

Welcome	1
President's Report	2
Memorial for Neil Gibbs	3
Memorial for Pamela Glozier.....	3
Members Stories –	
Letters to the editor	4
Recent Zoom Meeting.....	5
World Scleroderma Day	8
Jane Sainsbury – Family Walk.....	9
Dianne Purdie – Climbing Aoraki Mount Cook.....	10
If you need help at home	
- Get a Needs Assessment.....	11
Needs Assessment Service Coordination (NASC).....	13
About Disability Allowance:.....	14
Members News	16
Members Update	18
Give a Little to Scleroderma New Zealand Inc.....	20
Scleroderma NZ Inc. – Rewardhub.....	20
Group Meetings:.....	21
Welcome to Scleroderma NZ Inc & Contacts	22

Scleroderma

New Zealand support group

WINTER 2023

Greetings to you all...

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



We hope everyone is well and keeping safe at home.



The months are going by so fast, and now we are already half way through the year and winter is here. I hope everyone is keeping warm and well wrapped up. If you haven't had a flu injection, it's not too late to get your flu jab.

We hear first from Jenny Andrews with the Presidents report. Jenny keeps us up to date with what's going on around New Zealand.



We have a Memorial page for **Neil Gibb** and **Pamela Glozier** from Southland.

We have stories to share from our members and some interesting articles. A section on Getting a needs assessment, another on the Disability Allowance. Plus an awesome display from World Scleroderma Day. Thanks to all those who made it possible.

We have our regular Members News and Updates from our different support groups.

There is a small section about information on our **Give a Little page**, and **Rewards Hubb**.

Then as always we have our Facebook, Website and support Leaders Information at the end.

Be safe and take care everyone.
Warmest regards,

Tina and Jenny



Presidents Report:

Winter 2023



Happy Scleroderma Awareness Month

Welcome to Winter. Brrrr. This is a perfect time to take that holiday to somewhere slightly warmer ☺

Condolences to all those who have lost loved ones in the last few months. Sadly Southland has had a very tough time of it lately with members passing. Please remember to talk to someone if you are feeling that things are getting a bit much for you. It is very tough when we lose our Scleroderma Friends.

Well we had a fantastic AGM recently and have got some interesting things on the go. We have had a couple of changes on the committee so firstly a huge Thank you to both Catherine Thompson and Maureen Anderson for all your years of support on the committee. You have both been very valued members of the team. We wish you both well in your future endeavours.

We welcome two new members on to the committee. Welcome to Helen Parsons of Auckland/Dunedin and Racheal Burgoyne of Waitoa. Thank you for joining us and I'm sure you will bring some fantastic ideas and knowledge to the team. Thanks to everyone else for staying on: Dianne, Gordon, Tina, Jane, Heather, Erena, Linda, Alumie, Frances and Cushla. You are all amazing and Scleroderma New Zealand couldn't run without you all.

We have had quite a bit of feedback from members wanting us to hold seminars again, so we have made the decision to hold annual seminars beginning next year now that life has settled down a little. We will do year about North and South Island. The first one will be held around March/April 2024 in Southland. So that is exciting to have that to look forward to.

We are in the process of designing lapel badges for purchase. We are just finalising the design and price for these. They will be available to all members and support people to purchase. These will be our fundraiser but also about raising awareness.

For World Scleroderma Day we had a couple of places light up for us. Wellington and Invercargill which was fabulous. You will see photos further through the newsletter of these. Thank you to all those who went out to view the lights in support.

This is the most important time for you all to be looking after yourselves and keeping warm. Make sure you have your hat and gloves on when venturing outside and lots of layers on your core. The flu jab is also an important part of caring for yourself.

Thank you to Dianne for your continued work in regards to Podiatrists who are able to also cut finger nails.

I am very happy to be able to share some great news on behalf of one of our Southland members. Check out Page:18 ☺

As always we need members contributions to make our newsletter more interesting to our readers, so please get in touch with either Tina or myself if you have done something that you would like to share in our next edition. This can be anything at all.

For me personally; we have just had my baby's 21st birthday. With 15 extras and 6 family staying on the Saturday night it was a pretty full house. This was a fantastic weekend filled with lots of fun and laughter and a couple of lemonades to top it off.
Jenny ☺



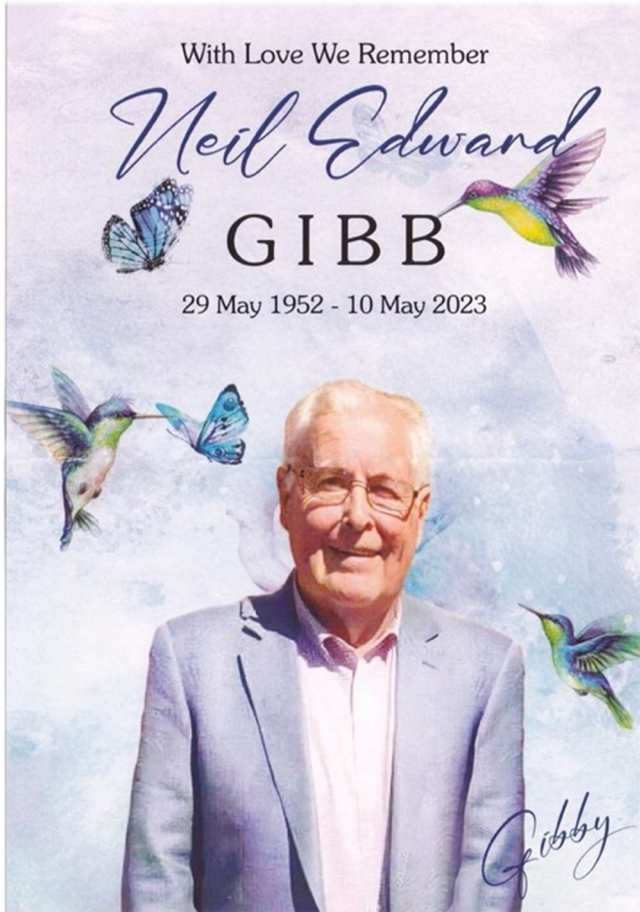
Jeff, me, Quinn the birthday boy, Maddy and Jordan



