

Welcome.....	1
President's Report.....	2
Flu and Covid-19 Vaccine	3
COVID-19: Pfizer vaccine.....	4
Management of Xerostomia	7
What is MGD?.....	8
Calcinosis.....	10
Gut feelings	11
Members Stories.....	12
WSD -Art Exhibition 2021 NZ.....	15
WSD -Scleroderma Awareness Day.....	16
Scleroderma NZ Inc. Appeal Day.....	16
Members News.....	17
Useful Websites.....	19
2021 Virtual National Scleroderma.....	20
Useful Hints.....	21
Recipes/Joke.....	22
Book Club	23
Upcoming Events	24
Events & Happenings.....	25
Notice Board / Contacts.....	26
Scleroderma NZ Inc.....	27

Scleroderma

New Zealand support group

Autumn 2021

Greetings to you all.

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

We hope everyone is keeping well, keeping safe and getting ready for the colder season.



Well time has flown by pretty quickly and we are now into the start of the cold season. For most of us the mild weather we are having is good, as it's still warm here in Wellington as I write this newsletter. I hope everyone else around the country are also enjoying the mild Autumn weather we are having.

We are pretty lucky at the moment with signs that we are soon going to have a Travel Bubble with the Cook Islands, just like the Travel Bubble that we already have with Australia.

We have lots of information to share and news from our members in our Scleroderma Community.

We hear first from Dianne Purdie with the President's report. Dianne gives us good advice and keeps us up to date with what's going on around New Zealand.

We have some information on the **Covid-19 Pfizer vaccine**. We also have some helpful advice and information on Management of Xerostomia, Calcinosis, and Gut Feelings.

We are having an online **Art Exhibition** for Scleroderma awareness on **World Scleroderma Day**. For the first time this year we are also having our **Scleroderma Appeal Day**.

We have the usual Members News, Useful Websites, Book Club, and Upcoming Events as well as many other interesting articles.

Members are encouraged to submit any stories, jokes, items of interest they would like to share to keep the newsletter fresh and interesting.

We hope you enjoy reading this issue of the newsletter.

Keep warm and safe everyone.

Warmest regards,

Jenny and Tina



Presidents Report:

April 2021



Presidents report 27 April 2021

Welcome to our Autumn and very soon winter. I hope that you are all looking after yourselves and my key point as always keeping those layers on to keep warm.

It has been a bit of an unsettling time for us here in New Zealand with some semi lockdowns and now the NZ OZ bubble, which I'm sure will add another dimension, good and tricky, but hopefully the government services will be alert with all the gained experience over the past year.

You will all be thinking when will our COVID Vaccine appear? It shouldn't be too long now probably May for most of us. But don't forget to line up for your general Flu vaccine, the over 65's should be getting theirs now and the rest of us in May. We will then have to wait two weeks between the general vaccine and the covid vaccine.

I would like to welcome our new members these last few months. Welcome aboard and I hope you all get to meet others with Scleroderma and be good friends

It has been quiet on the society front, the groups around the country are however meeting up now which is great and we had a couple of zoom meetings this month. The first one was an education meeting on managing Raynaud's and there was a second one in the afternoon for those who wanted to make contact with others around the country for a chat.

I recently won \$100-00 Canadian, as a result in participating in research through the Scleroderma

Patient Information Network. I brought 5 sets of Arthritis gloves, four of which I will donate to Scleroderma NZ for anyone who would like a pair.

So if you would like a pair the first lucky four people will receive a pair by emailing me at diannepurdie@xtra.co.nz The size is medium.

Our Scleroderma NZ AGM will be on the 29th of June via email.

A huge thank you to all the committee for their work, I understand it has been relatively quiet this past few months, mainly due to our personal time being involved with family commitments.

As always a great depth of gratitude to our two lovely Newsletter Editors Tina Mclean and Jenny Andrews, they really have been the glue for the society they both do a wonderful job.

Also a huge thank you to all the groups that have kept running, I'm sure it has been much appreciated among your members, some of us have had some sad losses this past few months, a difficult time for some.

Also a great depth of gratitude to our lovely ladies Cushla Marsters and Catherine Thompson who look after the National Facebook page and do a wonderful job, being bright and happy informing and entertaining the troupes.

