing plaque to build up more easily. This may increase the risk of gingivitis, periodontitis, cavities, and tooth loss if not properly managed. Some people may also notice loosening of teeth due to changes in the supporting tissues around the teeth.

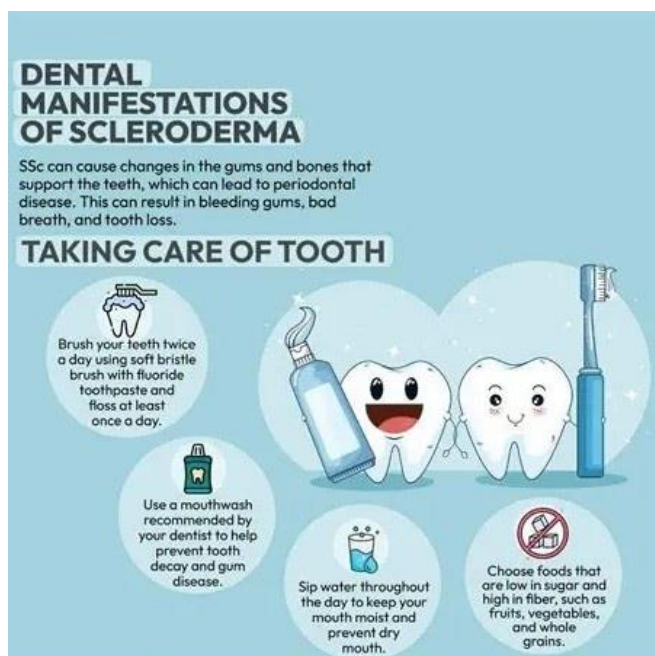
The jaw joints and muscles may also be affected. Fibrosis and inflammation can contribute to stiffness, jaw pain, or reduced jaw movement, making chewing



uncomfortable. Some individuals may experience temporomandibular joint (TMJ) discomfort or fatigue while eating.

Blood vessel changes associated with scleroderma can reduce blood flow to the tissues of the mouth, which may slow healing after dental procedures or mouth injuries. In some cases, people may develop painful mouth ulcers or areas of irritation that require medical or dental evaluation.

Acid reflux (gastroesophageal reflux disease or GERD), which is common in scleroderma, can also affect oral health. Stomach acid that reaches the mouth may gradually wear away tooth enamel, increasing the risk of tooth sensitivity, cavities, and dental erosion.



Doctors and dentists evaluate oral involvement through a comprehensive examination.

This may include assessing mouth opening, examining the teeth and gums, checking saliva production, reviewing symptoms such as dry mouth or jaw pain, and obtaining dental X-rays when necessary.

Regular dental visits are especially important because some oral problems may develop gradually without causing significant symptoms at first.

Although there is currently no cure for scleroderma, proper management can help reduce oral complications.

Treatment may include maintaining excellent oral hygiene, using fluoride toothpaste, staying well hydrated, using saliva substitutes or medications to stimulate saliva production when appropriate, performing mouth-stretching exercises to help maintain jaw mobility, treating GERD, and receiving regular dental cleanings and examinations.

Dentists may also recommend specialized toothbrushes or other tools to make oral care easier for people with limited mouth opening.

Living with mouth involvement can affect nutrition, communication, confidence, and overall well-being.

Therefore, early recognition of symptoms, consistent oral hygiene, regular dental care, and ongoing management with a rheumatologist and dentist familiar with scleroderma can help preserve oral health and improve quality of life for people living with scleroderma.

The above information has been sourced from a Facebook post created by [Scleroderma International](https://www.facebook.com/sclerodermainternational/).

As I've shared previously I have had the privilege of working with them over the past couple of years sharing aspects of my own story.

Scleroderma International was created with a simple purpose:

- to help spread awareness,
- to share stories,
- and bring people together through understanding and support.

I hope that you have found the above information not only informative, but also helpful in understanding aspects of this disease.

Blessings 'til next time



Life Hacks:

Boehringer Ingelheim - Life Hacks living with Scleroderma...



If you have scleroderma, daily life can be challenging, both practically and mentally. We can help you with a few easy life hacks helping you get on top of the cold, the cooking, childcare, holiday preparation and your mental health.

<https://patient.boehringer-ingelheim.com/more-than-scleroderma/>

Cold hacks

The cold weather can be challenging if you have scleroderma. But watch Annelise explain some tips that can make your day easier, including a hand warming trick using rice, a sock and a microwave.



Watch now

Kitchen hacks

Scleroderma can mean a few challenges in the kitchen.... Edith gives us a few handy tips that help her, including how to use hair rollers to help grip cutlery.



Watch now

Mental health hacks

Nathan is a counsellor, working in partnership with people living with chronic disease. He explains how to express any difficult feelings you have and ways to help yourself out of a low mood.



Watch now

Holiday hacks

Preparing for a big family gathering can be tiring. Watch to see how Joyce does it, saving precious energy and overcoming dexterity issues to wrap beautiful gifts.



Watch now

Childcare hacks

Looking after a family can be even more of a challenge with Scleroderma, but Natalie shows how a little creative thinking can help with everything from changing diapers to getting the kids out of the door with less fuss.



