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Scleroderma

New Zealand support group

Spring 2018

Greetings to you all.

With spring here, we can only hope for a lovely long, hot summer as it was last year. It has been a very wet spring so let's hope that the rain subsides, and the sun makes its presence known in our part of the world.

We have another full newsletter with plenty of articles for you to read. Dianne gives her president's report, keeping us up to date with things around the country. We have a leaflet for hospital care for people with scleroderma. This is aimed at nurses and hospital carers but good for those of us who have had a hospital stay.

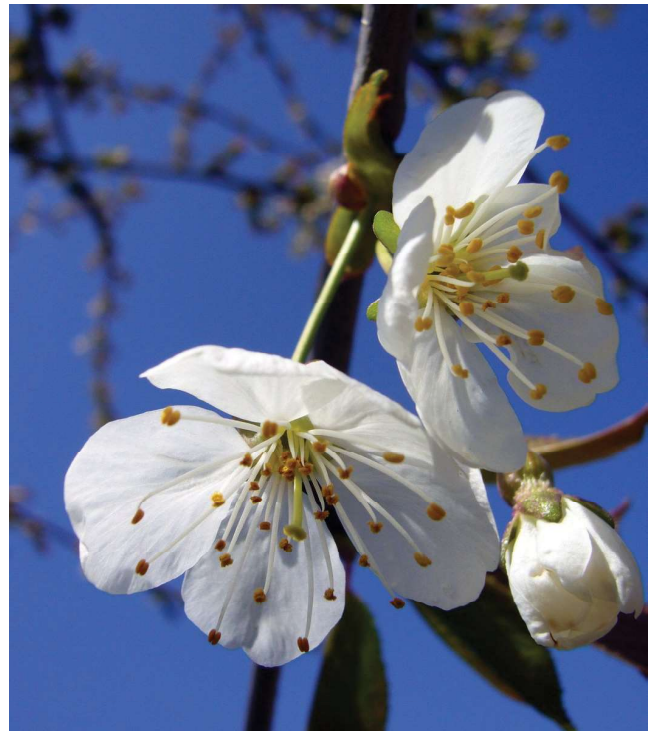
The results of the health survey are there for you to read, as is the heating survey. Some interesting results.

There is an article on the benefits of doing craft. I know many of you do a host of different things and I would like to hear from you about them. We could have a craft support group!

We also have some pics of people on World Scleroderma Day. Some Wellington sufferers had a fun time chatting over a nice meal and a glass of wine, and news from people in the south and the things that they are doing. Thanks go to Jenny and Heather.

Adrienne shows how her car-jack works and Jo has a bargain on merino gloves. Raewyn spoke to our group about accessing a disability park, and you can read her report here. Rob spotted an article on baking soda, which is worth a read, and Dot gave us her recipe for the Mumble bar. Most delicious.

Enjoy your read and I look forward to hearing your stories for the next newsletter.



President's Report

September 2018

Hello everyone, I bet you are all having a sigh of relief now that Spring is in the air, which means lots to do in the garden, be careful of your backs, I know I have just given myself a twinge or two from resting it all winter.

We had our AGM on the 29th of June and time has flown by since then. We have our 25 committee members, and two ladies Chris Carlyon, Palmerston North, and Lorraine Horlbrook Invercargill, who have stepped down. I would like to thank both Chris and Lorraine for all their work and support on the committee for the last couple of years. I wish them both well and good health for their future endeavours.

I would like to thank all the committee for all their hard work over the past two years and for staying on board for another round. A special thank you to Barbara and John Spavin for all their continued dedication to Scleroderma NZ by way of producing the excellent newsletter and website for us all. We are all very lucky to have them do this for us. Please help Barbara and John by sending in your special stories to help make this a community newsletter.

The 29th of June was World Scleroderma Day. Allan and Sandy Edmondson put together a celebratory dinner up at Tuakau, south of the Bombay Hills and it was enjoyed by many and especially attended by Linda Bell and friends from Hamilton.