Keep your eyes peeled for another Scleroderma NZ health survey coming your way via email, it will be interesting to compare with the other surveys.

Keep well and warm and wishing you all the very best of health over the coming winter.

Dianne and Gordon



Flu and Covid-19 Vaccine

Just a reminder, if you are 65 years old or over, the Flu vaccine is ready for you at your local GP or Chemist. If you are under 65 your Flu vaccine will be coming to you soon, most probably in May. Your local GP will be in contact with you.

You have to have your flu shot 2 weeks prior to receiving the Pfizer vaccine.

If you are immune-suppressed particularly by any of the medications you are on, please speak with your specialist and GP before taking the Pfizer vaccine.

Please see the below link to the Ministry of health's website.

<https://www.health.govt.nz/our-work/diseases-and-conditions/covid-19-novel-coronavirus/covid-19-vaccines/covid-19-types-vaccines/covid-19-pfizer-vaccine>

Dianne Purdie

Important reminders:

- Download and Use the **NZ COVID Tracer** app
- Turn on / Enable **Bluetooth Tracing** (Bluetooth tracing is not intended to replace our existing contact tracing processes or the **NZ COVID Tracer QR codes**).
- Scan the **QR codes** where ever you go to keep track of where you've been. (Bluetooth tracing is an added tool — it helps keep track of the people we've been near).
- Be aware of your physical distancing when out in public
- Wearing a mask is mandatory on public transport and domestic flights
- In taxis and when ride-sharing mask wearing is encouraged
- If you are sick, stay home and contact Healthline for advice
- Remember your cough etiquette – cough or sneeze into a tissue, your elbow or clothing, not your hands.
- Wash your hands as often as you can, for 20 seconds with soap and water, and dry thoroughly. If you can't do that, use hand sanitiser.
- Don't touch your face.

Remember to follow the advice of our Government.

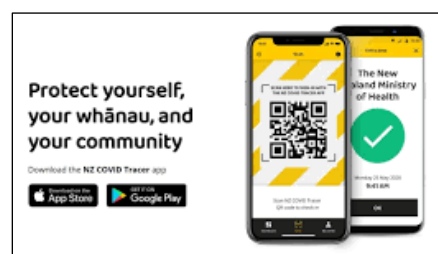
For official information go to: www.covid19.govt.nz

What we all need to do



For **COVID-19** health advice and information, contact the Healthline team (for free) on: **0800 358 5453**

1.



2.



3.



4.



COVID-19: Pfizer vaccine

The Pfizer vaccine has been approved for people 16 years and older. Find out more about the safety, effectiveness and side effects.

Last updated: 20 April 2021

On this page:

- [How Pfizer works](#)
- [Side effects and reactions to Pfizer](#)
- [What's in the Pfizer vaccine](#)
- [Monitoring international use of Pfizer](#)
- [Vaccine data](#)

Resources:

- [Comirnaty \(Pfizer\) COVID-19 vaccine – Consumer medicine information summary \(PDF, 193 KB\)](#)
- [Comirnaty \(Pfizer\) COVID-19 vaccine – New Zealand data sheet \(PDF, 1.2 MB\)](#)

The Pfizer vaccine has been approved to use in New Zealand for people 16 years and older.

We've now secured 10 million doses of the Pfizer vaccine in total. This is enough for 5 million people to get the two doses of the vaccine they need against COVID-19.

How Pfizer works

Vaccines protect your health and prevent disease by working with your body's natural defences, so you're ready to fight the virus if you're exposed.

The Pfizer vaccine will not give you COVID-19. It does not contain any live virus, or dead or deactivated virus. It works by triggering your immune system to produce antibodies and blood cells that work against the COVID-19 virus.

How the vaccine is given

Pfizer is given as an injection into the muscle of your upper arm.

You'll need two doses. The second dose is given at least three weeks later. It's very important you get your second dose, you have your best protection once you have both doses.

Staff will observe you for at least 20 minutes after your injection.

Effectiveness and protection

Getting a COVID-19 vaccine is an important step you can take to protect yourself from the effects of the virus.

As with any vaccine, Pfizer may not fully protect everyone who gets it. The clinical trials performed on the Pfizer vaccine show it's approximately 95% effective against symptomatic COVID-19, seven days after receiving two doses.

