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# Scleroderma

New Zealand support group

## Winter 2019

### Greetings to you all.

We hope that everyone is well. We have a wealth of information to share from the recent Wellington seminar and lots of news and happenings from our members..

Firstly, thank you to Dianne and Gordon for organising another successful, informative and very enjoyable seminar here in Wellington. Dianne did an excellent job organising a good line-up of speakers, who all gave their time to talk to us on their specialist topic. Many thanks to all our scleroderma members who travelled from all parts of the country both from the South Island and North Island, and all parts in between. Without you it wouldn't have been a success. We learned lots of new information, met up with new faces, met up with old friends and had heaps to eat.

We hear first from Dianne with her presidents report. She keeps us up to date with what's going on around New Zealand.

We have a Memorial to Sandy Edmondson.

We then have the presentations from the seminar. This year, we were lucky to have 5 excellent speakers, who each had very valuable information to share with us. I am sure that each person was able to take away some valuable information that they learned that day. We had: -

- Kirsten Lassey, Clinical Nurse Manager, Respiratory Services – **'Scleroderma and Lung Disease'**
- Gerrard Wake, Podiatrist, Hutt Foot Clinic – **'Looking after your feet with Scleroderma'**
- Dr Rebecca Grainger Rheumatologist - **'Empowerment - from managing self to managing systems'**
- Amanda Johnson and Theresa Vaughan, Working Hands – **'Hand care/ support and exercises'**
- Steve Russell, Dental Technician - **'Scleroderma and Oral health'**

We also have lots of news from our members, and events happening.



# Presidents Report:

## June 2019

Hello everyone, I hope that you are all keeping warm and as well as you can.



A big welcome and thank you to Tina McLean and Jenny Andrews our New Newsletter Editors.

We will all very much appreciate your efforts.

Don't forget to have your flu shots if you haven't already, The flu is a shocker this season..

We had a big storm here in Wellington last night so it's been a bit of a clean up today. With lots of layers on to keep the core warm. Something we all must be mindful of from now on. Get dressed up warm with all your layers before you head outside. We had a very sad start to the week, with Sandy Edmondson passing away. Sandy was a beautiful person. Sandy will be greatly missed by all that knew her. She was a very special lady. Allan and family will need lots of support over this rough time, so if you would like to write to Allan, just email me and I will get you in contact.

Barbara and John Spavin our just past newsletter editors are also having a rough time too with health, a nice email to them would be welcomed too.

Two weeks ago now we had the National Scleroderma Seminar here in Wellington, it was wonderful to see everyone that came.

A huge thank you as your presence is what makes the seminar a success along with all the great work our speakers put in.

We all learnt a lot, and came away feeling refreshed, and it was nice to meet old friends and make new ones too.

Gordon has been working on a submission for the Health and Disability Review.

They are seeking national input to ensure the Panel has a good understanding of how the system is working currently and to identify the issues most critical to improving the effectiveness and equity of the system. They were interested in our views on the system level changes which would have the most impact on improving equity of outcomes in the future.

There will be more on this later in the newsletter. It is great to see people getting together in groups around the country.

Starting with Allan's PAH/ Scleroderma group in Auckland, down to Linda's great coffee group in Hamilton, Chris' coffee group in Palmerston North, Our great Wellington group and now down to Nelson which is our latest group of scleroderma friends all looking after each other, then down to our lovely ladies in Christchurch who are also having a great time getting to know each other and right down to our very active largest group run by Jenny and Heather for Southland.

A huge thank you to all our members for keeping together and helping each other out especially when the going gets tough.

We will have our AGM soon and the end of the month on the 29th which is World Scleroderma Day, I hope you all find something nice to do on the day, if possible, even if it is going out, for a nice coffee/ lunch and chat with each other.

Or it is a chance to raise awareness for Scleroderma. You may have some nice ideas :-)

Take Care and KEEP WARM AND WELL  
All the Best

Dianne



## Memorial For Sandy



Sandy



It is was great sadness that we bring the news of Sandy Edmondson's Passing on the 27th of May 2019.

We have known Sandy for quite a few years now. Sandy had Pulmonary Hypertension and Scleroderma. Sandy had lots of encouragement for everyone she came across with these conditions, she was strong and positive and extremely helpful.

Sandy was always a very strong truthful, thoughtful lady. A huge spirit of kindness and a down to earth sense of humour, even when things were very difficult.

Sandy's truth was always just what you needed to hear, it always came kind and meaningful with a deep philosophy on what life is really about and that was caring for people no matter what!, And Sandy did that right till the end.

There was no mucking about, and getting to the point of what really mattered in life was what Sandy made her mission.

Both Sandy and Allan have been seen driving from one end of the country to the other and welcoming people into their home, to help someone in their hour of need, especially after receiving a tough diagnosis of Pulmonary Hypertension. Leaving these people with lots of encouragement to keep going and helping them feel purpose in their life after diagnosis.

Sandy and Allan put a lot into Pulmonary Hypertension New Zealand and Scleroderma New Zealand over the years and I know their work has been wonderfully respected.

We will miss Sandy and her kindness, but she will always be in our hearts.

# SCLERODERMA SEMINAR 2019:

## Scleroderma and Lung Disease

Kirsten Lassey, Clinical Nurse Manager,  
Respiratory Services

Kirsten Lassey, Specialist Nurse, Lung Disease, Hutt Hospital, shared her knowledge with us at the Scleroderma Seminar on 18th May this year.

80% of people with Scleroderma have some lung involvement.

Pulmonary Arterial Hypertension (PAH) and Interstitial Lung Disease (ILD) are the most common problems.

Interstitial Lung Disease is pulmonary fibrosis causing scarring, stiffness of lung tissue, less flexibility, and leading to shortness of breath.

Pulmonary Arterial Hypertension makes it hard to pump blood, resulting in sustained high blood pressure in the small arteries. It builds up slowly with the first symptoms being an increasing dry cough and shortness of breath.

Both diagnosis and treatment have improved in the past 10 – 15 years. Kirsten recommended to be judicious when looking up Google as many articles were not up to date; their prognosis was too grim for today's treatments.