Memorial

Southland Scleroderma Group Member

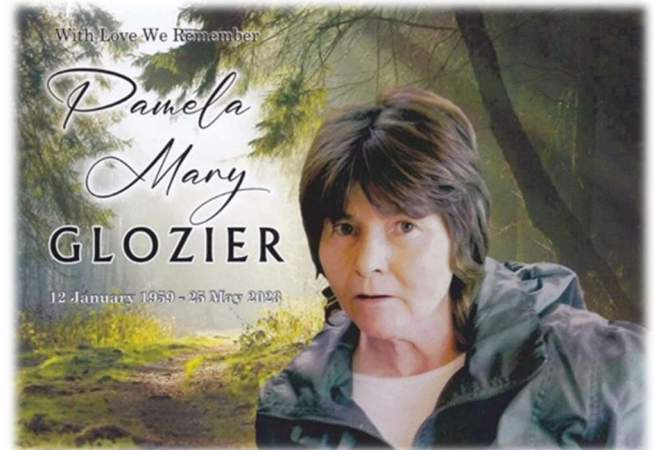
Neil Gibb



On the 10 May 2023 Southland Group lost our long time member Neil Gibb. Neil was one of our original members in the group. He was quite a character and always had that sparkle in his eye. Neil had lost his wife Jeanette just 18 months prior and had been missing her dreadfully. It is nice to know they are now together again. Neil's service was a beautiful celebration of a very funny, kind, intelligent and well-loved family man. Family was very important to Neil and he leaves behind his son, daughter and three Grandchildren. Neil kindly had donations at his funeral go towards Scleroderma New Zealand.

Southland Scleroderma Group Member

Pamela Glozier



On the 25th May 2023 our Southland Group also lost Pam Glozier. Pam had been a member of our group for quite some time, but in the past few years had been unable to make our meetings due to mobility issues. Pam had a beautiful service where her family were able to say their farewells. We heard some very funny stories about how she would call a spade a spade and didn't mince her words. She had the kindest heart though and will have left a hole in many peoples lives. Pam had two beautiful wee dogs who also attended the service who she loved with all her heart. Pam left behind her long-time partner, children and four grandchildren.



Scleroderma Members News:

A letter to the Editors:

Thank you for publishing Richard Jehan's: My journey with Helminthic Therapy article in the March 2023 edition.

I read this with interest and it was great talking to Richard on Dianne Purdie's Zoom meeting in May. He presented as passionate on his positive journey with Helminthic Therapy which has worked well for him.

I have been pondering on his conversation and thinking. Our bodies have been dealing with intestinal worms from the beginning of time.

At this very moment in New Zealand there would be many people with 'intestinal worms of all sorts including human hookworm' that they have inadvertently picked up on their overseas travels. Due to our sanitation systems they would soon be evacuated from their bodies never to return. If they develop problems I am sure that the medical fraternity can help.

If Helminthic Therapy was a New Zealand registered therapy I would be interested in trying. But I do not wish to try it, because with my other maladies I need to be honest with my doctors about my health and 'supplements' I am taking.

All the best to you Richard and thank you for putting your viewpoint to a very interesting subject.

Heather Milligan

I have just had my Yoga session with Dr Nikki Tugnet, (Rheumatologist in Auckland) I had a chat with her about Scleroderma awareness and she is busy raising quite a bit of awareness herself this month.

For this month for scleroderma awareness we have asked her if she is available to talk to us via a webinar and include people from Australia to join us also. It will include some yoga and strengthening exercises and information to help with inflammation. A link for this will be sent out via email to all members.

See her website here <https://yogadrnikki.com/> and facebook https://www.facebook.com/feed_story_share/?story_id=221738943960147

Pain Management

<https://www.youtube.com/watch?v=pMnTch8wjpQ>

From Dianne

Our recent Scleroderma Zoom meeting:

We had a nice relaxed catch up on zoom the 27th of May, we had about 11 members all up which was pretty good, 2 from Invercargill, 2 from Auckland, 2 from Australia 1 from CHCH, 1 from Alexandra and 3 of us from Wellington.

Richard shared some good info on heated gloves and a heated jacket which sounded brilliant, these were as follows:

1. The heated gloves are from **Toasty Touch** - www.toastytouch.com - not bulky - quite fine - more like a fine sock thickness - and 3 heating settings.
2. The heated jackets are at **Placemakers** - jackets are made by **Milwaukee** (yes the same people who make/supply tools) - come in Men's and Ladies sizes and also come as a vest. Again they have three temperature settings.

I mentioned about some online yoga classes I have been doing, I have found this beneficial for building up strength and flexibility after an onslaught of high dose prednisone and a cocktail of other medications.

The yoga teacher is a **Rheumatologist** in Auckland **Dr Nikki Tugnet**, we mostly do our flexibility and strength yoga on or using a chair for support. You can go on the floor if you want too, but I stay in the chair. Then we do Yin Yoga to work on the fascia which is important for Scleroderma arthritis and other autoimmune people.

We also do a guided relaxation which is very good too, which helps with lowering inflammation. The group is tailored to each of us in the session, which is brilliant. I learnt about this through a webinar from Arthritis NZ.

Here is the link to the Arthritis: -

<https://www.youtube.com/watch?v=pMnTch8wjpQ>

We talked about Hook worm therapy (Helminth therapy), Podiatry issues and skin care.

It was interesting to hear about the Australian health system particularly for those who live in the country away from the larger cities.

Cheers Dianne



World Scleroderma Day

29th June 2023

On Thursday last week the 29th of June we celebrate Paul Klee's life. Paul Klee (1879–1940), one of the most influential artists of the 20th century, died at 60 years of age from complications of systemic sclerosis (scleroderma).

Here is a very good article about Paul Klee
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2813781/>

Art does not reproduce what we see; rather, it makes us see. A drawing is simply a line going for a walk. A line is a dot that went for a walk (A famous quote from Paul Klee)



What is World Scleroderma Day ?

The first European Scleroderma Day on the 29th June 2009 was celebrated in almost all of FESCA's member countries as it was decided by the FESCA at a meeting in 2008.