We had a lovely bunch of people here in Wellington who went out for a celebratory lunch in Miramar Wellington and we managed to get up a display about Scleroderma at Wellington Hospital to raise awareness.

We have been busy completing another two surveys: one on heating your home and the scleroderma health survey. You will see the results of these two surveys later in the newsletter.

There are some serious concerns: 13% couldn't afford to heat



their home comfortably; 22% said they would go without things they need like food to pay the power bill; 7% could not afford to go to the doctor when they needed to this winter.

22% can only sometimes go to the doctor when they needed to.

These concerns I feel need addressing with some lobbying to the Government to see if we can get a heating subsidy for next winter. This will keep the committee busy the next few months.

The Health Survey drew attention to only 64 % of the responders not having a six minute walk test. I find this a concern because this is an easy non expensive accessible test which can give some important information for our ongoing care. I wish you all well and enjoy the lovely Spring just around the corner. Thank you all again for your ongoing support.

Best Wishes

Dianne and Gordon

Hospital care plan endorsed

The New Zealand Rheumatology Association has endorsed a hospital care plan prepared by Dianne, Gordon and Maureen

The leaflet aims to help nurses and other health professionals manage patients in hospital with scleroderma.

It is a check-list of some of the main problems a person with scleroderma may experience and how to manage these problems.



| Common Symptom | Management |
|--|---|
| Raynaud's phenomenon, including internal Raynaud's | Provide extra blankets. Keep core warm. Avoid drafts. Maintain warmth particularly pre & post-op. |
| Ulceration, Impaired healing | Assess for signs of infection. Provide appropriate dressings. Assist with activities of daily living as necessary. Refer to occupational therapist as necessary. |
| Tight skin | Provide protection during surgery and/or procedures. Assess for signs of skin breakdown. Extra care required with venipuncture and blood pressure measurement. |
| Dry skin | Assist with moisturising as required. Regular moisturising if important. |
| Painful hands and feet | Avoid injury, e.g. during transfer and ambulation. |
| Painful joints | Assist with repositioning. Provide extra pillows. Use massage and the application of heat. Assess pain and anti-inflammatory medications. Physiotherapy assessment. Encourage ambulation as tolerated. If available the extra thick mattresses. |
| Impaired movement and mobility | Assistance may be required with feeding, oral hygiene and other daily care. Possible difficulties with intubation. Important to sit upwards for meals to aid digestion. Assistance with walking, watch for balance issues. |
| Dry mouth, dry eyes (Sicca symptoms, Sjögren's Syndrome) | Ensure drinking water is readily accessible. Maintain good oral hygiene especially when patient unable to drink. Assist with application of eye drops or ointment if patient unable to self-administer, particularly pre and post-op and prior to sleeping. Provide sugar free gum if tolerated by patient. |
| Oesophageal involvement including difficulty swallowing | Elevate head of bed. Provide extra pillows. Position the patient in an upright position when eating and after meals. Administer antacids as required. Discuss food preferences while ensuring adequate and appropriate dietary intake. Consult with dietician as necessary. Monitor if using a feeding tube. Easy to eat food, soft, small meals often. Straws for drinking. Watch for choking. |