Watch now



Events Happening:

INFORMATION WANTED:

Does anyone know of any Rheumatologists in the Whangarei area who specialise in Scleroderma. We have a new member needing some help. If you live near there and wish to get in touch with her, please contact me and I will put you in touch with each other. Thanks Jenny 0273166124

Situations Vacant

NEWSLETTER EDITOR WANTED:

After 8 wonderful years of editing the newsletter, we think it is time to hand over the reins. We have truly loved working on it, but we are ready to see someone else put their own creative spin on the project! If you are interested in taking over the editing role, we would love to chat with you.

Jenny 027 3166 124; Tina 021 040 7598

Our next Scleroderma Zoom meeting:

Dear Members,

All welcome to the next online Scleroderma NZ support group meeting on the **5th December**
Time TBC

A great opportunity to have a great catch up with our Scleroderma friends.

The link for this will be put up on the Facebook page or feel free to contact Perry at perry.pacpe@gmail.com
Look forward to seeing you then.

Perry Bray



JOKES:

What do dentists call their X-rays?
Tooth pics!

Why did the melon jump into the lake?
It wanted to be a watermelon.

Why was 6 afraid of 7? Because 7 ate 9!

Grandma: Back in our days, you could buy bread, milk, soaps, spices, eggs, meat, all for a dollar.

Little Kid: You can't do that now. They have CCTVs everywhere!

When your teacher asks "Where's your homework?" It took a sick day. It had too many problems.

You can't trust atoms. They make up everything!

Why won't it hurt if you hit your friend with a 2-liter of soda? Because it's a soft drink!

Why did the mushrooms get invited to all the best parties? He was a fun-gi!

What has four wheels and flies? Garbage truck.



I got fired from my job at the bank today. An old lady came in and asked me to check her balance, so I pushed her over.

What do you call an elephant that doesn't matter? An irrelephant.

Dad, can you put my shoes on? No, I don't think they'll fit me.



Scleroderma New Zealand Survey Results

Scleroderma Health Care Survey 2026

In May 2026 Scleroderma New Zealand surveyed its members about access to health services. This survey looked at what was working well and access to health providers through the public or private health sector.

This survey repeated some questions from a similar survey of Scleroderma NZ members in 2018.

The survey was completed online. A link to the survey was emailed to Scleroderma NZ members and placed on the Scleroderma NZ Facebook pages. At the end of May people were reminded about the survey.

There were 99 New Zealand resident responders. 89% were members of Scleroderma NZ, a 33% response rate among Scleroderma NZ members. Most, 93%, were female. They were aged between 30 and 85 years old, mean 64, with half of the responders aged between 55 and 74 (the interquartile range – ages with 25% younger than 55 years old and 25% older than 74 years old).

There were people from across New Zealand.

Northland	4	4%
Auckland	17	17%
Waikato	15	15%
Bay of Plenty	9	9%
Hawke's Bay	6	6%
Taranaki	6	6%
Manawatu/Whanganui	8	8%
Wairarapa	1	1%
Wellington	18	18%
Nelson-Marlborough	1	1%
Canterbury	6	6%
Southern	8	8%

Most responders were European.

Māori	5	5%
Pacific	1	1%
Asian	4	4%
European	88	89%
Other	1	1%

People had been diagnosed with scleroderma ranging from recently, to more than 40 years ago. The median duration was 10 years, with 50% (the interquartile range) between 5 and 20 years.

The time between when people first saw a doctor for their symptoms of scleroderma and their scleroderma diagnosis ranged from immediately to 30 years. The median duration was six months, with 50% (the interquartile range) between three months and two years, with 10% diagnosed immediately. One person was diagnosed within a short time as they asked for blood tests to determine whether they had primary or secondary Raynaud's. Someone else commented that it took four years and they were going back to the doctor all the time about their pain and joints before the doctor did anything about it.

Most, 96%, see a rheumatologist and 3% see an immunologist. 2% saw both a rheumatologist and an immunologist. 3% do not see either a rheumatologist or an immunologist. They do not live in regions with a tertiary hospital. Of those who see a rheumatologist, 89% only saw them in the public health service, 5% only privately and 5% in both the public health service and privately. Of the three who see and immunologist one does so in the public health service and two privately. 16% see their rheumatologist or immunologist 3 monthly, 26% 6 monthly, 48% yearly, 6% 2 yearly and 4% less than 2 yearly.

94% have had a lung function test. Of those, 2% have one 3 monthly, 9% have one 6 monthly, 47% yearly, 25% 2 yearly and 17% less often. 95% have their lung function test through the public health service and 6% privately (two people have both).

47% have had a six-minute walk test. Of those, 2% have one 3 monthly, 11% 6 monthly, 29% yearly, 18% 2 yearly and 40% less often. 91% have their six-minute walk test through the public health service and 11% privately (two people have both). 88% have had an echocardiogram (an ultrasound scan of heart). Of those, 3% have one 6 monthly, 45% yearly, 22% 2 yearly and 29% less often. 89% have their echocardiogram through the public



Blood test monitoring	Percent having blood test
Kidney function	66%
Liver function	63%
ANA panel	29%
Thyroid	29%
Inflammatory markers (CRP)	44%
Vitamin D	20%
Sugar levels	21%
Cholesterol levels	29%
Full blood count	63%

health service and 12% privately (three people have both).

49% monitor their blood pressure at home. Of those, 14% daily, 39% weekly, 22% monthly, 14% 3 monthly and 10% less often.