Having a disease that nobody has heard of is a lonely business. When even the doctors cannot recognize it, or tell you what is going to happen, it is lonelier still. So Scleroderma Awareness Day was created to tell people, including the medical community, what it means to have this disabling disease. June 29 is a day to recognize the bravery of those who live with scleroderma, and to demand equal treatment and equal care for people with scleroderma across Europe and the rest of the world.

History of World Scleroderma Day

In February 2010 the 1st **SYSTEMIC SCLEROSIS WORLD CONGRESS** was held in Florence, Italy, with participants from countries from all over the world. At the world congress it was agreed that June 29th would be celebrated all over the world. Scleroderma day grew from zero to world scleroderma day in 2 years, and is celebrated in countries in Europe, Australia, Canada, Brazil, India, New Zealand and many more countries.

Why 29 June?

The gifted Swiss artist Paul Klee made painting his life's work, but it was strongly influenced by his illness, systemic scleroderma, as the painting chosen for Scleroderma Day demonstrates. He died June 29, 1940.

The Swiss Paul Klee Zentrum in Bern boasts the world's most important collection of paintings, watercolours and drawings as well as archives and biographical material from all the creative periods of Paul Klee's life which also can be visited through their website: www.zpk.org



World Scleroderma Day, a very special day in June being awareness month of scleroderma all over the world.



World Scleroderma Day

For Scleroderma Day on 29 June 2023 in Wellington:

This is Carter Fountain at Oriental Bay in Wellington. Thanks to the fabulous and what would we do without her - **Dianne Purdie**, who contacted the Wellington City Council to turn the fountain yellow for **World Scleroderma Day**. The fountain was yellow from **28-30 June**, how awesome is that!

Thanks Dianne, you rock!!! 🌻💛



Wellington's write up from Stuff

Golden Glow Raising awareness of Scleroderma

Scleroderma New Zealand is very grateful for the Wellington City Council's support in raising awareness for World Scleroderma Day. The Council has specially lit the Carter Fountain yellow as part of a nation-wide initiative to raise awareness of Scleroderma. The colour yellow is used to represent the sunflower. The sunflower is a symbol for scleroderma because it turns to the sun and people with Scleroderma need warmth which is provided by the sun. This year we have Invercargill and Wellington in the bright light. Next year we hope more towns and cities will come on board.

In the photo we have Cushla Marsters left and Tina Mclean right, bravely standing on a cold night flying our flag, with the support of family and friends.

Scleroderma affects approx. 1,000 people in New Zealand. It is an autoimmune, connective tissue disease that can affect many organs of the body. It is associated with excessive inflammation, fibrosis and vascular disease and causes hardening and restriction of the skin and internal organs such as the lungs and kidneys, sometimes progressing rapidly. It affects people of all ages with most of these patients being cared for by Rheumatologists, Immunologists, Respiratory Specialist, Gastroenterologists, Cardiologists, Dermatologists, Podiatry, Hand therapy, Dietician and Dental services.

In the last ten years there has been a big improvement in the quality and length of life from new medications and better monitoring protocols for the lungs, heart and kidneys.

World Scleroderma Day marks the death of leading Swiss expressionist artist Paul Klee who died on this day in 1940 of scleroderma. He was diagnosed in 1935. Paul's production slowed noticeably as scleroderma took hold. His artwork began to transform from light and joyful to murky and echoing. en.wikipedia.org/wiki/Paul_Klee

Scleroderma New Zealand is joining with other scleroderma groups around the world to raise awareness and improve health care for this serious condition. Scleroderma Wellington.

www.scleroderma.org.nz



Cushla Marsters and Tina McLean in front of Carter Fountain, Wellington



World Scleroderma Day

World Scleroderma Day in Invercargill was pretty exciting. This was all thanks to the wonderful Heather Milligan who after our last meeting thought she would contact Invercargill Central (our beautiful new mall) to see if they could light up for us. This took quite some emailing on her behalf and also writing a letter and sending off information about Scleroderma to them the old fashioned way through snail mail, without too much in the way of answers. In the end they told us they needed more notice. So we decided to go direct to the contractor and he was very helpful. We also contacted Invercargill City Council who put us on to Parks and Recreation and they kindly lit up the Water Fountain and Band Rotunda in Queens Park. Now we know what can be done I am really looking forward to next year to see if we can go even bigger and better. The Southland Times came along and took a photo and wrote an article, so a huge thank you to Judy Ramsay and Gwenda Gray for braving the cold to have your photo taken. Especially Judy who had spent the day in hospital receiving a transfusion of 3 bags of blood. What a star you are. My high light was seeing Perry Bray's family on Facebook supporting their Dad who lives in Wellington all the way from Invercargill. Go the Bray family.



Invercargill Central Facade



Band Rotunda – Queens Park, Invercargill



Perry Bray's Family in Invercargill



Water Fountain outside Queens Park, Invercargill



World Scleroderma Day

An article from the Southland Times – Stuff

Invercargill woman uses humour to help deal with horrible disease

Evan Harding05:00, Jul 03 2023



ROBYN EDIE/STUFF

Judy Ramsay of Invercargill suffers from the autoimmune disease Scleroderma and is speaking out to raise awareness.

When Judy Ramsay goes to the supermarket strangers sometimes ask her what has happened to her fingers. She has just one small finger and two thumbs fully intact, with the remainder of her digits partially cut off. When she explains she lost the fingers as a result of having Scleroderma, she is met with blank stares. It's a disease most people have never heard of, and it has no cure.

Ramsay, aged 72 from Invercargill, and Jenny Andrews who lives in Winton and is the Scleroderma New Zealand president, have spoken out about the disease to help raise awareness.

Scleroderma is an autoimmune disease that can harden and tighten the skin and cause problems in the blood vessels, internal organs and digestive tract.

While there is no cure, treatments can ease symptoms and slow progression.

Ramsay said she was diagnosed more than three years ago, but believed she had suffered with the disease for much longer.

"It attacked my kidneys, heart and lungs and the doctor came around and said I had Scleroderma. I had never heard of it."

Over time she lost parts of most of her fingers which she refers to as "monkeys claws". Humour was important to help deal with the disease, she said.