| Common Symptom | Management |
|---|---|
| Bowel involvement; diarrhoea and/or constipation; faecal incontinence | Assess for dietary requirements and medication regime. Consult with dietician as necessary. |
| Shortness of breath on exertion | Allow patient to set the pace during physical activity. Assess O2 saturation and need for oxygen. Refer to respiratory therapist as needed. |
| Reduced capacity to cope | Create calm, supportive environment. Encourage stress reduction and relaxation techniques. Refer for social work assessment. Limit visitors, group cares together |
| Increased skin sensitivity | Take extra care as patient has a low pain threshold. Ask nurses to remove watches or jewellery so skin tears don't occur. |
| Blood pressure irregularities, pulmonary arterial hypertension and pre-operative guide | It may signal kidney impairment requiring immediate intervention. If patient has pulmonary arterial hypertension, the anaesthetist needs to be alerted well in advance as anaesthesia carries increased risks. Extra care required with intubation. Maintain warmth to allow for optimal venous access. |
| Preparation for sleep. Insufficient clearance of mucus/saliva from airway can create breathing difficulties. Weakness of neck muscles – hard to find comfortable sleeping position. | Administer nebuliser just before bed-time, elevate head of bed. NB – For tall patients: if backrest is tilted, the foot of the bed may need to be extended. Arrange pillows – 'armchair' position may help. A rolled-up small towel may give support to the neck. |

This plan is based on those developed and modified by Scleroderma Australia, Scleroderma & Raynaud's UK and Scleroderma Association of BC.

Scleroderma health survey

Dianne thought it would be a good idea to run a quick health survey for Scleroderma Patients in New Zealand for 2018.

The emphasis was on monitoring for scleroderma and access to health services.

There were 61 responders, 90% were female. They were aged between 33 and 84, mean 60, with half of the responders aged between 54 and 66.

| Which DHB do you belong to? | Frequency | % |
|-----------------------------|-----------|------|
| Waitemata | 4 | 6.6 |
| Auckland | 7 | 11.5 |
| Counties Manukau | 1 | 1.6 |
| Waikato | 5 | 8.2 |
| Bay of Plenty | 1 | 1.6 |
| Hawkes Bay | 1 | 1.6 |
| Taranaki | 4 | 6.6 |
| Whanganui | 1 | 1.6 |
| Mid Central | 5 | 8.2 |
| Wairarapa | 1 | 1.6 |
| Hutt Valley | 3 | 4.9 |
| Capital and Coast | 6 | 9.8 |
| Nelson-Marlborough | 2 | 3.3 |
| West Coast | 1 | 1.6 |
| Canterbury | 7 | 11.5 |
| Southern | 11 | 18.0 |
| Unsure | 1 | 1.6 |

All have scleroderma and 71% are members of Scleroderma NZ (an approximately 30% response rate among Scleroderma NZ members).

Most, 85%, see a rheumatologist and 8% see an immunologist. 11% don't see either a rheumatologist or an immunologist. 6% see their rheumatologist or immunologist 1–3 monthly, 17% 3–6 monthly, 42% 6 monthly – 1 yearly, 32% 1–2 yearly and 4% less than 2 yearly. Of those seeing a rheumatologist or an immunologist 85% see them through the public health service (including one who sees a rheumatologist through the public health service and an immunologist privately and two who see rheumatologist both through the public health service and privately).

94% have had a lung function test, 5% have not and 2% are unsure. 18% have one 6-monthly, 41% yearly, 25% 2-yearly and 16% less often. 96% have their lung function test through the public health service and 5% privately (one person has both).

33% have had a six-minute walk test, 64% have not and 3% are unsure. 15% have one 3-monthly, 10% 6-monthly,

15% yearly, 30% 2-yearly and 30% less often. 90% have their six-minute walk test through the public health service and 15% privately (one person has both).

87% have had an echocardiogram (ultrasound scan of heart), 10% have not and 3% are unsure. 2% have one 3-monthly, 10% 6 monthly, 27% yearly, 27% 2-yearly and 33% less often. 89% have their echocardiogram through the public health service and 11% privately (one person has both).

44% monitor their blood pressure at home. 7% daily, 19% day – weekly, 30% weekly – monthly, 19% monthly – 3 monthly and 26% less often. GPs monitor blood pressure for 92% of people. 4% more often than monthly, 22% monthly – 3-monthly, 35% 3-monthly – 6-monthly, 33% 6-monthly – yearly and 6% less often. Of those seeing a rheumatologist or an immunologist, 69% said the rheumatologist or immunologist checked their blood pressure and 31% the rheumatology nurse does (73% either). One person did not report any monitoring of their blood pressure.