We don't yet know how long you'll be protected or if it will stop you from catching and passing on the virus. Research has shown that immunity following natural infection remains for at least eight months and we have every expectation the vaccine immunity will be even longer.

Side effects and reactions to Pfizer

Like all medicines, the vaccine may cause side effects in some people. These are common, are usually mild and don't last long. They may be more common after your second dose.

[See the list of known side effects](#)

What's in the Pfizer vaccine

Pfizer is a mRNA-based (messenger ribonucleic acid) vaccine.

The Pfizer vaccine does not contain any live, dead or deactivated viruses. There are no animal products in this vaccine.

Active ingredient

30µg of a nucleoside modified messenger RNA encoding the viral spike (S) glycoprotein of SARS-CoV-2



COVID-19: Pfizer vaccine

The Pfizer vaccine has been approved for people 16 years and older. Find out more about the safety, effectiveness and side effects.

Last updated: 20 April 2021 (continued from previous page..)

Fats

These ingredients make up the lipid nanoparticle which is the transport mechanism for the active ingredient to make it inside a cell without being broken down.

0.43 mg (4-hydroxybutyl)azanediylbis(hexane-6,1-diyl)bis(2-hexyldecanoate)
0.05 mg 2[(polyethylene glycol)-2000]-N,N-ditetradecylacetamide
0.09 mg 1,2-distearoyl-sn-glycero-3- phosphocholine
0.2 mg cholesterol

Salts

These ingredients help make sure the vaccine pH is close to that of human cells.

0.01 mg potassium chloride
0.01 mg monobasic potassium phosphate
0.36 mg sodium chloride
0.07 mg dibasic sodium phosphate dihydrate

Sugar

This ingredient protects the lipid nanoparticle at very cold temperatures (-80 degrees Celsius that the vaccine is stored at).

6 mg sucrose

Monitoring international use of Pfizer

We're aware of several deaths in elderly people in Norway who had received the Pfizer vaccine. Reports say the deaths were very frail patients who may have had only weeks or months to live. There is no confirmation they were linked to the vaccine. These deaths are being investigated further.

Medsafe is closely monitoring this as well as the results of the vaccine roll-out out in other countries. This will add to the clinical data we expect to receive from Pfizer. Including:

- the overall safety profile of the vaccine
- any reported reactions (the frequency, the severity, and any previously unknown reactions).

Vaccine data

Our vaccination dashboard shows a snapshot of our vaccination progress. You can see the number of people who have received the Pfizer vaccination in New Zealand so far.

[Vaccine data](#)

Source: <https://www.health.govt.nz/our-work/diseases-and-conditions/covid-19-novel-coronavirus/covid-19-vaccines/covid-19-types-vaccines/covid-19-pfizer-vaccine>

[COVID-19: Pfizer vaccine | Ministry of Health NZ](#)

Covid-19 Jokes



If anyone is gonna make a face mask out of an old bra, make sure you use the left cup.

You don't want to go out looking like a right tit.

COVID-19: When you can get a vaccine

Our vaccine rollout plan aims to protect Aotearoa. Everyone in the country aged 16 and over, falls into one of four groups. Find out when you may get the COVID-19 vaccine.

Last updated: 23 April 2021

On this page:

- [New Zealand's COVID-19 vaccine plan](#)
- [Find out what group you're in](#)
- [Group 1 – Border and MIQ workers and the people they live with](#)
- [Group 2 – High-risk frontline workers and people living in high-risk places](#)
- [Group 3 – People who are at risk of getting very sick from COVID-19](#)
- [Group 4 – General population](#)
- [Where vaccinations will happen](#)

Resources:

- [COVID-19 vaccine rollout plan \(PDF, 181 KB\)](#)
- [COVID-19 vaccine – estimated volumes and timing of vaccine rollout \(PDF, 435 KB\)](#)
- [COVID-19 vaccine – protecting Aotearoa \(PDF, 403 KB\)](#)

New Zealand's COVID-19 vaccine plan

We have a plan to provide a free vaccine to protect everyone in Aotearoa. We've secured enough Pfizer vaccine for everyone in New Zealand aged 16 and over to get the two doses they need against COVID-19.