ROBYN EDIE/STUFF

World Scleroderma Day was on June 29. Due to this, the Invercargill City Council lit up the Gala Street fountain (in photo), Feldwick Gates and the band rotunda in Queens Park in yellow colours. From left are Southlanders Judy Ramsay, Gwenda Gray and Jenny Andrews, all of whom have the autoimmune disease Scleroderma.

"My fingers went jet black on the ends and three rotted and fell off. The rest have been taken off in Dunedin Hospital."

Largely confined indoors during winter, she has to keep warm. When cold, the blood in her body diverts away from her hands and feet, hence the loss of fingers. Ramsay has lost 50kg as a result of the disease, struggles to keep her head from flopping forward and gets achy bones. She struggles to swallow, has shortness of breath and finds everyday tasks difficult, more-so with the loss of fingers.

She has very little strength in her arms.

"I can't lift my great-granddaughter."

Blood transfusions once a fortnight kept her alive, she said.

"If it wasn't for them, I wouldn't be here."

Andrews, who also has Scleroderma, said about 1000 people were known to have the disease in New Zealand, and 200 of them were members of support groups throughout the country, including 30 in the Southland-Otago group.

It could be a horrendous and lonely disease, with the partners of many sufferers walking out on them, Andrews said.

"They can't cope with the health issues. If you don't have it you don't understand it. We had a member who passed away recently, and he hadn't told his friends he had it."

June 29 was World Scleroderma Day, and to mark the occasion, the Invercargill City Council and Invercargill Central lit up in yellow the Invercargill Central development, Feldwick Gates, Gala Street Fountain and band rotunda in Queens Park.



Members Stories:

Jane Sainsbury (A resident of the USA): Scleroderma Family Walk Event

On June 3 Scleroderma Kansas City, Mo USA held a family 1 mile walk event. It was held in a park just North of downtown, called Macken Park. We were blessed with perfect weather for the beginning of summer. The entry fee was \$30 which got you a lovely T-shirt in teal that had a footprint saying 'Stepping out for a Cure', a scleroderma coolie, a foam ball for hand exercises, a lanyard, and information about a clinical trial. The event brought in about 60 people, 10 of whom had Scleroderma.

The mile long walk took us about 20 minutes. A very easy walk at your own pace. The organizers met their goal that day to raise awareness and at least \$5,000. Under a park shelter there were tables lined with silent auction items & baskets filled with all sorts of goodies you could write your name on and bid. Those of us with Scleroderma lined up and had our photo taken.

Our team's name was called 'Schmidt's Fan Club', to honor our very caring and knowledgeable rheumatologist at Kansas University. We also had Dr Schmidt's right hander and nurse who promptly answers our questions and acts on our needs. Also in attendance was our special hand therapist. All of whom walked with our team and the KC Chapter.



Lunch was brought in and we sat around getting to know others and chatting. We had homemade chocolate chip cookies for dessert. These were kindly donated by one of the participants whose mother recently passed from Scleroderma.

All in all, it was heart-warming to see friends and family supporting our fight against this autoimmune disease one step at a time.

For a little background we ended up in Kansas because I grew up here. After marrying we lived here for 10 years, then moved to New Zealand to raise our children. We moved back to the USA for several reasons. Most of my husband's work is in the USA, Europe and some in Australia. And we also felt with my challenges having been diagnosed with Limited Cutaneous Scleroderma in 2016 that it wouldn't hurt to explore the medical field and expertise of Scleroderma clinics.



Members Stories:

Dianne Purdie: Climbing Aoraki Mt Cook from sea level to raise awareness of Scleroderma

It is time to get my lungs into action for my up and coming lung function and six minute walk tests in July.

The old lungs took a hit with ANCA vasculitis on top of ILD from Scleroderma and my lung function had dropped a lot last year. So what better things could I do to help open up those airways! So I took myself Nordic walking, also to strengthen my back and shoulder muscles after heavy prednisone treatment.

Over the lockdowns, Gordon built a track through our bush clade hill here in Wellington. One loop is half a km and 34 metres in elevation, so we do 6 loops a day which has got us to the top of Mt Cook just in time for world Scleroderma Day.

Gordon and I take our little dog Hami along for the trip. He loves it every time, with squeals of excitement. We will keep going to reach the summit of Mt Everest just in time for the lung function.

I'll be able to walk in with a clear conscience knowing that I have done my best, so fingers crossed for a better result this time round. It will be cold through the hard winter months so keeping fingers crossed with gloves on and many warm clothes.

We completed the Everest Climb from sea level on our bush track in summer over 30 days with 9 loops a day.

I had my IV treatment for ANCA vasculitis this month and with the worsening weather conditions I'm taking it easier, but keeping the body moving. Good for mind, body and soul :-))

While Gordon waits for me to catch up, he looks for interesting fungi and other goodies on the way to take photos of for example the flowers on winter growing Kohekohe and tiny little fungi, Hami and thunder thighs me when we reach a mile stone at the top :-)



If you need help at home: - Get a Needs Assessment

Get a needs assessment | New Zealand Government (www.govt.nz)

If you need help to stay in your home, or long-term care in a rest home or hospital, you can only get government help if you have a **needs assessment** first.

On this page:

- [What is a needs assessment?](#)
- [Contacts](#)
- [Who can have one](#)
- [How you apply](#)
- [What happens next](#)
- [Related services](#)

What is a needs assessment?

When you get a needs assessment, a **Needs Assessment Service Coordination (NASC)** team works with you, and your family if appropriate, to work out the care you need. The team may include nurses, social workers or occupational therapists. The aim is to help you stay independent or get the best possible help to maintain your quality of life.

After a needs assessment, you can get help with:

- personal care, such as showering or dressing
- cleaning, preparing a meal or essential shopping
- making your home safer
- moving into residential care in a rest home or hospital
- working out how to pay for your care.

Contacts

Needs Assessment Service Coordination (NASC) contacts

There are NASCs in your region that look after needs assessments for people who:

- are living with a disability
- are 65 years or older
- have mental health problems.

[NASCs — regional contact details\(external link\)](#)

You can also contact Seniorline to find your local NASC.

- Phone: [+64 9 375 4395](tel:+6493754395), or
- Freephone: [0800 725 463](tel:0800725463)

Who can have one

A needs assessment supports 3 main groups of people to get help.