For 58% their rheumatologist / immunologist checked their blood pressure. and for 46% their rheumatologist / immunologist nurse checked their blood pressure. For 76% their rheumatologist / immunologist or their nurse checked their blood pressure. A GP or medical centre nurse check their blood pressure for 78%. 4% were checked monthly, 35% 3 monthly and 61% less often. 9% of people did not have their blood pressure checked by these. Two of these nine people monitored their blood pressure at home, leaving seven who did not have their blood pressure monitored.

36% see their GP for Scleroderma health related checks. Among those 36% see them 1–3 monthly, 5% 3–6 monthly, 15% 6–12 monthly and 3% less often.

Most people have regular blood tests from their GP, rheumatologist or immunologist to monitor their health.

People have regular blood tests from their GP to monitor their kidney function (66%), liver function (63%), ANA Panel (29%), thyroid (29%), inflammatory markers (CRP)

(44%), vitamin D (20%), sugar levels (21%), cholesterol levels (29%) and full blood count (63%). 6% did not have any of the above tests. 16% were unsure what test they had and a further 9% had one or more of the above tests and were unsure what else.

8% are on care-plus (funding provided to general practices to improve chronic care management, 3 monthly GP visits at reduced fee), 2% just for scleroderma, 3% just for another chronic health condition and 3% for both scleroderma and another chronic health condition.

61% have straightforward access to medical professionals and the care they need in the public health system.

8% knew about the Access and Choice programme (publicly funded mental wellbeing support services, provided by some GP services and other providers in New Zealand). They all used the Access and Choice programme. None received their services related to Scleroderma.

	Accessed	Public only	Public and private	Private only
Ophthalmology (eye clinic)	27%	12%	4%	11%
Gastroenterology	51%	33%	7%	10%
Cardiology	59%	44%	9%	5%
Respiratory Clinic	63%	54%	6%	3%
Orthopaedic Clinic	14%	6%	3%	5%
Renal Clinic	5%	4%	1%	0%
Physiotherapy	30%	16%	4%	10%
Hand Therapy	31%	22%	3%	6%
Podiatry	22%	6%	2%	14%
Dietician	21%	16%	1%	4%
Dentistry	25%	6%	0%	19%
Neurology	5%	2%	0%	3%
Dermatology	19%	11%	1%	7%
ENT (Ear Nose and Throat)	13%	7%	1%	5%
Exercise programme	9%	6%	0%	3%
Home help	8%	4%	1%	3%
Mobility parking permit	30%	30%	-	-



	Currently	Previously	Not had
Cyclophosphamide	0%	20%	80%
Mycophenolate mofetil (CellCept)	40%	9%	46% (51%*)
Nintedanib	0%	0%	89% (100%*)
Pirfenidone	0%	0%	91% (100%*)
Rituximab	3%	6%	83% (91%*)
Tocilizumab	3%	0%	89% (97%*)
Any of the above	46%	11%†	34% (43%*)

* including not answered as not had.

† not including those currently on treatment.

Health services accessed for Scleroderma related diagnosis through the public or private health system

35% have been told that they have Lung Fibrosis (Interstitial Lung disease, ILD). They had the following treatments.

Of the 17 who had mycophenolate for 3 months or more, 15 said they receive benefit from it. One of them experienced intolerable side effects. The two who said they did not receive benefit from it experienced intolerable side effects. One other person did not have mycophenolate because it might be harmful for them.

Fourteen, 14%, reported having lung deterioration without a diagnosis of ILD. Four people said they might have lung fibrosis and four said their deterioration was due to another cause.

20% have ulcers on their fingers (but not their toes), 3% have ulcers on the fingers and toes and 1% have ulcers only on their toes. Of the 24 people with ulcers, 8 were treated with sildenafil (1 also with nifedipine, 1 also with rectogesic, to treat fissures, and 1 also with an antibiotic and CBD balm, a herbal cream), 1 other was treated with nifedipine and Iloprost, 2 were treated with antibiotics, 2 were treated surgically, and 1 with an anaesthetic. Seven were not on treatment and three did not say what treatment they were on.

7% have lost fingers and 1% their toes. Most losing one finger, with one losing two and one losing three. The person who lost their toes is a double amputee.

People were asked if they had any concerns or helpful information they would like to share about

their scleroderma care. About half, 49 people, responded with comments.

A common concern was that people thought there were not enough health care services available. Concern was expressed about staffing workloads 'our health care system is so under resourced they can't give us the treatment and care we need', 'long delay between rheumatology appointments' and 'I waited nearly a year to see a dermatologist'. Some areas of New Zealand like Northland, Taranaki and Palmerston North have poor access for patients to see a rheumatologist and the patients had to travel to other centres. Tauranga is without a rheumatology nurse, 'They were the go between and would pass a concern on to the rheumatologist. No way to contact now'. Concern was expressed about a lack funds for podiatry, dentistry and opticians. One person has 'been wondering if it would be worth going to a scleroderma clinic in Australia'.

Serval expressed concern that they felt there was a lack of knowledge about scleroderma among their health professionals and others. 'Too little is known by too few'. 'There is a lack of knowledge from health services regarding Scleroderma'. A GP said 'I don't look like I Have Scleroderma'. 'My GP doesn't seem engaged or interested'. 'It's an unknown disease and wish more people would understand the silent pain we go through'. One implying that more research is needed 'Still not enough understood on treating Scleroderma'.