### Screening:

There is no Gold Standard, with not all tests available in all DHBs. All patients should be screened at diagnosis of scleroderma (not ILD and PAH). Stethoscope, clinical questioning, and ability to walk upstairs are common starting points.

**Spirometry tests** and **other Pulmonary Function.** Spirometry measures how much air can be breathed in/out and how quickly. Other pulmonary function tests will reveal if there is reduced diffusion oxygen into the blood.

**BNP** is a blood test for chemicals that are released by the body when the heart muscle is stretched

**6 minute walk** tests heart rate and oxygen levels on exertion. This is a good test without being invasive.

**HRCT** scans for pulmonary fibrosis.

**ECHO** test when PAH is suspected, but tends to give lots of false negative results. There are very long waiting lists for this test in some hospitals.

**Right heart catheter** can give a specific diagnosis of PAH but is very intrusive.

Tests should be annually in the first years when fibrosis is more likely to be rearing its head, then every couple of years. Patients should advocate for screening if shortness of breath is becoming a greater issue.

### Treatment for ILD:

There is not much treatment.

Prednisone which has many side effects, may be used.

Oxygen if needed. Low oxygen levels do not correlate with breathlessness though. Oxygen is given to increase the oxygen reaching the vital organs: liver, kidney, brain, heart will all work better.

### Treatment for PAH

Drugs have increased, with more being available.

#### First Line of Drugs:

Diltiazem, a calcium channel blocker has good outcomes but only works for a small minority.

Warfarin, but clinicians are more cautious now because of risk from bleeding.

Sildenafil (Viagra) is a first line drug available because of Pharmac funding. Many respond well to this drug. It dilates the arteries leading to lower blood pressure for PAH.

#### Second line of drugs:

Bosentan can help to reduce narrowing of arteries.

Iloprost, a nebuliser that opens up arteries, ideally taken 7-9 times a day as it won't stay in the system. It takes 4 -5 minutes to work, but it's not taken at night, for obvious reasons.

### Self-Management of Lung Disease:

Don't stop drugs suddenly as there can be a rapid rebound effect.

Be aware that any sudden and extreme change in diet can affect warfarin; e.g. Sudden increase in broccoli can impact on warfarin.

Build a good relationship with your G.P. and Pharmacists so that they are aware of your needs, and stock supplies as needed.



# SCLERODERMA SEMINAR 2019:

## Scleroderma and Lung Disease

### *Continued...*

Google does not show that different patients react differently to drugs. Research is only now beginning to understand why.

Exercise is really important; 'Use it or Lose it.'

**Better to have consistency and "Pace Yourself" so you are exercising continually - Not 1 day exercise and the next day you are unable to do anything as you are shattered.**

Pulmonary Rehabilitation Programmes run by Physiotherapists and/or nurses are available at **DHBs**. These are 9 weeks of twice weekly exercise and education programmes usually focussed on COPD & emphysema patients; sometimes PAH patients are included.

Wear protective masks when working with pollutants as lungs are more susceptible.

Pregnancy is particularly difficult to manage in PAH, a high percentage of pregnant women with PAH do not survive pregnancy, and some drugs can affect the unborn baby.

Manage breathlessness by pacing yourself so your breathlessness is around 4 out of 10. Consistent activity is better than 'boom and bust.'

In cold weather do circuits inside the local mall.

Breathe through your nose or wear a scarf to protect your airways from cold weather.

Choose an exercise you enjoy as you're more likely to continue with it.

Lung Disease tends to be progressive so track your breathlessness over 6 months to see how it progresses. Try drugs to see what your journey is like. How you respond to your first drug suggests how the disease will progress.

Scleroderma based pulmonary hypertension has less positive outcomes than other forms of PAH.

## Looking after your feet with Scleroderma

Gerrard Wake, Podiatrist, Hutt Foot Clinic

Gerrard Wake, our Podiatrist, spoke at the seminar about looking after our feet [Nail Care, Skin-related conditions, chilblains, Footwear. Foot exercises to maintain mobility, and the audience mentioned – soaking feet in Epsom Salts is very good].

### Nail care :

Podiatry NZ has concerns about standards of hygiene in salons for both toenails and fingernails.

Cut straight or slightly concave (sides higher than middle) across top. Don't cut too far down sides to avoid ingrown toenails.

### Skin-related conditions & chilblains.

Impaired circulations with chilblains can lead to ulcers.

Use foot creams to moisturise and help warm tissues. Wear warm socks – possum fur best but wear out quickly. Really important to use insulating insoles to insulate against cold – **plastazote**.

### Footwear – to maintain mobility

Technical shoe shops for good shoes, advice and fitting e.g. Shoe Clinic, Athlete's Foot, Smith Shoes (Hamilton shop has a podiatrist), Shoe Science.

Most important is mid-sole density and thickness. Hoka is a good brand. Rocker sole also good.

**Foot exercises also to maintain mobility** – see arthritis exercises

Gerrard also spoke about how important to insulate feet from cold, and the best product was **plastazote**. Plastazote is available online or through some outlets, such as Chemist Warehouse.



# SCLERODERMA

## SEMINAR 2019:

### Looking after your feet with Scleroderma

*Continued...*

#### Plastazote Construction:



Plastazote is widely recommended for people with diabetes, arthritis or any skin disorder that requires your foot to remain friction-free. This is an anatomically designed footbed with longitudinal arch support which uses your own body heat to mold the insole and evenly distribute the weight. A bottom layer of ultra-cushioning polyurethane is combined with a top layer of self-molding Plastazote foam to form precisely to your foot. Medical professionals regularly use Plastazote for its superior ability to relieve pressure on sensitive foot areas.

<https://www.pharmacydirect.co.nz/Neat-Feat-Orthotics-Self-Moulding-Insole-Small.html>

#### Information from UK Scleroderma & Raynaud's website

##### How can systemic sclerosis affect the feet?

Most people tend to give their feet little consideration until they develop problems.