First, we're protecting those most at risk of catching COVID-19 in their workplace. This will reduce the risk of future outbreaks and lockdowns. Next, we'll vaccinate people most at risk of getting seriously sick or dying if they get the virus.

New Zealand's vaccine plan is to:

- put safety first with all COVID-19 vaccines
- secure enough safe and effective vaccines to protect Aotearoa and the Pacific
- protect Māori, Pacific peoples, and other groups at greater risk of COVID-19
- make it easy for people to get vaccinated
- ensure we are prepared for future outbreaks
- support New Zealand's contribution to global wellbeing.

The rollout at a glance

We're rolling out the vaccine in stages. We've created four groups that everyone in the country aged 16 and over will fall under.

From February	From March
Group 1 – Border and MIQ workers and the people they live with	Group 2 – High-risk frontline workers and people living in high-risk places
<i>Underway and on track</i>	<i>Underway</i>
From May	From July
Group 3 – People who are at risk of getting very sick from COVID-19	Group 4 – General population
<i>You don't need to do anything just yet</i>	<i>You don't need to do anything just yet</i>

Dates and timings may change

Time frames are approximate and may overlap. The actual start dates will depend on when vaccines are delivered and whether there is community transmission at the time.

Vaccine data

Our vaccination dashboard shows a snapshot of our vaccination progress. You can see the number of people who have received their vaccination in New Zealand so far.

[Vaccine data](#)

Find out what group you're in

What group you're in depends on your age and situation. You can use the Unite against COVID-19 tool to find out what group you're probably in and when you can get a vaccine.

[Find out when you can get a vaccine — Unite against COVID-19 tool](#)

Source: <https://www.health.govt.nz/our-work/diseases-and-conditions/covid-19-novel-coronavirus/covid-19-vaccines/covid-19-getting-vaccine/covid-19-when-you-can-get-vaccine>



Management of Xerostomia:

Information below was given to one of our members regarding the management of Xerostomia for flossing and brushing techniques.

I thought this information would be nice to share with other members here...

Xerostomia or Dry mouth as it's more commonly named refers to a condition in which the salivary glands in the mouth do not make enough saliva to keep the mouth wet.

Dry mouth is often due to the side effect of certain medications, aging issues or as a result of radiation therapy for cancer. Less often, dry mouth may be caused by a condition that directly effects the salivary glands.

It was advised for you to use **Neutrafluor 220 mouthwash**. Research does indicate **Cetylpyridinium Chloride (CPC)** can help to alleviate temporally the symptoms of dry mouth (article 1) its main mode of action is for high caries (decay) risk patients.

Although, caries can be caused from xerostomia (As saliva helps by neutralizing acids produced by bacteria, limiting bacterial growth and washing away food particles which in turn helps to prevent tooth decay), the mouthwash does not directly affect the xerostomia in the long term. The mode of action of **Neutrafluor 220** is that 'sodium fluoride reduces caries by inhibiting demineralisation and promoting remineralisation of the tooth surface'.

Please see attached research (article 2) for your reading so you can make an informed choice.

In my professional opinion, I would advise to stop or limit using **Neutrafluor 220** mouthwash and look at other management options.

Research indicates the management of xerostomia is mainly palliative and is aimed at symptomatic relief.

I have collated a list to help in the management of your condition: -

- Ensure adequate hydration by drinking water, consider having a glass of water next to the bed during the night
- Avoid cariogenic foods i.e. sugars and refined carbohydrates
- Avoid the use of alcohol containing oral products
- Use **sodium lauryl sulphate (SLS) FREE** toothpaste. These includes Colgate Sensitive pro-relief, Sensodyne
- Repair and protect and Biotene dry mouth toothpaste.
- Limit caffeine, and have in one sitting, with food, and flush with water after.
- Avoid waiting to brush your teeth for 30 minutes after intake.
- Avoid smoking and alcohol.