People also felt they need to know more about scleroderma and its care. 'I don't know what's available and how to access it'. 'It's the unknown that gets to me, like am I going to grow old with my family I know it's life limiting but how limiting?'. 'Not sure how serious scleroderma is or should be treated by medical professionals'. 'Not informed of care-plus program'. 'No information given on support group or help available from the rheumatologists'. 'I'm still working through everything and quite confused and to be honest scared'.

People expressed concern about delays and long wait times. 'Health system issues: - Very slow, long waiting times'. 'there was a delay of 21 days before the prescription reached my chemist'.



Some felt there was a lack of coordination. 'No real co-ordinator between rheumatologist and other specialists'. 'I feel there is no coordinated care'.

A few had private health care, one saying 'I seem to have to pay to get any treatments privately'.

Some expressed appreciation for the health professionals. 'The docs I see are great'. 'most doctors and very kind but not that knowledgeable about treatment', 'While the local rheumatology team are fantastic, our health care system is so under resourced they can't give us the treatment and care we need'.

A few express appreciation for the support that Scleroderma New Zealand provides. 'I am glad there is a scleroderma NZ because sometimes you feel isolated as people around you don't really understand the extent of this chronic condition'. 'I do like the newsletter you put out'. 'I am only starting hand therapy next week as I went to Te Awamutu for a Scleroderma seminar last year and they said to get referred sooner rather than later'.

Comparison with 2018

There were similar responses to most comparable questions in 2018. The response rate among Scleroderma NZ members was similar in both surveys, 30% in 2018 and 33% in 2026. A higher proportion of 2026 responders are members of Scleroderma NZ (89% in 2026 and 71% in 2018). Responders were, on average, four and a half years older in 2026 than 2018.

More people saw either a rheumatologist or an immunologist in the 2026 survey (97%) than the 2018 survey (88%). With more seeing a rheumatologist in 2026, 96%, than in 2018, 76%. They were being seen by a rheumatologist or an immunologist more frequently in 2026.

People who monitored their blood pressure at home were doing so more frequently in 2026. In 2018 more people reported that their GP monitored their blood pressure (92%) than said in 2026 that their GP or medical centre nurse checked their blood pressure (78%).

Fewer people see their GP in 2026 for scleroderma health related checks (36%) than in 2018 (75%). Fewer people are you on care-plus in 2026 (5%) than in 2018 (26%).

Summary

Most people receive their specialist health care through the public system.

Responders to the surveys reported and increase in access to rheumatologists. However, many responders said they needed more and better access to rheumatologists.

There were lower proportions reporting GP care for scleroderma in 2026.

In 2026 half have had a six-minute walk test. This is still a low proportion, although higher than in 2018 when a third had had a six-minute walk test.

Seven percent of responders did not have their blood pressure monitored.

About a third of responders, 36%, said they did not have straightforward access to medical professionals and the care they need in the public health system.

There was an amputation rate of 8%.

Conclusion

There is a need for more rheumatologists and increased funding and scope of the public health service.

People were concerned about the level of care they received and the knowledge about scleroderma, among health professionals, themselves and generally.



Scleroderma New Zealand Inc Conference

Scleroderma New Zealand Incorporated Conference 2027

You are invited to attend the 2027 Conference hosted by Wellington...



Everyone is warmly invited to the

Scleroderma NZ Conference

17 April 2027
James Coe Centre, Dowse Art Museum
Lower Hutt

Topics include:
Dental, Gastroenterology, Rheumatology, Cardiac,
Podiatry, Hand Therapy and Emotional Fitness.

\$30-00 for the day
All Food included at the conference.
Evening meal at the Angus Hotel
(pay your own.).

Go to: **scleroderma.org.nz**
for details and registration.



Scleroderma New Zealand Inc Conference

Scleroderma New Zealand Incorporated Conference 2027

A Warm Invitation to the 2027 Scleroderma Inc Conference

Held at the James Coe Centre, Dowse Art Museum

45 Laings Road Lower Hutt

April Saturday 17th 2027

We will have a good line up of medical specialists and allied health professionals in the areas of Rheumatology, Gastroenterology, Cardiology, Dental, Podiatry, Hand therapy and Emotional Fitness

There will be an opportunity to email Dianne Purdie with any questions you would like answered by any specialist prior to the conference.

Your name will be kept confidential.

Conference Day Proceedings

Registration 8.20am

Main Conference from 8.50am to 4.30 pm

Evening meal at the Carnmore Hotel 6.30pm Registration \$30.00 pp

Registration Covers lunch and morning and afternoon teas

We want to make you feel as comfortable as possible, so please let Dianne know your dietary requirements on the registration form, i.e. soft foods, GF , Dairy free and Allergies etc.

An Electronic Registration form is attached or post to
Dianne Purdie 19 Thatcher Cres Crofton Downs Wellington 6035.

Evening meal on Saturday night.

Everyone is warmly invited to an Evening meal on Saturday night at the Carnmore Hotel Restaurant (previously called the Angus.)

Mains range from \$25 to \$45 currently you can view the menu on line, but if we have enough people we can arrange a menu.

<https://theangusrestaurantandbar.co.nz/menu/our-menu>

James Coe Centre at the Dowse

The Dowse Art Museum is centrally located in Lower Hutt, we have three Hotels within walking distance, from 5 mins to 10 minutes.

Important dates to note

Conference Date Saturday April 17 2027 at the James Coe Centre, Dowse Art Museum Lower Hutt

Registrations Now Open

Registrations Close 9th of April 2027

Any questions, please email or Phone Dianne on 04 4795548

Please fill out the Registration form.