- Anyone with a physical or intellectual impairment or disability that:
 - is likely to last for 6 months or more, and
 - means you need ongoing help to be independent.
- Anyone over 65 who, because of health concerns or a disability, needs extra support with their day-to-day lives at home or in care.
- Anyone who has been injured and is getting help to recover through the Accident Compensation Corporation (ACC). In this case, ACC first carries out its own Social Rehabilitation Assessment and only suggests a needs assessment if they think you need support that's not related to your injury.

You can only get a needs assessment if you're eligible to receive healthcare in New Zealand.

[Getting publicly funded health services](#)

How you apply

A needs assessment is usually arranged by:

- You or your family contacting your local Needs Assessment Coordination Service (NASC) directly
- Your doctor referring you
- If you're in hospital, the staff looking after you contacting the NASC.

You must agree to have a needs assessment before someone arranges one for you.

[NASCs — regional contact details\(external link\)](#)

Local disability advisory services or Seniorline can also help you find a NASC near you.

[Disability information advisory services\(external link\)](#) [Seniorline\(external link\)](#)

If you're under 65

If you're under 65 and need help, talk to your GP. They'll put you in contact with your local NASC team who will help you work out what care you need



If you need Help at home: - continued

Get a needs assessment | New Zealand Government (www.govt.nz)

What happens next

The **Needs Assessment Coordination Service (NASC)** team contacts you within 2 days to make an appointment if you urgently need help. Otherwise they usually contact you within 2 weeks.

An assessor visits to find out what you need help with. You can invite family, whānau or someone else to support you during the meeting. If your situation is straightforward, the assessor might contact you by phone first.

The assessor will want to know about:

- Your health
- Any support you have from family and friends
- How you cope with day-to-day tasks, and
- How you're feeling about the future.

Levels of care

After the assessment, they'll recommend 1 of 4 options for your care.

1. **You need home support services.** The team then makes a plan for all the care you need and who will provide this. Once you've agreed, the services you need should start within a couple of weeks. If it's urgent, help can be arranged more quickly.
2. **You can manage with the informal support of your family, friends and community.** The team suggests places you can get help or services that you can choose to pay for yourself.
3. **You can no longer manage at home.** The team discusses options for residential care with you. If you agree that you need this care, then you need to choose a rest home or hospital. If you're likely to need government help to pay, they give you a Residential Care Subsidy application form. They complete the part of the form that confirms the level of care you need.
4. **You, your partner or family could all benefit if you had a short stay in a rest home or hospital — this is known as respite care.** This option is only available if you live with your partner or family.

Rest homes and residential care

Support at home after a needs assessment

If you do not agree

If you do not agree with the assessment or any part of the process, you can ask the NASC for a review.

You can also ask for a review from:

- **Te Whatu Ora** — Health New Zealand, if you're 65 or older
- The **Ministry of Health**, if you're under 65.

If your situation changes

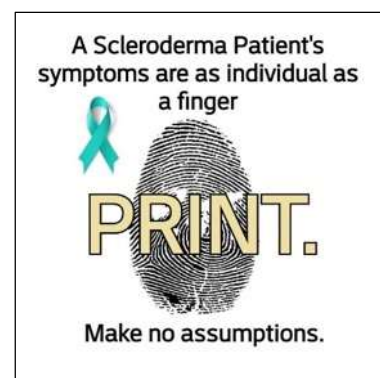
The NASC team review the help you're getting at least once a year. The review is sometimes done by phone or they arrange a meeting with you. If your needs change, you can be reassessed at any time.

Related services

If you're ill or have a disability, there is other government help you can apply for.

- [Disability allowance](#)
- [Lottery grants for people with disabilities](#)
- [Home modifications](#)
- [Coping without a car when you're over 65](#)

Source: <https://www.govt.nz/browse/health/help-in-your-home/needs-assessment/>



Needs Assessment Service Co-ordination (NASC):

<https://www.nznasca.co.nz/regions/>

The Needs Assessment Service Co-ordination Association (NASCA) is the national association for **Needs Assessment Services Co-ordination (NASC)** agency managers and other senior NASC team members within the disability and health sectors.

NASCA is a not for profit incorporated society whose purpose is to further the interests of needs assessment and service coordination for children and adults with disabilities, older people, and people with mental health needs, as well as other sectors in New Zealand.

Our mission statement is “to provide national strategic leadership, promoting growth and service excellence”

<https://www.nznasca.co.nz/regions/>

What is a NASC?

NASC services are contracted by the **Ministry of Health** or **District Health Boards** to serve:

- people with disabilities,
- people with mental health issues,
- older people needing age-related support.

NASCs may specialise and be contracted to provide one or more of these areas, so each region of New Zealand may have several NASC services. There are 15 younger peoples NASCs and 21 older peoples NASCs based throughout New Zealand. NASCs are generally required to do three things:

1. Facilitate needs assessment
2. Service planning and co-ordination
3. Resource allocation within a defined budget.

Help from a NASC

A NASC is obliged to establish if each person meets **criteria to be eligible**. Staff will talk to you about this, and will work with you and your family/whanau to find out your abilities, resources, goals and needs, and then help you to identify which of these needs are the most important. They will then work with you to plan what supports or services are available to help meet your goals and needs. This includes ‘natural supports’ (family, whanau, aiga, community services, etc).

The NASC then identifies with you:

- which services or supports you are eligible for, and
- which of the supports and services are funded

The NASC then facilitates the commencement of these services and supports. If funded services are needed these services are delivered by provider organisations contracted by the Ministry of Health or by District Health Boards. These services could include help in the home (such as housework), help with personal cares (such as showering), respite care, support for independent living, and many others. The NASC service will keep in touch yearly, or you can contact them at any stage if your needs change.

Find your local NASC service

Below is the website image page for the Needs Assessment Coordination Services (NASC) listed by your local regions.

To find out the contact details for the **Needs Assessment Coordination Service (NASC)** in your area, visit their website.