- Consider using cool air humidifiers to assist sleep. Sleep on the side to reduce mouth breathing
- Continue using **GC dry mouth gel** - smear it on your cheek or tongue not your teeth.
- Chew on **GC recaldent** gum - its active ingredient is CPC-ACB which helps to stimulate saliva flow. However, they are limited in altering the composition of saliva. Here is the study to back the evidence:

The Anticariogenic Effect of Sugar-Free Gum Containing CPP-ACP Noncomplexes on Approximol Cories Determined Using Digital Bitewing Radiography M.V. Morgon, G.G. Adoms, D.L. Boilely, C.E. Tsdo, S.L. Fischmon, E.C. Reynolds Cories Res 2008;42:777-784

The Biotene range which includes mouth spray, chewing gum and toothpaste have shown some efficacy in reducing symptoms associated with xerostomia.

Overall, as the products are mostly designed for palliative relief from dry mouth symptoms, improvements seen in the shorter duration can be considered more meaningful.

<https://mail.google.com/mailui/ik=6853c20d62&view=pt&sea.ch=all&permmsgid=msg-P/o3A1672152285063882758&simpl=msg-f/63A1672152-..ll2>

Flossing and Brushing Techniques ...

Effective brushing is all about the technique. You could have the best toothbrush available but with bad technique it will not make a difference.

When doing the bottom front inside teeth (teeth closest to the tongue) - tilt your chin down for best access for the toothbrush and will be able to reach the gum-line. This will also be a natural movement for your wrist.

With the electric toothbrush go up and down each tooth. For the front teeth on the lip side - pull the lip out as the lip blocks part of your teeth so you can see full teeth and gums.

When brushing the inside surfaces of the middle teeth and molar - move your electric toothbrush more vertical as opposed to horizontal. This will be a better access for the brush to reach the gum-lines and then proceed to move the toothbrush in a motion you prefer.

FLOSSING TECHNIQUE

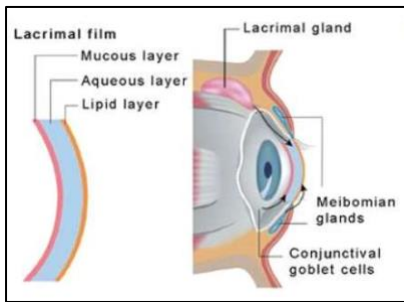
Floss right down to the gum-lines gently and then wrap floss around the tooth like the letter 'C' shape. Floss up and down several times.

Sapna Patel
Dental Hygienist



What is Meibomian Gland Dysfunction (MGD)?

What is MGD?



Meibomian Gland Dysfunction (MGD) is a condition where the meibomian glands are inflamed and are releasing poorer quality oils in reduced quantities or in some cases, not at all. Meibomian Gland Dysfunction is a common eye condition and is considered a form of posterior blepharitis.

The meibomian glands are oil producing glands that are located on both the top and bottom eyelid margin. This oil creates the front layer of your tear film and its main role is to help create a smooth tear layer on the eye as well as prevent the tears from evaporating. It is an important component needed to create clear, crisp vision.

What are the symptoms of MGD?

Symptoms of meibomian gland dysfunction are dependent on the severity of the case and can vary person to person. Common MGD symptoms include:

- Gritty Eyes
- Burning and stinging eyes
- Fluctuations in vision
- Itchy eyes
- Watery eyes in windy environments
- Red eyes
- Styes

These symptoms are similar to dry eye, as the oils produced by meibomian glands are an active part of the tear film. When these oils are not being produced in the correct quantity, or if the quality of oils is suffering, moisture from the tear film will evaporate reducing the amount of lubrication on the front of the eye and as a result, the tear film will be irregular or break down more quickly.

Symptoms of MGD can be constant or intermittent. Environmental changes like air conditioning, computer use and heating may increase symptoms.

Source: Wellington Eye Centre

<https://www.wefixeyes.co.nz/conditions/meibomian-gland-dysfunction/>

The problem of dry eyes ...

Almost one in five people know the problem: the eyes are stinging, scratchy, reddened, and feel as if filled with sand. This is also known as the dry eye syndrome. Many influences of daily (modern) life strain the eye and cause and trigger later discomfort and eye pain that may often be persistent.

Redness, fatigue, blurred vision and scratchy eyes are the first signs of eye discomfort. Over time many other symptoms and serious complications can occur, like uncomfortable changes in vision comfort and infections.

Dry eye treatment by E-Eye

It has been proven in several neurological studies that the emission on a nerve of infrared as a train of pulses leads to the creation of a micro gradient of temperature between the inner and the outer layer of the myelin sheath.