23% see their GP for scleroderma related health checks 1–3 monthly, 25% 3–6 monthly, 15% 6-monthly – yearly, 12% less often and 25% do not see their GP for scleroderma related health checks,

People have regular blood tests from their GP to monitor their kidney function (62%), liver function (64%), ANA Panel (18%), thyroid (20%), inflammatory markers (CRP) (41%), vitamin D (25%), sugar levels (21%), cholesterol levels (28%) and full blood count (66%). 30% are you on care-plus (3-monthly GP visits at reduced fee), 15% just for scleroderma, 3% just for another chronic health condition and 11% for both scleroderma and another chronic health condition. 5% have visits from a District Health Nurse for ulcer care and 4% for any other scleroderma related problem. Most people can cut their own finger nails. Two cannot cut their own finger nails, four people needed help to cut their finger nails. Four people, 7%, need help or can't cut their finger nails and only one said they had access to a health service, others relying on family and friends.

Craft as therapy

Stuff website reports that doing a craft as a hobby can help those with an illness improve their mental and physical state.

Crafts such as knitting, crochet, weaving, ceramics, needlework and woodwork focus on repetitive actions and a skill level that can always be improved upon. According to the famous psychologist Mihaly Csikszentmihalyi this allows us to enter a "flow" state, a perfect immersive state of balance between skill and challenge.



Photo credit: stuff.co.nz

Stuff reports that what is increasingly referred to today as "mindfulness" being a much-desired quality for many people, it's not surprising crafts are being sought out for their mental and even physical benefits.

For over a century, arts and craft-based activity have been a core part of occupational therapy that emerged as a distinct health field around the end of the first world war in response to the needs of returned soldiers.

This includes many suffering from what we now refer to as post-traumatic stress disorder, but then referred to as "shell shock".

A large-scale international online survey of knitters found respondents derived a wide range of perceived psychological benefits from the practice: relaxation; relief from stress; a sense of accomplishment; connection to tradition; increased happiness; reduced anxiety; enhanced confidence, as well as cognitive abilities (improved memory, concentration and ability to think through problems).

Some 74% of research participants described feeling "distracted" or "distanced" from these negative emotional and cognitive states, as well as more relaxed and comfortable. Over half said they felt less stressed, a feeling of accomplishment, and less likely to act on their "ruminating thoughts".

Home heating survey

Recently the Salvation Army surveyed 1,005 random people aged 18 years and over. They found 45% could not afford to heat their homes. Concerned, Scleroderma NZ decided to survey people with scleroderma.

There were 60 responders, 93% were female. They were aged between 34 and 78, mean 61, with half of the responders aged between 56 and 67.

83% are members of Scleroderma NZ (an approximately 35% response rate among Scleroderma NZ members).

| Region | Frequency | % |
|----------------------|-----------|------|
| Auckland | 8 | 14.8 |
| Waikato | 4 | 7.4 |
| Bay of Plenty | 2 | 3.7 |
| Taranaki | 2 | 3.7 |
| Hawkes bay | 1 | 1.9 |
| Manawatu - Whanganui | 8 | 14.0 |
| Wairarapa | 2 | 3.7 |
| Wellington | 9 | 16.7 |
| Nelson | 1 | 1.85 |
| Canterbury | 5 | 9.3 |
| Central Otago | 1 | 1.9 |
| Southland | 11 | 20.4 |

13% couldn't afford to heat their home comfortably and 28% could only sometimes afford to heat their home comfortably.

The average temperature that people keep their home heated to during winter ranges from 16C (in lounge with the rest of house cold), with someone else noting that overnight temps can fall to 14C, to one reporting 30C, the next highest being 25C.