Scleroderma New Zealand Inc Conference

Accommodation

Group Booking for accommodation.

We have access to a group booking with a 10% discount at the **Carnmore Hotel, (previously known as the Angus Hotel)**

You will need to use this particular link when you book at the Carnmore Hotel to receive your 10% discount.

<https://www.swiftbook.io/inst/#home?propertyId=902NTM73JtWKa9lonhMMALTBKp pdhwKkLDisRvRIbkTydyZsZGQ4NjM=&JDRN=Y&fixp=MTE3NDBARVZFTIQxMA=&checkIn=2027-04-01>

We will be having the Saturday night conference dinner held at the Carnmore Hotel Restaurant called the Angus.

*Our lovely Wellington Members will be happy to pick anyone up from the Carnmore Hotel and drop them back after the conference.
If anyone would like a lift on Saturday morning to the Dowse, just notify us on the **registration form** or call **Dianne Purdie 021 165 7559***

Carnmore Hotel

5 Cornwall Street Lower Hutt

Phone: 04 560 1100 reception@theangus.co.nz

<https://theangus.co.nz/hotel-rooms>

Rooms \$144 to \$189 with 10% discount

10 Minute walk to Dowse Art Museum

Riddiford Hotel

21 Knights Road, Lower Hutt, 5010, Lower Hutt

<https://riddiford-hotel.northislandnz.net/> Ph +64 4586 6318

Rooms Single room \$150-00

Double room \$150 to \$180

4 minute Walk to Dowse Art Museum

The Sebel

15 Queens Drive, Hutt Central, Lower Hutt 5010

Phone: +64 4 568 7547 Email: info@thesebelwellington.co.nz

<https://www.thesebel.com/new-zealand/sebel-wellington-lower-hutt/accommodation>

Rooms Single \$359 to 523.926- 7 min walk to Dowse Art Museum



Scleroderma New Zealand Inc Conference

Transport from Wellington Airport by Bus

If you are flying into Wellington, there is an Airport Bus which takes you to Central Lower Hutt to Bunny Street outside the Westfield Shopping centre. The Angus Inn Hotel is a good 10 minute walk from the bus stop. The bus ride costs \$19-00 per person each way (details below)

Wellington Airport (WLG) to Lower Hutt

Buses run hourly between Wellington Airport (WLG) and Lower Hutt final stop at Queens Gate Bunny Street. The earliest departure is at 6:52 am, and the last departure from Wellington Airport (WLG) is at 10:25 pm which arrives into Lower Hutt at 12:06 AM. All services require a transfer, and take on average 1h 10m.

Fare:- \$19-00 each way

<https://www.rome2rio.com/Bus/Wellington-Airport-WLG/Lower-Hutt>

Street parking at the Dowse Art Museum

The Dowse is on the corner of Laings Rd and Myrtle Street.

The best value parking is \$12-00 for the day, which is seen in the yellow zones which are pointed out with red and white arrows as seen in the map below.

This map also shows the Angus Hotel and the Riddiford Hotel in relation to the Dowse Museum. The Westfield bus stop is also identified.

Street Map



Scleroderma New Zealand Inc Conference

Speakers Biographies

Professor Rebecca Grainger



Professor Rebecca Grainger is a rheumatologist, educator and health systems researcher whose work focuses on improving outcomes for people living with arthritis and other immune-mediated diseases. She is Head of the Department of Medicine at the University of Otago, Wellington, and a consultant rheumatologist in the Wellington region.

Rebecca leads research spanning inflammatory arthritis, gout and systemic autoimmune disease, with a particular focus on digital health, models of care, patient-reported outcomes, and health service innovation. Her research aims to translate evidence into practical solutions that improve access, quality and equity of care for people with chronic conditions.

A recognised leader in medical education, Rebecca has extensive experience in curriculum design, assessment and health professions education research. She works closely with clinicians, patients, policy makers and community organisations to ensure that research delivers meaningful benefits for people, whānau and health systems.

Associate Professor Stephen Inns



Stephen is a gastroenterologist and general physician who is dedicated to providing high quality, modern, gastroenterological services to the Hutt Valley. He works at both Hutt Valley and The Rutherford Clinic. He offers a friendly, patient centred and evidence based approach to the full range of gastroenterological conditions.

Stephen's doctoral thesis work was regarding dietary interventions in inflammatory bowel disease and irritable bowel syndrome. He has completed a 3 year fellowship in luminal gastroenterology and endoscopy at University College Hospital, London.

Dr Andrew Aitken



Andrew studied medicine at University of Otago, qualifying in 1987. He was a junior doctor in Wellington region and pursued cardiology, achieving FRACP in 1998. Post fellowship training in Edinburgh. Andrew returned to New Zealand in 2000, and has been a full time cardiologist in the Wellington region since then.

In addition to being an Interventional Cardiologist, Andrew has a specific interest in the care of children and young adults with congenital heart disease. Andrew also has expertise in the management of pulmonary hypertension and the oversight of cardiology conditions for women during pregnancy.

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Andrew also has expertise in the management of pulmonary hypertension and the oversight of cardiology conditions for women during pregnancy.



Scleroderma New Zealand Inc Conference

Amanda Johnson



Amanda has been practicing as a physiotherapist since 1998 and specialising in hand therapy since 2000. During her initial years of practice, Amanda worked in the public system mostly treating neurological conditions, such as stroke and spinal cord injuries.