Systemic sclerosis (systemic scleroderma) can affect the feet in many ways including the circulation, nails and skin.

##### **NAILS**

The nails can be affected in several ways. We know from looking after many patients with systemic sclerosis that the bones at the end of toes may alter their shape (be re-absorbed), which in turn alters the shape of the nail. This may lead to an increased incidence of ingrowing toe nails, which can be both painful and prone to infection.

##### **SKIN**

Many patients with systemic sclerosis experience patches of thickened skin, and these patches may be found on the feet, commonly on the dorsum (top) of the foot. You may also notice that your skin generally becomes dry and itchy. Some people may experience calcinosis where bumps of calcium form under the skin and can be painful. Sometimes the calcium breaks through the surface of the skin and a soft chalky substance is released which often eases the discomfort. It is very important not to attempt to treat these yourself but to observe the calcinosis for signs of infection, which will require assessment by your doctor for antibiotics, and to seek medical advice if the calcinosis is a problem to you. Some people with systemic sclerosis experience a feeling of 'walking on pebbles', particularly when walking on uneven surfaces. This may be due to changes in the fibro-fatty pad which normally protects the ball of the foot. This discomfort can be helped by podiatric input to provide appropriate padding or the use of footwear with a thick sole which will add a layer of protection to the ball of the foot.

##### **INFECTIONS**

Some people with systemic sclerosis may find that they are more prone to developing infections, or that infections take a long while to get rid of, even with prompt use of antibiotics. The reason for this may be related to the underlying effect of systemic sclerosis itself, or indeed from some of the treatments associated with systemic sclerosis such as immuno-suppression.

It is very important that people with systemic sclerosis visit their GP promptly if they notice any sign of infection. Signs of infection include heat, swelling, pain and redness.

[https://www.sruk.co.uk/media/filer\\_public/98/7b/987b4074-787a-43f9-bad8-501f1dd8453d/foot\\_factsheet\\_v4.pdf](https://www.sruk.co.uk/media/filer_public/98/7b/987b4074-787a-43f9-bad8-501f1dd8453d/foot_factsheet_v4.pdf)



# SCLERODERMA SEMINAR 2019:

## EMPOWERMENT:

### From Managing Self to Managing Systems



Dr Rebecca Grainger,  
Consultant Rheumatologist  
Hutt Valley DHB  
Associate Professor  
University of Otago  
Wellington

2. **Expertise:** patients self-manage their condition every day so they have a unique expertise on healthcare which needs to be supported.
3. **Equality:** patients need support to become equal partners with health professionals in the management of their condition.
4. **Experience:** individual patients work with patient organisations to represent them, and channel their experience and collective voice.
5. **Engagement:** patients need to be involved in designing more effective healthcare for all, and in research to deliver new and better treatments and services

## Education:

**Patients can make informed decisions about their health if they are able to access all the relevant information, in an easily understandable format.**

Dr Grainger talked about using the **Health Navigator** website: <https://www.healthnavigator.org.nz>

The Health Navigator website is for New Zealanders and New Zealand Practitioners.

## General Health Information



The website states *“You need to have confidence that you can trust the information you are receiving online. This is why we go to great lengths to ensure our website provides you with the reliable, New Zealand-focused health information you are seeking.”*

## Your Health Information:

Dr Grainger, mentioned that we need to ask our General Practice if they use the Health Navigator Portal called **“Manage My Health”** for their patient file – if not, ask them why not, and suggest they should consider using it. Members who have a General Practice offering **“Manage My Health”** should ask practice staff how they can access it.

Dr Grainger started her presentation by asking us all the two questions below:

- What does **Empowerment** mean to each one of us ?
- What aspects of **Empowerment** do you want to hear about ?

Dr Grainger then put up the slide below, I refer to it as the 5 E’s.

## 5 E’s of Empowerment:



1. **Education:** patients can make informed decisions about their health if they are able to access all the relevant information, in an easily understandable format.



# EMPOWERMENT: From Managing Self to Managing Systems *continued...*

## Manage My Health Portal:



### Benefits for patients:

Manage My Health, allows members to access their file, history and medications. They can send emails to their practice and ask for prescription repeats. They can also see results to all their tests.

### Expertise:

Patients self-manage their condition every day so they have a unique expertise on healthcare which needs to be supported.

### Self-Management:

Choose a topic below or simply scroll down:

- **Stanford self-management programme** (learn a range of generic skills and tips to maximise your health and wellbeing)
- **Green Prescription** (a recommendation from your doctor or nurse that for your health's sake, you need to increase your physical activity levels)
- **Steady as You Go** (a peer-led exercise programme)
- **Walking groups** (there are hundreds of walking groups around NZ for all ages. Find one near you)
- **Beating the Blues** (online programme that helps treat mild to moderate depression and anxiety)
- **The Journal** (self-help online programme that will help you learn a range of skills to reduce depression)

Arthritis New Zealand runs Self-Management courses. Dr Grainger asked us all to state what was our important *“Self-Management is”* – each one of us said a different thing. Mine was – *“time for myself”*

In the **Health Navigator** there is a link to download **My Tool Kit** or you can order copies by **contacting HN team**.

Resource	What is it?
<p>My Toolkit</p>	<p><b>Take Charge: My Toolkit</b></p> <p>This booklet is ideal for anyone wanting to get back in the 'driver's seat' of their health and improve the areas they can influence. Nearly everyone can improve some aspects of their health and wellbeing with the right knowledge, support and skills which this booklet will help you learn.</p> <ul style="list-style-type: none"> <li>• Can be worked through on your own and then with your healthcare team</li> <li>• Ideal assessment and care planning tool for nurses, GPs, allied health staff and health coaches</li> <li>• 40 pages</li> <li>• <a href="#">Download My Toolkit</a></li> <li>• Order copies by <a href="#">contacting HN team</a></li> </ul>

## Equality:

Patients need support to become equal partners with health professionals in the management of their condition.