Source: <https://www.nznasca.co.nz/regions/>



About Disability Allowance:

<https://www.workandincome.govt.nz/providers/health-and-disability-practitioners/guides/disability-allowance-allowable-costs.html>

Kia ora,

This country is pretty good! There is a disability allowance of **\$75.10** a week for on going medical costs to cover the cost of appointments with general practitioners, specialists or hospital fees if the costs are additional and ongoing. This can also include fees for the some other health services (if a registered medical practitioner verifies the need and its relationship to the documented disability or health condition), **for example occupational therapy, physiotherapy, audiology, podiatry or dental services. (Under Medical fees)**

With best wishes Ngā manaakitanga

Dianne

More below <https://www.workandincome.govt.nz/providers/health-and-disability-practitioners/guides/disability-allowance-allowable-costs.html>

Disability Allowance - for medical and nurse practitioners

Information about Disability Allowance for medical and nurse practitioners.

Disability Allowance is a weekly amount (up to \$75.10) for people who have regular, ongoing additional costs because of a disability or health condition. These could be costs like:

- visits to the doctor or hospital
- medicines
- extra clothing, or
- travel.

There are certain criteria people need to meet to qualify for the Disability Allowance.

- It's available to most people who qualify for a Community Services Card.
- People don't have to be on a benefit.
- It depends on their income.

[Criteria for Disability Allowance](#)

More on Disability Allowance on the link below:

<https://www.workandincome.govt.nz/products/a-z-benefits/disability-allowance.html#null>

About the Disability Allowance

Costs covered by Disability Allowance

There's a wide range of costs a Disability Allowance can help pay for. The costs must be related to the person's health condition or disability.

Cost	When it can be paid for
Alternative treatment	must be supported by a medical practitioner as being necessary to be publicly funded for the person's condition, and the treatment provided or supervised by a health practitioner (under the HPCAA).
Ambulance fees and subscriptions	when a person is required to pay ambulance fees or subscription fees on an annual on-going basis.
Authorised consumables	can cover the ongoing additional cost of consumable items needed by a person, eg hearing aids, vet's fees etc for guide dogs, incontinence pads (if they are not provided through Health).
Clothing	for additional clothing costs that a person has which may arise because of greater frequency of washing, wear and tear resulting from use of a prosthetic aid or wheelchair or the need to have clothes or shoes made-to-measure.
Counselling	for counselling fees if the need for counselling is directly related to the person's disability. It is limited to 10 sessions with the opportunity for some additional sessions if clinically indicated (uncommon). Transport costs may also be paid.
Day care for older disabled people	to help meet the costs of an older disabled person (usually aged 65 or over) to attend a day care centre, and/or the cost of transport to the centre.
Gardening, lawns and outside window cleaning	covers the costs of gardening, lawn-mowing, and outside window cleaning for the person's own home or private residence where the person or another resident in the home is unable to do these tasks themselves.
Gym and swimming pool fees	may be paid when the exercise activities are directly related to a person's disability and will have a therapeutic value.



About Disability Allowance: – continued...

<https://www.workandincome.govt.nz/providers/health-and-disability-practitioners/guides/disability-allowance-allowable-costs.html>

Medical alarms	to cover the costs of medical alarm rental and monitoring if a medical alarm is necessary for normal daily living and without it, the person's life or health would be put at risk, or their disability would be aggravated.
MedicAlert costs	to cover the ongoing MedicAlert membership fee (also known as service fee) in order to provide medical information in an emergency situation. This could be for people who may be unable to speak for themselves in a medical emergency, such as people with insulin dependent diabetes, epilepsy, life-threatening allergies or haemophilia.
Medical fees	to cover the cost of appointments with general practitioners, specialists or hospital fees if the costs are additional and ongoing. This can also include fees for the some other health services (if a registered medical practitioner verifies the need and its relationship to the documented disability or health condition), for example occupational therapy, physiotherapy, audiology, podiatry or dental services.
Nicotine replacement products	when a nicotine replacement product has been prescribed by a health practitioner as part of the treatment/management of the health condition or disability.
Pharmaceutical charges	to cover the costs of regular and ongoing pharmaceutical charges. Note: It is generally only paid to assist with the cost of pharmaceutical products that are subsidised or partially subsidised under the New Zealand Public Health and Disability Act. This may also include nicotine replacement products when a person is giving up smoking as part of the treatment of a health condition or disability such cardiovascular disease.
Power, gas and heating	for the additional electricity, gas or heating costs that a person has. It is for the costs over and above the normal power consumption of similar-sized households.
Private paying patients	when a person is in a rest home as a private paying patient, costs can be paid for if they are in addition to the rest home fee for service and directly related to their disability.
Rental equipment	for necessary rental equipment when the client has a need for the item or service but can't receive funding through the District Health Board or another state funded agency and their life or health would be put at risk, or their disability aggravated if they could not hire the equipment.
Residential care services	for costs not covered by a person's contract with the residential care services provider when they get Residential Support Subsidy.
Special foods	to cover the additional costs of special foods, ie for costs over and above the normal cost of food. Vitamins, supplements, herbal remedies and minerals can also be included when they are recommended as necessary for the management of the condition.
Telephone	for telephone costs to a person with a disability only when the ongoing cost of the telephone is directly related to the person's disability.
Transport - counselling	for the costs of travel to counselling for the number of sessions that Disability Allowance is being paid for.
Transport - disability	for additional travel costs that a person has because of their disability. These additional travel costs can be incurred when a person with a disability is carrying out everyday activities. Examples of everyday activities may include (but is not limited to) shopping, vocational services and work.
Transport - personal health	to cover the costs of regular travel to a health practitioner for supervision or treatment of the person's disability.
Vitamins, supplements, herbal remedies and minerals	for costs not covered by alternative subsidised pharmaceutical items, and that either PHARMAC has funded it under their Named Patient Pharmaceutical Assessment Policy or the medical practitioner has verified the cost is essential and there are no suitable alternatives.

If someone wants to apply for a Disability Allowance, you need to complete the Disability Certificate section of the person's Disability Allowance application form.

By filling out the form, you are confirming the person has:

- a health condition or disability that's likely to last at least 6 months
- regular, ongoing costs because of a health condition or disability that aren't fully covered by another agency.

Source: <https://www.workandincome.govt.nz/providers/health-and-disability-practitioners/guides/disability-allowance-allowable-costs.html>



Members News



Bay of Plenty Scleroderma Group

The Bay of Plenty group had a catch up recently and certainly look like they are having fun together.