Amanda has the following qualifications and memberships:

- Bachelor of Physiotherapy (1997)
- Post-Graduate Diploma in Health Sciences – endorsed in Musculoskeletal Management (2002)
- Member of Hand Therapy New Zealand (Registered Member in 2004)
- Member of Physiotherapy New Zealand

Adrienne Walton – Jones



Adrienne has an Occupational Therapy background, graduating from Otago in 1993. Adrienne worked at Wellington Hospital on the New Graduate Rotation before heading to Hutt Hospital in 1995 to take up a Role as the Occupational Therapist and Hand Therapist for the Burns and Adrienne has the following qualifications and memberships:

- Bachelor of Occupational Therapy – Otago 1993
- Member of Hand Therapy New Zealand (Registered Member since 2001)
- Member of Occupational Therapy NZ – Whakaora
- Ngangahau Aotearoa Registered
- Member of the Occupational Therapy Board

Jenny Cousins BHSc (Podiatry)



Jenny was born and raised in the Hutt Valley. She became a podiatrist after seeking treatment for a minor foot complaint herself and was introduced to the world of podiatry. She has been the Petone Foot Clinic owner for the past 18 years.

Particular areas of expertise include orthotic prescription and minor surgeries on ingrown toenails and verrucae. You'll feel at ease during your consultation discussing your lifestyle, occupation, limitations, goals and footwear needs. She works with her patients to develop treatment plans providing a variety of options.

Outside of work you'll find Jenny walking in the hills of the Hutt Valley and further afield.



Scleroderma New Zealand Inc Conference



**Scleroderma NZ
National Conference
17 April 2027
James Coe Centre
Dowse Art Museum
Lower Hutt.**

Programme

8:20am Registration

8:50am Welcome

9:00am - 9:30am Scleroderma/ Sjögren's and the Mouth (Dentist and Hygienist)
Speaker TBC

9.30 - 10:15am Scleroderma and the Gastrointestinal Tract Dr Stephen Inns

10:15am - 10:35am Morning Tea

10:35am - 11:35am Scleroderma 101 Professor Rebecca Grainger

11:35am - 12:20am Scleroderma and PAH Dr Andrew Aitken

12:20 - 1:20pm Lunch

1:25 - 2:15pm Hand Therapy Amanda Johnson and Adrienne Walton Jones

2:15 - 3:00pm Podiatry Jenny Cousins

3:00 - 3:30pm Afternoon Tea

3:30 - 4:15pm Emotional Fitness Tory Garnham and Jo Miller Arthritis NZ

4:20 - 4:35pm Raffle draw

4:45pm Finish

Free time

6:30pm Meet at the Angus Restaurant at the Carnmore Hotel for the Evening Meal



Members Update:

Podiatrists and Fingernail cutting

Please see below a list of Podiatrists who also work with our finger nails.

Jessica Dobbs Podiatry, Hamilton

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

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

2 Endeavour Avenue, Flagstaff, Hamilton 3210.

Mobile: **0274 242 442**

Dr Althea Page-Carruth, Central Otago

Dr Carruth does this only as part of general foot care.

To get in touch with her, her contact details are:

Mobile: **020 41785262**

Clinics are in Cromwell and Alexandra

Elaine Yelland, Kapiti Coast

Podiatrist & Business Owner

Foot Focus Podiatry Ltd, Kapiti Coast

Mobile: **021 578 601**

Saf Kear, Tauranga

Write: hello@thegoodpodiatrist.co.nz

Phone: **(07) 219 7811**, Mobile: **021 121 0435**

Simon Speight, Auckland

www.speightspodiatry.co.nz

<https://www.facebook.com/Speights-Podiatry>

<https://www.instagram.com/speightspodiatry>

2nd floor, 43 High Street, Auckland Central

Phone: **(09) 306 4006**, Mobile: **021-535511**

Catie Rowe Podiatry, Timaru

17 Dee St, Seaview, Timaru

Phone: **(03) 683-1448**, Mobile: **027 6882036**



Give a little: Scleroderma NZ Inc.

From Scleroderma New Zealand Incorporated - Givealittle



Scleroderma New Zealand Incorporated

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

An example of what our give a little website page looks like 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-O63nj0FrySOCpV44mBCpIPHtXV7Uff9KIAAnAzM>

And can also be shown like this (the URL address within):

[Scleroderma New Zealand Incorporated - Givealittle](https://givealittle.co.nz/org/sclerodermanz1?fbclid=IwAR29Znk701JSOWf9n0Ew-O63nj0FrySOCpV44mBCpIPHtXV7Uff9KIAAnAzM)

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

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



Members News



Wanaka Scleroderma Group

A beautiful time of year for Wanaka, snow-capped mountains and daffodils flowering - spring is here! Only a small group of three met for coffee catchup last month. Everyone is doing pretty well, interestingly we agreed this winter has been relatively kind from a Raynaud's perspective yay!



Southland Scleroderma Group

Thank you so much, Jenny, for organising a different lunch for us in Invercargill on Sunday, 16 August. Jenny invited CanBead, a New Zealand non-profit charity that offers free creative workshops for people experiencing illness.

We enjoyed delicious pumpkin soup, yummy sandwiches, and beautiful bite-sized sweet treats.

Then it was time for beading.