22% said they would go without things they need like food to pay the power bill

7% could not afford to go to the doctor when they needed to this winter and 22% can only sometimes afford to go.

Power bills ranged from \$80 - \$600 per month. The person who spent \$600 said they definitely could not afford it and they will have to go back to having a cold house.

Many expressed concerns. Some are listed below.



"People are reporting serious difficulties due to the cold, like having to take three showers a day to keep warm.

People feel guilty about having to keep their house warm.

Having Scleroderma is a very expensive illness and costs involved should be subsidised by the government.

I would love a subsidy on heating costs for those with chronic conditions. I don't heat my house as much as I should and more than 1 room because of cost. Moving to eg bathroom gives me terrible Raynaud's attacks and ulcer pains. "

There were a lot of concerns expressed and many people were in financial difficulty heating their home and paying for health costs visits. We intended to lobby the Government for greater support.

Scleroderma Day celebrated

World Scleroderma Day had quiet commeration this time around. Most activities seem to have been companionship to share experiences

Thew Auckland Respiratory group staged a luncheon get-together



Scleroderma Day celebrated

Wellington, typically, chose wine. Oh, and a nice meal.



Somewhere in deepest Miramar there was a small turnout but great company!

Jo Harris spots a great buy

I found these wonderful Butte Merino Wool Baselayer gloves at Kathmandu.

They were originally \$39.98 but are on sale for \$18.00.

They are 100% merino wool. They are a very fine knit and can be worn either on their own or under other gloves so are suitable all year round.

They are very comfortable and don't inhibit your movement like some other gloves. They might be of interest to other people.



You can shop online at:

www.kathmandu.co.nz/

News from the south

The Southland Scleroderma Social Group met in Winton for lunch in August.

We did enjoy having a catch up with others who know about feeling cold, coping with fatigue, ulcers on our fingers and toes and all the daily living challenges.



We looked over NZ Scleroderma Hospital Care Plan, which has been endorsed by the New Zealand Rheumatology Association, and decided it was well worth us having a copy ready to take if have to go to hospital.

It was great that Lorraine, who was discharged from hospital the previous day, joined us.

Thanks to Jenny for getting us together and handing out delightful invitations to a Christmas get together in November. Wow you are so organised!

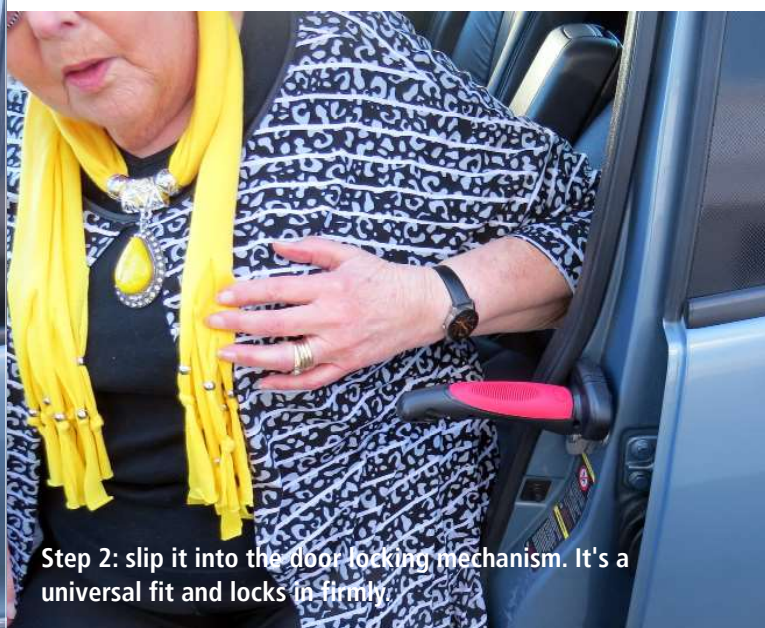
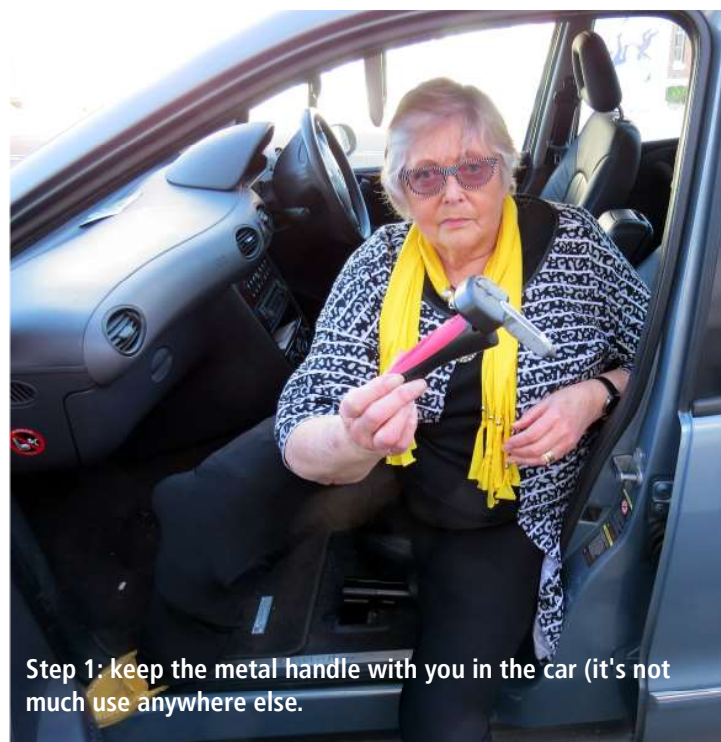