Dr Grainger said that we should take better care by following the Four steps for our next health care visit:

# Let's P.L.A.N. for better care Four steps for your next health care visit



## EMPOWERMENT:

### From Managing Self to Managing Systems

*continued...*

#### Let's P.L.A.N. for better care

##### Prepare for your visit

- Write down your main concerns or questions
- Make a list of your medicines and supplements
- Did you know you can take a support person with you and ask for a translator?

##### Listen and share

- Say if you don't understand and if a drawing could help
- Say if you're having problems with your medicines or treatment, or can't afford them
- Is there anything else you can tell your doctor or nurse about your health?

#### Ask questions

- What is my health problem?
- What happens next?
- Why is that important?
- Are there any other options?
- What can I do to help with my health?

**Note down what you need to do next**

## Experience:

**Individual patients work with patient organisations to represent them, and channel their experience and collective voice..**



Scleroderma New Zealand Inc.



## Engagement:

**Patients need to be involved in designing more effective healthcare for all, and in research to deliver new and better treatments and services**

## Scleroderma and Oral Health

Steve Russell, Dental Technician,  
Petone Dental Laboratory Ltd.

Steve Russell spoke about oral health. He said one of the risks was underproduction of saliva, which resulted in increased tooth decay because of higher acidity in the mouth and reduced salivary cleaning. OralSeven mouthwash is formulated to maintain a neutral pH of 7 to counteract acidity. It also contains Aloe Vera which addresses the dry mouth problem. Many thanks to Adrienne for sharing this information.



<https://yourchemist.co.nz/s.../oralseven-mouth-wash-500ml.html>

**Two problems with mouth:** not enough saliva and tight mouth/face muscles. Saliva is an antiseptic, necessary for cleaning mouth. Also important to aid digestion and swallowing. Insufficient saliva leads to reduced oral hygiene and swallowing difficulties. Saliva replacements are not very effective. Can suck on sugar-free gum or mints (Eclipse) to stimulate saliva production, and/or use aloe vera juice to supplement saliva. Exercises for mouth muscles were included in respiratory section – opening wide, puckering closed, broad smile, puffing out cheeks. Moisturise and massage to warm before exercises. Hold a warm facecloth over your mouth. Don't use Vaseline often, but do use before going to the dentist, and massage and exercise.

**Dental appointments:** Get a recommendation for a dentist from the Scleroderma Society, or other people locally. Discuss with dentist before making an appointment. Keep appointments short. May need to see a dentist or hygienist more often if having difficulty cleaning teeth. Use fluoride toothpaste and leave on overnight rather than rinsing off.

After eating or drinking, rinse mouth with water to restore neutral pH, then wait for half an hour or so before brushing teeth. Food and drinks tend to be acidic and soften enamel. Allow to harden again before brushing.

**Tooth implants** are not recommended with scleroderma. And not plastic partial plates. These days 3D printed chrome cobalt.

<https://www.sruk.co.uk/scleroderma/scleroderma-and-your-body/oral-and-dental/>



## Hand care / support and exercises:

Amanda Johnson and Theresa Vaughn, Working Hands.

After a lovely lunch, our speakers were Amanda Johnson & Theresa Vaughn from Working Hands. They talked about Hand Care/Support & Exercises.

Amanda and Theresa brought a whole bunch of products to show us and also gave us a bag of goodies to take away.

They talked to us about Hand Therapy for Scleroderma and covered a whole range of topics.

### Typical Symptoms:

- Painful and Stiffness of the Joints
- Swelling or puffiness of the hands
- Sclerodactyly and Joint Contractures
- Raynaud's Phenomenon
- Ulcers/sores on fingertips
- Calcinosis

They talked about Joint Protection and the ways to protect the joints.

### Joint Protection:

- Respect pain
- Avoid prolonged static positions, avoid positions of deformity

### Ways to Protect the Joints:



- Avoid tiredness by:
  - Pacing
  - Plan ahead and set priorities
- Maintain muscle strength and joint range of motion
- Use larger muscle groups
- Use Adaptive aids
- Splints

They talked and showed us different splints for hands and how they were used. They sent around the splints so that we could all have a try.



They talked about Adaptive aids and brought out some, which were handed out for members to try.

### Examples of Adaptive aids:



Spring loaded scissors, so that when you cut down they spring back, similar action as secateurs.

These scissors save on time and are so helpful for sore hands or joints as you don't have to put in so much effort.

### Skin Protection:

- Keep the skin moisturised. Any good cream will do.
- Avoid Deep Heat and Tiger Balm.
- Use Gloves to prevent trauma to the skin

### Raynaud's Phenomenon:



Amanda showed a slide that had products that could assist keep the hands warm.

- Wear gloves
- Heating Hands
- Use Hand warmers when outside

My favourite was the USB Heated gloves that plug to your computer / laptop, while working.



There are even USB heated gloves that come in a Toast shape!



# Hand care/ support and exercises continued...

## Cutting Nails:

- Soak nails first
- Remove dead skin around the nail with exfoliants, files, and pumice stones.
- Use Adaptive aids (if you have difficulties cutting your nails).

## Tips on exercising:

- Warm up hands before exercising them
- Heat +/- massage
- Do little and often
- Symptoms to aim for: -
  - o Stretches – moderate pulling feeling
  - o Strengthening – slight fatigue
- Symptoms to avoid: -
  - o Never – long lasting pain
  - o Swelling

## Exercises for the Hand:

The primary goal is to preserve:

- MCPJ flexion (bending)
- PIPJ extension (straight knuckles)
- Webspace
- Lateral pinch (MPJ flexion of the thumb, in order to hold things and turn e.g. keys)

## Monitor Range of Movement:

- Finger Extension
- Finger bending and straightening
- Finger /thumb extension and spanning out



## Strengthening Exercise:

- High repetition, low loads (endurance vs big muscle bulk)
- 1-2x/ day (recovery time)

## Summary: (Hand Therapy Goals)

- Moderation is key
- Maintain maximal ROM (Range of Motion) MCPJ flexion, PIPJ extension and thumb abduction.
- Prevent unnecessary contractures; e.g. wrist/elbow
- Maintain Lateral Pinch
- Improve functional ability & reduce hand pain
- Encourage optimal skin care
- Promote circulation / blood flow.