Several of us were unable to do the beading ourselves, but we enjoyed chatting and admiring the work of the other attendees.

The photos capture the afternoon perfectly.

A heartfelt thank you to the CanBead Southland group for generously sharing such a delightful afternoon with us. They have also posted about the event on Facebook.

<https://www.facebook.com/share/p/1GDc6vNcW3/>

Something completely different: from the building, we could see the Otepuni Beach Tennis Club in "downtown Invercargill"! We had heard it was there, but it looked so surprisingly tropical for Invercargill in midwinter!

Heather Milligan



Members News continued



Hawkes Bay Scleroderma Group

Our last two meetings have gone well with an average of six people each time. We have had three new members over the last four months. Our meetings are full of chatter and laughter. Regards, Frances



New Plymouth Scleroderma Group

If you would like to attend the New Plymouth Support Group please get in contact with

Kelsi Tidswell: kelsitidswell@gmail.com

This photo was taken at our last meeting. Sadly one of our new members died unexpectedly recently, Shirley McGlinchey. Our thoughts and love go out to Shirley's Family.



From left to right in the photo is Kelsi, Shirley, Janice, Barbara, Sarah, Wendy, and Judy.



Palmerston North Scleroderma Group

If you would like to join in with the Palmerston North group please get in contact with:

Anne Allan: anneallan95@gmail.com



Otago Scleroderma Group

If you would like to join in with the Otago group please contact Gaynor: gaymeddings@gmail.com



Bay of Plenty Scleroderma Group

We didn't meet up during the Winter but will be meeting again in October. See Group Meeting Dates page.

If you would like to join the Bay of Plenty group get in touch with Alumie Nguyen: alumie.uow@gmail.com



Christchurch Scleroderma Group

On Saturday 18 July the Christchurch Scleroderma Support Group met at Koji Japanese Buffet Restaurant in Addington for a mid-winter meal. It was awesome to have some of the partners attend and for all of us to catch up on a unseasonably warmer day, as the previous week was certainly cold and wet.

Many interesting conversations were had, and it allowed the partners to gain a broader understanding of some of the wide-ranging symptoms that we experience and the different treatment regimes that those of us with Scleroderma go through.

The food wasn't half bad either – if you are ever in Christchurch, it is certainly a place to check out for lunch or dinner 😊

If you would like to attend the Christchurch Support Group please get in contact with **Perry Bray:**





Waipa and Waikato Scleroderma Group

In August we met in Tamahere Cafe. Lots of lively chatter. Lots of discussion about current medication, symptoms and Winter bugs. So good to see how folks are managing, keeping positive looking forward to seminar in 2027.

If you would like to join in with the group please get in touch with Erena. Please contact Erena Bruce bruceerena@gmail.com



Scleroderma Zoom Meeting

Perry organises these at different times throughout the year. The next date at this stage December 5th. The Meeting details will be confirmed closer to the time via our Facebook page.



Northland/Auckland Scleroderma Group

This group is to make it easier for the Northern Folks to join in with our group. It is a very warm, friendly, and informative catchup.

Helen Parsons

helenparsons@artcardsandposters.co.nz

021 248 3869

We are easy to find with our sunflowers and badge.



Auckland Scleroderma Group

We're a friendly supportive group. Utterly casual. And we hope that people from wider Auckland can join us. But also, we're always available for a FB chat, or emails, or phone calls.

Helen Parsons

helenparsons@artcardsandposters.co.nz

021 248 3869



From left
Liz George, Colleen Scoble, Kate Bailey, Rob George, Cheryl Madsen, Roger Parsons



From left:-
Tony & Daphne Hiett, Rose McKinnon, Helen Parsons, Cheryl Madsen, Lisa Cato.



Roger Parsons, Rose McKinnon



Members News continued.



Wellington / Kapiti and Wairarapa Scleroderma Group

The Wellington / Kapiti and Wairarapa support group met at Water Front Bar and Kitchen at Raumati Beach, Kapiti Coast on the-Saturday 18th July for our mid-winter lunch. It was a beautiful sunny day and the weather was very warm for mid-winter.

We had a large turn out and got to meet with some of our members whom we hadn't seen in a while. We all had a good time chatting and catching up with each other and had a lovely lunch.

Our next group lunch will be on **Saturday 19th Sept: -**

Place: **The James Coe, Room 2**

Dowse Art Centre, 45 Laings Road, Lower Hutt

Time: **12.30pm – 3.30pm**



If you would like to join in with our group, get in touch with:

Dianne Purdie: diannepurdie@xtra.co.nz

Cushla Marsters: cushlam@outlook.com

Tina McLean: tinaoaisamclean@outlook.com



Kapiti Island – Kapiti Coast.

JOKES

Why do you smear peanut butter on the road? To go with the traffic jam.

Where did Napoleon keep his armies? In his sleeves.

Did you hear about the actor who fell through the floorboards? He was just going through a stage.

What kind of music do the mummies listen to? Wrap music.

The broom was late today because it overswept last night!

What happens if a seagull flies over the bay? It will become a bagel (Bay-gull)!

What caused the bicycle to collapse? Because it was two tired.

What does a sea monster snack on? Fish and ships.

What music do planets like to listen to? Neptunes.

What lights up a stadium? A match.

How do you think the barber won the race? He took a shortcut.

Two monkeys share an Amazon account. What do you call them? Prime mates!

Why do they not play poker in the jungle? There are too many cheetahs.