New Plymouth Scleroderma Group

The New Plymouth group met up recently and had a lovely catch up. Great to hear you are getting together. We look forward to seeing some photos of your next catch up. ☺



Waikato Scleroderma Group

The Waikato Group met up recently and had 7 turn up for a nice lunch. Thank you Linda for organising this. It was lovely to meet some new members and all had a nice time.



Hawkes Bay Scleroderma Group

Francis and I met up with Jane today. It was so lovely to catch up again - been 1 year since we last saw her. We generally talked about scleroderma and America where Jane is now residing. We hope to catch up with Jane at Xmas time again which is fab. We are all plodding along with nothing new really. We are not looking forward to winter as you all can imagine. We will be hankering down for the Winter. Hope everyone is well. Cheers Gail ☐☐☐



Christchurch Scleroderma Group

The Christchurch group had their first meeting in March at the Great Escape Café, Burwood Hospital. They had 8 turn up and look like they are having a lovely time. Thanks for sharing the photo Kim and Thank you to Dianne for organising this.



Members News continued...



Wellington Scleroderma Group



Thank you to Dianne for organising another enjoyable Wellington group's lunch to celebrate Scleroderma Day. We all met on 24 June at the Chocolate Frog in Palmers Garden centre in Miramar. We had 9 members come along, even though it was a cold day. We welcomed Janet, a new member to our group and had a wonderful catchup. Everyone had a lovely time catching up while enjoying a delicious lunch.



Southland Scleroderma Group

Southland Scleroderma 30 April 2023, at Invercargill

It was so good to get together with others in Southland over lunch.

We did have a large group, I realised when over half of the group left we didn't have a photo. This photo shows the remaining of us and the lovely waitress clearing where the others sat!!!!

Again lots of conversation, empathy with others and awareness of our battle with Scleroderma.

Heather



Southland Scleroderma 25 June 2023, at Gore, celebrating World Scleroderma Day

A smaller group, but so much talking. We were not deliberately at two tables, just the way it happened. Four support people at one and a mix of support people and those with scleroderma at the other.

We were impressed with Raewyn's doctor diagnosing her by a red dot on her leg. We admired Lynette's morphoea on her leg, Terry's kidneys were discussed. It was interesting in Gay's communication with her naturopath and the path she is taking. Helen going from no medication to quite a few to take, I got the giggles about her endeavours using her cell phone alarm as reminder to take them, the alarms beeped but until Helen realised she could name that alarm with the medication it was a puzzle for her as to which one to take.

Thanks to Gay for getting together with our 2 Dunedin members the previous week.

More organised with the photos this time.

Thank you so much to Jenny for organising our get together and to our members for coming. It is so good to see you in person and for you to share your knowledge with us.

Heather



Southland Members enjoying their lunch



Southland Members awesome group of supporters ☺



Members Update

Podiatrists and Fingernail cutting

We are waiting to hear from Podiatrists throughout the country who are able to cut fingernails as well as toe nails. This is fantastic news as there has never been anyone specifically able to cut our fingernails. So far we have heard from a couple of them. Please see below.

***Jessica Dobbs Podiatry** 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

***Dr Althea Carruth – Central Otago**

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

To get in touch with her, her contact details are

02041785262

ENGAGEMENT NOTICE

It is very exciting to be able to share the news that Gwenda Gray of the Southland Group and Ronnie Mooyman are engaged. It is so nice to see Gwenda so happy and sporting a pretty awesome piece of bling. Congratulations to you both



Gwenda & Ronnie
Gwenda's new bling



Information wanted:

Does anyone have issues with their body not making red blood cells and needing blood transfusions on a regular basis. If so, did they get to the bottom of it and find something to help. We have a lovely member who is going through this and would like to know of any others. Please get in touch with me on 0273166124 or jennyred@xtra.co.nz

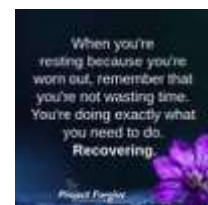
Has anyone been using the drug Pirfenidone or other name of (Esbriet)

We have had some members asking about it and Rare Disorders NZ were wondering if anyone had received it through the NPPA program. If you have anything you would like to share, please contact me on : jennyred@xtra.co.nz Thank you

How to stay Young

- Throw out non-essential numbers. This includes age, weight, and height. Let the doctor worry about them. That is why you pay them.
- Keep only cheerful friends. The grouches pull you down.
- Keep learning. Learn about the computer, crafts, gardening, whatever. Never let the brain idle. "An idle mind is the devils workshop" and the devils name is Alzheimer's.
- Enjoy the simple things.
- The tears happen. Endure, grieve and move on. The only person who is with us our entire life, is ourselves. Be ALIVE while you are alive.
- Laugh often, long and loud. Laugh until you gasp for breath.
- Surround yourself with what you love, whether it is family, pets, keepsakes, music, plants, hobbies whatever. Your home is your refuge.
- Cherish your health. If it is good preserve it. If it is unstable, improve it. If it is beyond what you can improve, get help.
- Don't take guilt trips. Take a trip to the mall, to the next county, to a foreign county, but NOT to where the guilt is.
- Tell the people you love that you love them at every opportunity.

Shared by Betty Wilson



Members Update

Useful Tips for Winter...

Good Morning we have some good tips from Richard to help keep warm this winter. Thanks Richard. 😊



1. The heated gloves are from **Toasty Touch** - www.toastytouch.com - not bulky - quite fine - more like a fine sock thickness - and 3 heating settings.



2. The heated jackets are at **Placemakers** - jackets are made by Milwaukee (yes the same people who make/supply tools) - come in Men's and Ladies sizes and also come as a vest. Again they have three temperature settings.

The information below was given to me by Kelly for keeping warm in winter in our previous group meeting. Thanks Kelly.



3. Under works – Heat Bods: Thermal Baselayer - Long Johns: - can be bought from the **Warehouse**. It is Brushed Cotton inside for softness and warmth.



4. Under works – Heat Bods: Thermal Baselayer - Long Sleeve: - can be bought from the **Warehouse**. It is Brushed Cotton inside for softness and warmth.



5. Under works – Heat Bods : Thermal Insulated Socks: - can be bought from the **Warehouse**. It is 5 times warmer than cotton socks.