Things that people think of dept.

Adrienne brings her latest cool thing to the Wellington meeting

They say that one of the things that makes SUVs so popular with New Zealand drivers these days is the ease with which passengers and driver can slide in and out of the seats without having to contort and bend to get down into a low seat or climb back out of it.

But wait. There is no need to empty the bank account just to improve the ease of getting in and out of a low-slung car. Adrienne found that a small piece of metal can achieve the same result. Hunt for them on Google, they're in New Zealand shops.



Raewyn Hails

Access co-ordinator from Disability Action

Getting a car park can be fraught at the best of times. But those who can't get about because of a disability or illness can find it impossible.

Raewyn Hails from Disability Action told Wellington's Spring meeting that she and her organisation can help.

Disability Action administers the Mobility Parking Scheme to provide parking access to 140 thousand permit holders.

People in need of mobility parking access can ask their GP to sign an authorisation and then apply for the card. The permits are bar-coded to help local body ensure that only genuine and current permits are in use.



In 2008, fines for misuse of the permits rose from \$40 to \$150.

The group also lobbies for more and better car parks through local bodies and improved road signage. Contact the organisation if you believe you can make use of a permit



Free call 0800 227 2255

info@ccsdisabilityaction.org.nz

www.ccsdisabilityaction.org.nz



**ccs
disability action**
Including all people

www.scleroderma.org.nz

Drinking baking soda could be a cheap and safe way to combat autoimmune disease

A daily dose of baking soda may help reduce the destructive inflammation of autoimmune diseases like rheumatoid arthritis, scientists say (spotted by Rob).

They have some of the first evidence of how the cheap, over-the-counter antacid can encourage your spleen to promote instead an anti-inflammatory environment that could be therapeutic against inflammatory disease. The claim comes from Medical College of Georgia scientists, reported in the US Journal of Immunology.

They say that when rats or healthy people drink a solution of baking soda, or sodium bicarbonate, it triggers the stomach to make more acid to digest the next meal. Little-studied mesothelial cells sitting on the spleen tell the fist-sized organ that there's no need to mount a protective immune response.

"It's most likely a hamburger not a bacterial infection," is basically the message, says Dr. Paul O'Connor, renal physiologist in the MCG Department of Physiology at Augusta University and the study's corresponding author.