Which tea is hard to swallow? Reality.

What is the easiest way to burn 1000 calories? Leave the pizza in the oven.

The ball kept getting bigger and bigger. I was wondering why, and then it hit me.



Group Meetings Dates 2026: Regional

Wellington/Kapiti/Wairarapa support group meets:

Date and Time:	Venue:
Sat 19 th September @ 12:30pm	James Coe, Dowse Art Centre 45 Laings Road, Lower Hutt
Sat 21 st November @ 12:30pm	The Farm Café & Bar 33 Military Road, Boulcott, Lower Hutt

Manawatu support group:

Date and Time:	Venue:
Wednesday 23 rd September @ 10.30am	Manawatu Golf Club Cafe 19 Centennial Drive, Palmerston North

Christchurch support group meets:

Date and Time:	Venue:
Sat 19 th September @ 2.00pm – 4.00pm	Urban Eatery Barrington Oderings Garden Centre, Chch
Sat 21 st November @ 2.00pm – 4.00pm	Portstone Garden Cafe Ferry Road, Chch

Bay of Plenty support group meets:

The Next 3 Upcoming Meetup Dates (First Saturday Every Two Months): Location and Time to be confirmed depending on who can make it (minimum of 2 to go ahead) so that we can optimise our travelling time.

Date and Time	Venue
Saturday 3 rd October @ 12.30pm	Med Lounge and Garden, The Historic Village

New Plymouth support group:

Date and Time:	Venue:
Thursday 17 th September @ 11.00am	Simply Divine Cafe, Egmont Village New Plymouth

Waikato/Waipaa support group meets:

Date and Time:	Venue:
Saturday 26 th September @ TBC. Contact Erena	TBA Tirau or Cambridge

Hawkes Bay support group meets:

Date and Time:	Venue:
Third Saturday of the month 19 th September @ 11:30am	Serendipity Café 1412 Pakowhai Road, Hastings

Southland support group meets:

Date and Time	Venue
Sunday 22 nd November @ 12:00pm	Croydon Lodge, Gore

Wanaka support group meets:

Date and Time	Venue
Saturday 19 th September @ 10am	Monkey Farm, Northlake, Wanaka

Auckland support group meets:

Date and Time:	Venue:
September	No Meetup-Helen's Overseas
Monday 5 th October @ 10.00am	Daily Bread, Kings Plant Barn 11 Porana Road, Takapuna, Auckland, 0627
Monday 2 nd November @ 10.00am	Daily Bread, Kings Plant Barn 11 Porana Road, Takapuna, Auckland, 0627
Monday 7 th December @ 10.00am	Daily Bread, Kings Plant Barn 11 Porana Road, Takapuna, Auckland, 0627
Monday 11 th January 2027 @ 10.00am	Daily Bread, Kings Plant Barn 11 Porana Road, Takapuna, Auckland, 0627
Monday 8 th February 2027 @ 10.00am	Daily Bread, Kings Plant Barn 11 Porana Road, Takapuna, Auckland, 0627

Northland/Auckland support group meets:

Date and Time:	Venue:
September	No meetup – Helen's Overseas
Wednesday 14 th October @ 10.30am	Columbus Café, 35 Colin Chester Drive, Silverdale, Auckland 0932 (in Mitre 10)
Wednesday 11 th November @ 10.30am	Columbus Café, 35 Colin Chester Drive, Silverdale, Auckland 0932 (in Mitre 10)
Wednesday 9 th December @ 10.30am	Columbus Café, 35 Colin Chester Drive, Silverdale, Auckland 0932 (in Mitre 10)
Wednesday 13 th January 2027 @ 10.30am	Columbus Café, 35 Colin Chester Drive, Silverdale, Auckland 0932 (in Mitre 10)
Wednesday 17 th February 2027 @ 10.30am	Columbus Café, 35 Colin Chester Drive, Silverdale, Auckland 0932 (in Mitre 10)

Online Zoom Meeting with Perry

Date and Time:	Venue:
Saturday 5 th December Time TBC	Online link will come out nearer the time via email

Waimate/Oamaru support group:

We have members meeting up in these areas so if you are interested in joining them please get in touch with

Helene Sunitsch at: hkjsunitsch@gmail.com

Otago support group:

Please contact Gaynor if you wish to join us.
gaymeddings@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

sclerodermanz@gmail.com

Vice President:

Tina McLean

tinaoaisamclean@outlook.com

Secretary:

Jane Sainsbury

jsainsbury@xtra.co.nz

Treasurer:

Gordon Purdie

gordon.purdie@xtra.co.nz

Newsletter:

Tina McLean

tinaoaisamclean@outlook.com

Jenny Andrews

jennyred@xtra.co.nz

Committee Members:

Alumie Nguyen, Cushla Marsters, Dianne Purdie, Erena Bruce, Frances Tod, Heather Milligan, Helen Parsons, Helene Sunitsch, Perry Bray, Rachel Burgoyne, Sandra McAuley and Di Minehan

Contacts:

Find a Scleroderma a Support Group near You:

Auckland/Northland:

Helen Parsons, Email:

helenparsons@artcardsandposters.co.nz

Bay of Plenty:

Alumie Nguyen, Email:

alumie.uow@gmail.com

Waikato / Waipa:

Erena Bruce, Email:

bruceerena@gmail.com

Hawkes Bay:

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Wanaka

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