6. **Goldair** – Electric Heated Throw: can be bought from **Briscoes**. It is lovely to use while sitting and watching TV.

Scleroderma and what it effects:

Conditions - PAH Pulmonary arterial hypertension (PAH), or high pressure in the blood vessels of the lungs, is a common complication of scleroderma. Scleroderma can also cause inflammation and scarring in the blood vessels of the lungs. The damage can trigger vasoconstriction, or the narrowing of the blood vessels, which makes it more difficult for blood to flow and increases blood pressure in the arteries.	Conditions - ILD Scleroderma can result in inflammation and scarring of the lung tissue causing interstitial lung disease (ILD). The scarring results in the lung tissue becoming stiffer and thicker, which restricts lung function and reduces the volume of air that can enter and leave the lungs. As a result, patients with scleroderma and ILD can be short of breath, and as the disease progresses, find simple daily tasks difficult to complete.
Conditions - Muscle & Joint Muscle weakness, especially in the upper arms and thighs, can occur due to different causes, including damage from inflammation or muscle fibrosis (scarring), or wasting from malnutrition due to gastrointestinal problems. Scleroderma can also cause inflammation in the joints. This can cause pain, stiffness, swelling, warmth, and tenderness in the joints.	Conditions - Renal Crisis Scleroderma can affect the kidneys and, in severe cases, may lead to renal crisis. Renal crisis may be difficult to identify as the early symptoms may be seen in all scleroderma patients. Renal crisis can come on suddenly and is normally associated with a rapid increase in blood pressure that can cause headaches, blurred vision, or even seizures.

Jokes of the day

<p>A giggle a day, keeps the grumps away!</p>  <p>Snoopy is Awesome on FB</p>	<p>DON'T BE WORRIED ABOUT YOUR SMARTPHONE AND TV SPYING ON YOU. YOUR VACUUM CLEANER HAS BEEN GATHERING DIRT ON YOU FOR YEARS.</p>
---	--



Give a little: Scleroderma NZ Inc.

From [Scleroderma New Zealand Incorporated - Givealittle](#)

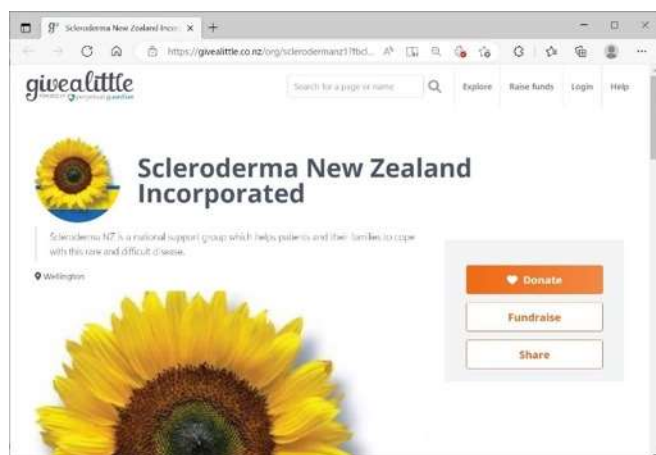


Scleroderma New Zealand Incorporated

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 is shown below:

[Scleroderma New Zealand Incorporated - Givealittle](#)



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

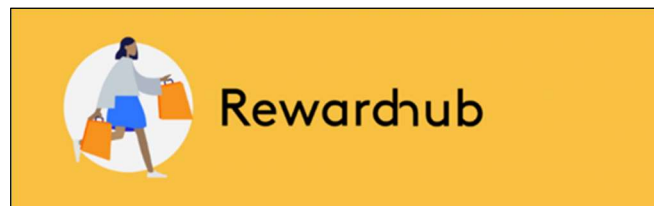
<https://givealittle.co.nz/org/sclerodermanz1?fbclid=IwAR29Znk701JSOwf9n0Ew-O63nj0FrySOCpV44mBCpIPhtXV7Uff9KlAnAzM>

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

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.

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.

Scleroderma NZ Inc. Shopping



REWARDHUB

Is it hard to leave the home when you aren't feeling the best. Why not do your shopping 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 some 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



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.



Group Meetings:

Wellington support group meets:

Venue: *Fisherman's Table, 29 State Highway 59, Paekākāriki*

Saturday September 2nd, 2023

For any enquiries please contact Dianne:

diannepurdie@xtra.co.nz

Christchurch support group meets:

Venue: *Garden Restaurant, Marshlands Rd, Christchurch*

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

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 September 10th, 12pm. *Buster Crabb, Invercargill*

Sunday November 19th, 12pm. **venue TBA**

Please contact Heather if you wish to join us.

milliganseeds@xtra.co.nz

Waikato support group meets:

Venue: *Robert Harris Café, Chartwell Hamilton.*

Saturday 25th November, 2023 Christmas Lunch

Unfortunately due to illness and low attendance there will be no coffee group in the near future. We are working on this so watch this space. ☺ 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 Support group.

New Plymouth support group meets:

Venue: *The Bach on Breakwater*

Saturday 15th July, 12pm

So if you would like to attend the New Plymouth Support Group please get in contact with Kelsi Tidswell:

kelsitidswell@gmail.com

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:

Venue: *The Village Kitchen Ahuriri*

Friday 30th June 2023, 10.30am

To join in with the Hawkes Bay Support group please get in touch with Gail Nelson gail_neilson@hotmail.com

Bay of Plenty support group meets:

We will be meeting again soon. Date and venue to be advised. Please contact one of us for information.

Jane: janeputkey99@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



Zoom Session with Dr Nikki Tugnet, (Rheumatologist in Auckland)

When: *Tuesday 15th August 2023 @ 7pm*

It will include an explanation of the scientific benefits of yoga and movement in scleroderma and then a practical chair-based demo. A link for this will be sent out via email to all members.

This will also be recorded for all those who are unable to make the session.





Welcome to Scleroderma New Zealand Inc

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

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

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



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



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



Scleroderma New Zealand

President:	Jenny Andrews 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: neilson_gail@hotmail.co.nz
Waipa:	Erena Bruce, Email: glenanderena@xtra.co.nz
New Plymouth:	Kelsi Tidswell, Email: kelsitidswell@gmail.com
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