# Health and Disability System Review submission

## Submission from Scleroderma New Zealand

Scleroderma New Zealand would like to see changes to the health systems to make it fair and equitable for people with scleroderma and other conditions. Scleroderma New Zealand notes the following issues where the health system could be improved.

## Variation in provided health care

Scleroderma New Zealand has noticed variation in the health care provided to people with scleroderma and some other conditions in New Zealand. Some people are receiving care that puts them at greater risk of ill health and death. The current system is unsafe and has probably resulted in premature deaths. This variation in health care is driven by both policy variation between DHBs and variation between individual health practitioners. It is probably unreasonable to expect every health practitioner to understand what is good practice for all conditions and it is certainly unreasonable to expect people with a condition to know what is good practice for their condition.



# Health and Disability System Review submission

...continued

Scleroderma New Zealand also notes there are inequalities between the health care provided to different conditions.

Examples:

A survey of Scleroderma New Zealand members, with about a 50% response rate, found that only 33% had had a 6-minute walk test.

A survey of New Zealand rheumatologists, with a 65% response rate, found that 82% screened for pulmonary arterial hypertension (PAH) in all scleroderma patients. The researchers concluded that the study has shown a wide variability of how NZ rheumatologists screen for PAH in scleroderma patients. They said that the development of a PAH Scleroderma guideline for screening and diagnosis may help standardise treatment practices in NZ.<sup>1</sup>

An audit of screening of 49 scleroderma patients at Middlemore Hospital found that for investigations for scleroderma lung disease 71% had lung function tests, 69% a chest x-ray and 59% high resolution chest CT scan. To assess for pulmonary arterial hypertension 47% had an echocardiogram. To screen for renal involvement 80% had blood pressure measurements, 41% urine dipstick analysis and 71% electrolyte. They concluded that scleroderma lung disease had been poorly screened for. Most of the patients did not have the recommended annual screening echocardiography.<sup>2</sup>

Scleroderma New Zealand understands that people with diabetes receive funded foot care that is not provided to people with scleroderma, despite people with scleroderma also having foot care needs and amputations.

The survey of Scleroderma New Zealand members found that virtually everybody, 99%, had problems with their

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<sup>1</sup> Ghosh, S.K., Corkill, M.M., Hart, H.H., Ng, K.P. Screening for pulmonary arterial hypertension in patients with scleroderma—a New Zealand perspective. *The New Zealand Medical Journal*. 2014, 127(1400):30-38

<sup>2</sup> Ng, K and Gow, P. Management of scleroderma in a New Zealand tertiary rheumatology centre: emphasis on pulmonary complications. *The New Zealand Medical Journal*. 2007; 120 (1254):18-26

feet. For 64% the costs prevented them, or sometimes prevented them from seeing a podiatrist and 16% of people could not fully care for their feet and do not see a podiatrist.

Proposal: A solution to these inequities would be to have a health system with protocols covering all conditions.

## Scopes of practice

Some people with scleroderma have health care needs that are not included in any registered health practitioners' scope of practice. This is resulting in people receiving unsafe care from unregulated providers. The scopes of practice appear to be focused on the practices of health practitioners rather than the health needs of those with health conditions.

Example: Some people with scleroderma are unable to cut their finger nails. There appears to be no health practitioners with a scope practice that includes finger nail cutting. When people with scleroderma have asked nurses, podiatrists and hand therapists if they would cut their finger nails, they have been told it is not in their scope of practice.

People with scleroderma have had to go to unregulated nail salons to meet this health need. Nail salons have been found to be unsafe.<sup>3</sup>

Proposal: There needs to be a health system that ensures all health needs of people are covered by a scope of practice for a health practitioner.

## Heating

The health of people with scleroderma is affected by temperature. Being cold can damage a person's tissues. Some people with scleroderma cannot afford to heat their homes adequately. This is sometimes compounded by people being unable to work as a consequence of having scleroderma. Providing a warm environment for people with scleroderma should be part of the provision of health care.

Example: A survey of Scleroderma New Zealand members found that 13% couldn't afford to heat their home comfortably, 28% could only sometimes afford to heat

<sup>3</sup> Regional Public Health. 2018. Survey of Knowledge and Infection Control Practices in Salons Offering Nail Services. Wellington. Regional Public Health.



their home comfortably, and 22% said they would go without things they need like food to pay the power bill. One person spent \$600 in a month heating their house and said they definitely could not afford it and they will have to go back to having a cold house.

Proposal: There should be a health system that provides adequately for health needs, including when those needs, for example heating, have not traditionally been part of the health system.

## DEA Clears Cannabinoid-derived Active Ingredient in Investigational Scleroderma Therapy EHP-101

*Source Scleroderma News*



The U.S. Drug Enforcement Administration (DEA) has cleared the use of the active ingredient in EHP-101, an investigational therapy for treating multiple sclerosis (MS) and systemic sclerosis (SSc), according to Emerald Health Pharmaceuticals, the therapy's developer.

After a detailed review, the regulatory agency has determined that the active pharmaceutical ingredient in EHP-101 — a non-reactive, non-psychotropic compound called VCE-004.8, derived from synthetic cannabidiol— is not classified as a controlled substance under the Controlled Substances Act.

This new status means EHP-101 is not defined as substance that could be associated with a potential for

abuse, such as hallucinogens, narcotics, depressants, and stimulants, the company said.

"This determination by the DEA that our lead product candidate, EHP-101, is not considered a controlled substance in the U.S. is of great benefit to us," Jim DeMesa, MD, CEO of Emerald Health, said in a press release.

EHP-101 is an orally available therapy that is being explored as a potential treatment for systemic sclerosis. It was found to modulate inflammatory and fibrotic processes in earlier mouse models of the disease.

Results from previous studies in animals also have shown that treatment with EHP-101 can potentially promote the formation of new blood vessels and prevent vascular damage, which is common in systemic sclerosis patients.