Mesothelial cells line body cavities, like the one that contains our digestive tract, and they also cover the exterior of our organs to keep them from rubbing together. About a decade ago, researchers found that these cells also provide another level of protection. They have little fingers, called microvilli, that sense the environment, and warn the organs they cover

that there is an invader and an immune response is needed.

The spleen is part of the immune system. Drinking baking soda, MCG scientists think, tells the spleen to go easy on the immune response.

In the spleen, as well as the blood and kidneys, they found after drinking water with baking soda for two weeks, the population of immune cells called macrophages, shifted from primarily those that promote inflammation, called M1, to those that reduce it, called M2. Macrophages.

Researchers discovered the effect when treating lab animals for kidney disease.

That's when they saw reduced numbers of M1s and increased M2s in their kidney disease model after consuming the common compound.

Then they tried it on healthy medical students who drank baking soda in a bottle of water. The effect was similar. They hope drinking baking soda can one day produce similar results for people with autoimmune disease.



Dr. Paul O'Connor renal physiologist in the lab at the Medical College of Georgia University Department of Physiology at Augusta University

Mumble Bar

A recipe for you to try from Wellington member, Dot

Dot brought mumble bars to our August meeting. We had to have the recipe.

125 gm butter

1 cup sugar

2 tblsp golden syrup

1 cup flour

1 cup coconut

1 egg

3 Weetbix crushed.

Melt butter, sugar and golden syrup in a pot.

Add all other ingredients and mix.

Press into a greased sponge roll tin.

Bake at 180 degrees C for 15 – 20 minutes until lightly browned.

(It's easier to cut into squares whilst hot and then leave to cool in tin before removing)

Extra

I am inclined to add some raisins or sultanas.

Sometimes I ice it or add melted chocolate to the top.

It enhances the plain look of the slice when it's baked, although it tastes just as nice without.



Noticeboard

Wellington next meeting date

Saturday 10 Nov 2018 1:00 pm to 4:30 pm

Venue:- Russell Keown House, Queens Drive, Lower Hutt

Christchurch next meeting date

Thursday 20th of September 2-4pm

Venue:- Mc Donalds Merivale 217 Papanui Rd, Merivale, Christchurch in the free community room, as long as you buy a coffee at the Mc Cafe.

Auckland Central meeting dates

Sunday 28 October 1pm - 4pm

Venue:- Highbury House, 110 Hinemoa St, Birkenhead, Auckland

Auckland Contacts:

sclero.akl@gmail.com

Ph Ann 021-0277-4544 or 550-5690

Ph Michelle 027-277-5773

Respiratory support group meeting dates

13 October 2018

24th November 2018 Christmas Meeting 2018

Venue:- 327a Whangarata Road, Tuakau, Auckland 2694

Hamilton Seminar

27 October

Contacts

Find a Scleroderma support group near You

Auckland: Ann Wills
sclero.akl@gmail.com

Auckland Respiratory: Allan Edmondson Email-
allanedmondson@xtra.co.nz

Hamilton: Linda Bell Email:-
linda.bell@hotmail.co.nz

Palmerston North: Chris Carlyon
ningandalley@clear.net.nz

Invercargill: Heather Milligan
03 248 5147

Wellington / Christchurch: Dianne Purdie-
diannepurdie@xtra.co.nz

New Support Groups

If you would like a support group in your area please contact Dianne Purdie 04 479 5548 or email diannepurdie@xtra.co.nz and I will be happy to help you set one up.

Scleroderma New Zealand Inc.

President: Dianne Purdie
diannepurdie@xtra.co.nz

Newsletter: Barbara Spavin
barbara@spavin.com

Does your area plan a meeting? For times, venue and directions to all meetings that we know about:

www.scleroderma.org.nz/calendar/

www.scleroderma.org.nz