Emerald is now conducting a Phase 1 clinical trial (NCT03745001) in Australia to test EHP-101's safety, tolerability, overall stability, and activity.

The study is recruiting up to 104 healthy adults who will be randomly selected to receive single ascending doses or multiple ascending doses of EHP-101, or a placebo. Results from this initial study, scheduled for completion in May, are expected to support further Phase 2 trials in patients with systemic sclerosis.

"Not being a controlled substance eliminates the many costs and complexities associated with developing controlled substances," DeMesa said. "It facilitates the manufacturing and import of the product to the U.S. and simplifies the conduct of our non-clinical and clinical studies, including the selection of U.S. clinical sites to conduct our planned Phase 2 studies for MS and SSc patients."

EHP-101 received orphan drug designation from the U.S. Food and Drug Administration in 2017, and also from the European Medicines Agency in 2018 for the treatment of systemic sclerosis.

Orphan drug status, which allows for a faster schedule of development and review for approval, is given to potential therapies that have demonstrated promise to treat rare diseases.



# GENERAL NEWS: Celebrating our 10<sup>th</sup> Birthday



**Scleroderma  
New Zealand Inc**



## Members Stories:



### Lisa Furness

So 6 months ago in September last year I was in Christchurch Hospital for two weeks, very very ill and in so much pain I just wanted to die to escape the terrible pain my body was in...it was then I was diagnosed with scleroderma. It came on very quick for me, within four weeks... from being what I thought was fit and healthy, I was running 4 times a week competing in many runs. Then just out of nowhere I got sick, real sick and they flew me from Nelson hospital to Christchurch where after many test I was diagnosed...as they figured out my medication I slowly but surely improved... after all sorts of medication I was allowed home late September... since then I have been determined to beat this disease the best I can... staying fit with plenty of exercise and cutting out all processed foods...before my diagnoses I was a very active person running 4 times a week and competing in running events...so 4 months ago I slowly started riding my pedal assist mountain bike...and on Friday we travelled to the West Coast to compete in the mountain view moonlight 22 km mountain

bike race... my first competitive race since becoming a scleroderma sufferer... I am very proud today, I came across the finish line in first place.... Such a huge achievement for me from where I was 6 months ago... so I have attached my photo and in typical West Coast fashion it was raining so I was wet and covered in mud.. but it was the best day I've had in a long time...then I went on to do my first competitive run since getting scleroderma... and wow it felt so good... I ran my heart out for all us scleroderma sufferers.... And I hope to be running plenty more...positive thinking and determination is my motto.... I hope this story inspires even one scleroderma sufferer...

Take care everyone and stay positive...



# Members Stories:

## Catherine Thompson

Congratulations to Catherine Thompson. She has had one of her photo's published in the latest **Time Magazine**, that is a great honour!!!

Copy of the page and photo of my **Clematis Seed** in the **National Geographic Traveler Magazine, June 2019 Issue**. (Traveler is spelled correctly – USA spelling - Catherine can't give us the original as they have the rights to it).

### In Catherine's own words: -

My photo was chosen by a National Geographic Editor in the USA for inclusion in this Issue. You do not approach them they come to you. I have been a member of the National Geographic Your Shot site for a couple of years. You post your photographs up and they get awarded and commented on by other photographers. You can also enter challenges. I was honoured when my photo was selected though was not sure it was all for real. I initially thought it could be a scam as I had been receiving so many strange emails. Eventually after a few emails over a couple of months it all came together and the photo was published and is now in shops. A friend in Canada walked into a shop and was thrilled to find My Photo in a magazine on the shelf. She has sent me a couple of magazines by snail mail.

The article was written by a women who travelled from Bluff to Cape Reinga. She chose my photo because she was told that to the Maori, the white Clematis is the first sign of Spring. I took the shot in my garden and to me it looked like a star or world



floating against the fence. Each of the feathery tails highlighted in the sun. Once the seed head dries out the feathery tails carry the seeds off where they drop to the ground and germinate.

**The photo is called:**

### Windmill Star Seed

A feathery windmill clematis seed head shining in the sunlight in a Manawatu Summer garden, New Zealand. A shiny world of promise on the grey fence, hanging as if in the sky and drawing the eye. These seed heads are so delicate but are able to survive the storms as they break up and drop each tiny seed to the ground where the sunlight and water will nurture and encourage germination. We need each of nature's tiny, delicate wonders if we are to survive. Nature in balance is life for us all.



# My Scleroderma Seminar Trip was just What the Doctor ordered....

Kim's column from [sclerodermanews.com](http://sclerodermanews.com)

## SCLERODERMA AND THE ORDINARY GIRL

by Kim Tocker



The last two weeks have been extremely challenging. Living the scleroderma lifestyle means I never know what is around the next corner. Waking up brings a daily surprise, sometimes good, and other times not so pleasant. I have learned to go with whatever the disease presents me with each morning.

However, no matter how adaptable I think I am, kidney infections seem to sneak up on me. They arrive unannounced and become acute very quickly. They have sparked late-night visits to emergency doctors resulting in IV antibiotics and fluids. The discomfort is terrible, leaving me feeling unwell for days afterward.

I felt one coming on suddenly a fortnight ago; the signs were obvious about 60 minutes before its onset. In addition to the dread I felt, I knew that in six days, I would fly to Wellington to attend the Scleroderma NZ National Seminar 2019. I needed to be treated with antibiotics as soon as possible if I were to have a chance of attending.

While sitting in the emergency room at 4 a.m., with IV fluids and antibiotics running through a drip, I considered whether traveling the following week would be worth it. I have learned over the years that pushing myself when I am unwell is unhelpful and can cause a delay in my healing.

Deciding to go was tricky, but in the end, my husband, Max, and I chose to make the trip. We knew this was somewhat risky, as a day or two later, I still had symptoms, although the intravenous antibiotics gave me hope. The treatment resulted in a swifter resolution of my most distressing symptoms and a slight improvement in how I felt. But I wondered if it would be enough?

We set out with trepidation, my suitcase laden with all manner of prescription medications just in case — and

a hope that all of the action wouldn't exacerbate my symptoms.

I had a strange feeling that I was making a mistake and knew that if I consulted with my doctors they would likely have advised me to rest at home. As we flew out of Christchurch, I worried that this trip was not what the doctor ordered!

After an early night, Max and I set out to the conference the next morning. As we made our way into the seminar room, I was hit with a massive wave of friendliness and welcoming smiles. I experienced an innate feeling of belonging. I was with "my people."

We learned a lot from the speakers and came away feeling empowered. I felt unwell at times but managed OK. However, something happened that I hadn't expected. That feeling of belonging while in the presence of "my people" gave me a superpower that changed something for me.

It is difficult to explain precisely what shifted, but the change was one of healing and it was helpful. Gathering with other scleroderma warriors in one room offered a sense of belonging and a powerful feeling of kinship. This experience held me together inside because I knew that I was surrounded by others who fully understood my daily experience of living with scleroderma.

Thank you to all of the New Zealand scleroderma warriors who came to the weekend and love to those who couldn't make it. Whether we talked or not, your presence was part of something bigger for me, and I am eternally grateful. I am so happy I made it to the weekend — as it turns out, it was just what the doctor ordered!



# Members News: Southland Update -

Heather brings us up-to-date with happenings from down in Southland



Southland Group at Waxy O'Sheas, Invercargill

We were delighted in mid-April to have a get together for a meal in Invercargill. Lots of people with Scleroderma and their partners and lots of talking.

Is Southland unique that everyone knows everyone? For example, our newest member had been diagnosed recently. Her partner knows Alistair, a friend of ours, who knows I have Scleroderma, so contact was made. It was a delight that she was able to join us, but a bit sad that yet another person has been diagnosed that take the number in Southland on Jenny's list to 25.

Thank you so much Jenny for organising the lunch and organising our name badges. We look forward to the end of June to another lunch. I got an 'out of the blue' hospital appointment with my Rheumatologist at Southland hospital for an appointment last week. While Graham and I were waiting, Betty (a fellow sufferer with scleroderma) came out of the Drs room after her appointment and talking ensued, my turn and the Rheumatologist said she was checking up on her scleroderma people before winter, out of the consulting room we went and there were

Lorraine and David waiting.. which resulted in more talking. Pondering later that if we did not have our meetings we would not have known each other (Heather).

If you would like to join in with the Southland Group, please contact either:

Heather: [milliganseeds@xtra.co.nz](mailto:milliganseeds@xtra.co.nz)

Jenny: [jennyred@xtra.co.nz](mailto:jennyred@xtra.co.nz)

## Scleroderma Waikato news -

We have 10 members and we have been meeting at **Robert Harris Café, Chartwell, Hamilton** once a month for the past 7 Years now.

On the 29<sup>th</sup> **June World Scleroderma Day** we will be having lunch together at **Willow Glen Gordington**.

Next year will be another seminar for Hamilton which helps the newly diagnosed and family's to learn and understand and most of all to meet other people around the Waikato area.

Dr Solanki and Rheumatology Department at the Waikato Hospital are most helpful to me in preparing presentation's .

We have raffles and Morning and Afternoon tea and a lovely lunch and a good chance to chat with others.

I have had Scleroderma now for 31 years now and have seen to big change not only with Facebook, Google also with the medical staff and more information then I was given 31 years ago.

If anyone gets the Entertainment Books go to my Facebook page and where you can either get online anywhere in NZ or call in to Target Hamilton only to pick a book up. The money raised goes towards Scleroderma Waikato funds to help with the cost of Seminars.

Sadly a dear friend and coffee group member passed away on the 27th May, Sandy Edmondson had had Scleroderma, and PAH for 10 years . On Sunday the 9th June I will be at Sandys Life Celebration at her home in Tuakau.

**LINDA BELL**  
**SCLERODERMA WAIKATO**



## Helpful Hints, Useful Tips and Suggestions...

With the onset of Winter, it is very important to stay warm. Jenny has been looking into some different things that can help us with that.

The Warehouse: Living & Co **Electric Throw** (120x160cm) \$49.00  
Heat Extreme **Body Warmers** 1 pack (14 Hours of heat) \$4.00

Briscoes: Goldair **Electric Throw** with LCD Controller (120x160cm) \$149.99

Your Local Chemist: **Electric Hotties**  
Approx. \$40.00

(This is what I use under my jacket standing on the hockey side-line)

[www.cozee.co.nz](http://www.cozee.co.nz): **Back Warmer** \$59.95



**Waist warmer** \$59.95



(These are also electric and look fantastic if you have to leave the house. Would be wonderful for keeping your core warm. Because they tie around your waist, they are not going to fall down like my hottie does. )

## Joke of the day:



A magician was working on a cruise ship in the Caribbean. The audience was different each week so he did the same tricks over and over.

The problem was, the captain's parrot saw all the shows and began to understand how the magician did every trick.

He started shouting in the middle of the show: 'Look, it's not the same hat. Look, he's hiding the flowers under the table. Hey, why are all the cards the ace of spades?' The magician was furious but, as it was the captain's parrot, he could do nothing. Then one day the ship sank and the magician found himself floating on a piece of wood with the parrot.

They glared at each other but said nothing. Finally, after a week, the parrot said: 'OK, I give up. Where's the boat?'



# Events & Happenings:

29th June - World Scleroderma Day



## NOTICE of Scleroderma NZ AGM 29th and 30th of June 2019

Nominations of officers  
President:  
Vice President:  
Secretary:  
Treasurer:  
Nominations Committee:

Nominations for officers and committee to  
Gordon Purdie our secretary  
email:- [gordon.purdie@xtra.co.nz](mailto:gordon.purdie@xtra.co.nz)  
by the 20th of June.

If you have any General Business, could you please  
notify Dianne Purdie by the **20th of June**.  
This will help the meeting run efficiently.  
If you would prefer not to be part of the AGM  
dialog please let Dianne Purdie know by the  
**20th of June**



### June is Scleroderma Awareness Month



#### What is Scleroderma?

In short, Scleroderma is a rare, invisible, debilitating and extremely painful autoimmune disease which there is no cure for. It's often progressive and sometimes, fatal. It affects every age and gender and it's neither preventable or contagious. It confuses the best of the medical field by making it difficult to diagnose. Scleroderma attacks the Circulatory System, cutting off blood flow to extremities, resulting in Gangrene and amputation. It affects the Gastrointestinal Tract, Heart, Kidneys, Lungs, and Esophagus. Scleroderma causes hardening, thickening, and tightening of the skin which oftentimes, causes devastating results to one's facial appearance and one's mobility.

Those who have been diagnosed with Scleroderma are known in the medical community to be "SUFFERING IN SILENCE," because the nature of the disease manifests itself with internal symptoms and the patient seems outwardly to have nothing noticeably wrong. These internal manifestations are also seen as one of the main reasons why Scleroderma has a low awareness level among the general public.

Dreadful difficulties affect those living with Scleroderma. This disease steals people's freedom, jobs, friends, families, and it takes many lives.





# Regional Happenings:

News on what members are doing on  
Scleroderma Day – June 29<sup>th</sup> 2019

## Wellington

Wellington has just recently held the **National Seminar** on the 18<sup>th</sup> of May at Hutt Hospital. We had 42 people register for the day. It was a great turn out we all had a great time, meeting old and new friends, learning a lot of helpful information and being too well fed. A big thank you to all the help received on the day it was perfect and much appreciated.

- We hope to head out for lunch on the **29<sup>th</sup> June - World Scleroderma Day** for our annual celebration.
- Our next Meeting will be on the **17<sup>th</sup> of August**, Topic to be advised.

Please contact Dianne Purdie if you would like to join in, you would be most welcome. Email: [diannepurdie@xtra.co.nz](mailto:diannepurdie@xtra.co.nz)

## Christchurch

Our hard core group of ladies still meet every couple of months in Christchurch at the **Merivale McDonalds Community Rooms**. A good time is had by all, they have recently had a couple of new people join with them, but they welcome more to come along too.

- Their next meeting will be held on the **27<sup>th</sup> of July**.

Please contact Dianne Purdie if you would like to join in, you would be most welcome.  
Email: [diannepurdie@xtra.co.nz](mailto:diannepurdie@xtra.co.nz)

## Hamilton

- On the **29<sup>th</sup> June - World Scleroderma Day** we will be having Lunch together at **Willow Glen Gordington** . If you would like to join in with the **Hamilton Group**, please contact Linda Bell.

Email: [Linda.bell@hotmail.co.nz](mailto:Linda.bell@hotmail.co.nz)

## Southland

- On the **29<sup>th</sup> June - World Scleroderma Day** the Southland group will meet at **The Croydon Lodge in Gore, at 12.00pm**.

If you would like to join in with the **Southland Group**, please contact either:

Heather: [milliganseeds@xtra.co.nz](mailto:milliganseeds@xtra.co.nz)  
Jenny: [jennyred@xtra.co.nz](mailto:jennyred@xtra.co.nz)



# Noticeboard:

## Wellington support group meets:

Saturday 18 May 2019 1.30pm to 4.00pm  
Saturday 17 Aug 2019 1.30pm to 4.00pm  
Saturday 16th Nov 2019 1.30pm to 4.00pm

### Venue:

Russell Keown House, Queens Drive, Lower Hutt

## Christchurch support group meets:

Saturday 25th May 2019 2:00pm to 4:00pm  
Saturday 27th July 2019 2:00pm to 4:00pm  
Saturday 28th Sept 2019 2:00pm to 4:00pm  
Saturday 23rd Nov 2019 2:00pm to 4:00pm

### Venue:

McDonalds Merivale, 217 Papanui Road, Merivale, Christchurch in the free community room, as long as you buy a coffee at the McCafe.

## Respiratory support group meets:

### Venue:

327a Whangarata Road, Taukau Auckland 2694

## Southland support group meets:

Saturday 29th June 2019 12:00pm **Gore**  
(Scleroderma Day)  
Sunday 15th Sept 2019 12:00pm **Winton**  
Sunday 24th Nov 2019 12:00pm **In'gill**

## Hamilton support group meets:

Saturday 29th June 2019 - World Scleroderma Day, we will be having lunch together at **Willow Glen Gordington**. There will be **no meeting in July**  
August will be a guest speaker at Linda's Place.  
Date and details to be advised

# Contacts:

## Find a Scleroderma a Support Group near You:

Auckland Respiratory: Allan Edmondson, Email [allanedmondson@xtra.co.nz](mailto:allanedmondson@xtra.co.nz)  
Hamilton: Linda Bell, Email: [linda.bell@hotmail.co.nz](mailto:linda.bell@hotmail.co.nz)  
Palmerston North: Chris Carlyon, Email: [ningandalley@clear.net.nz](mailto:ningandalley@clear.net.nz)  
Southland: Heather Milligan, Email: [milliganseeds@xtra.co.nz](mailto:milliganseeds@xtra.co.nz)  
Wellington: Dianne Purdie, Email: [diannepurdie@xtra.co.nz](mailto:diannepurdie@xtra.co.nz)  
Christchurch: Dianne Purdie, Email: [diannepurdie@xtra.co.nz](mailto:diannepurdie@xtra.co.nz)  
Nelson: Beth Richards, Email: [ronbethrichards3@gmail.com](mailto:ronbethrichards3@gmail.com)

## Scleroderma New Zealand Inc.

**President:** Dianne Purdie  
[diannepurdie@xtra.co.nz](mailto:diannepurdie@xtra.co.nz)

**Newsletter:** Tina McLean  
[altinamclean@xtra.co.nz](mailto:altinamclean@xtra.co.nz)

Jenny Andrews  
[jennyred@xtra.co.nz](mailto:jennyred@xtra.co.nz)

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

[www.scleroderma.org.nz/calendar/](http://www.scleroderma.org.nz/calendar/)

## 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](mailto:diannepurdie@xtra.co.nz) and she will be happy to help you set one up.