This micro gradient of temperature triggers the liberation of neurotransmitters. Automatically, the parasympathetic nerve is connected to the Meibomian glands by some of its branches. The neurotransmitters released will then be able to interact with the glands, stimulating the secretion and the contraction of the latter.

E-Eye does not directly affect the Meibomian glands. Its action is indirect. The “flushed” areas (buccal and zygomatic region) are the areas where the parasympathetic nerve passes.

How it works?

The dry eye treatment with E-Eye only takes a few minutes, sitting in a comfortable chair. The eyes from the patient are covered by protective eyecups. Hydrogel is applied to the lower eyelid. A series of light pulses is performed around the lower eye, gentle and non-invasive. The series is repeated in the same way for both eyes. The treatment restores the normal activity of the Meibomian gland, with very rapid improvement for the patient from the very first session. The effect of the first two treatments lasts a few days up to 2 to 3 weeks. The long-lasting effect is expected for a minimum 6 months up to 3 years. The E-Eye protocol comprises three to four sessions. It is recommended to repeat one application once symptoms are coming back.

Source: [E>Eye](#) | [ESW Vision \(esw-vision.com\)](#)



What is Meibomian Gland Dysfunction (MGD)?

Result

As a result, the dry lipid layer receives a natural boost of lipids, which reduces the evaporation of tear fluid and prevents the eye from drying out. In addition, the quality of the glandular secretions is improved, and the tear film's lipid layer is stabilized.

The latest IRPL® technology



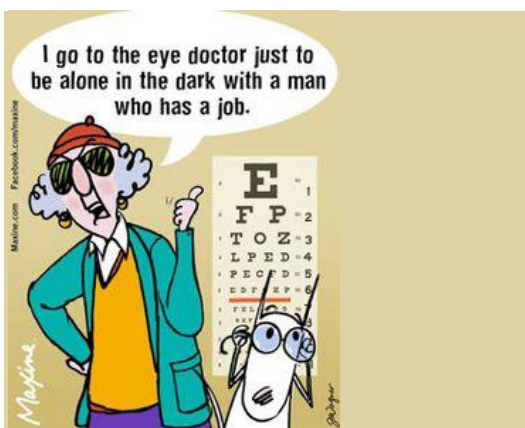
E-Eye is a medical device that has been specifically designed for treating dry eye syndrome due to MGD.

It generates Intense Regulated Pulsed Light by producing perfectly calibrated and homogeneously sequenced light pulses. The sculpted pulses are delivered under the shape of a train of pulses. The energy, spectrum and time period are precisely set to stimulate the Meibomian glands in order for them to return their normal function. E-Eye is the medical solution to treat and to prevent dry eyes.

Source: [E>Eye | ESW Vision \(esw-vision.com\)](http://www.esw-vision.com/e-eye#:~:text=E%2DEye%20is%20a%20medical,of%20a%20train%20of%20pulses)

<https://www.esw-vision.com/e-eye#:~:text=E%2DEye%20is%20a%20medical,of%20a%20train%20of%20pulses>.

The brochure below was given to our member Carolyn, regarding Dry eye treatment by E-Eye. Carolyn has kindly shared this information with us...



Calcinosis

Dianne Purdie talks to us about Calcinosis...

Over the years I have had numerous queries from members asking about Calcinosis.

Some people have a particularly difficult time with it, and my sympathy goes out. Unfortunately calcinosis is difficult and there is not a lot that they can do to help. The below information from a small article from the Scleroderma News website and an abstract from a paper I read gives an explanation. And sometimes an explanation can be of help a little bit.

Calcinosis or calcinosis cutis is the accumulation of calcium deposits in or under the skin. These deposits resemble small white lumps and may be hard or soft. If the lumps break through the skin, they leak a white, chalky fluid. They tend to form on pressure points such as the fingertips, hands and feet, and around joints.

Calcinosis cutis is the deposition of insoluble calcium in the skin and subcutaneous tissues. It represents a major clinical problem in patients with SSc affecting at least one quarter of patients. It is associated with longer disease duration, digital ulcers, acro-osteolysis, positive anticentromere antibody, and positive anti-PM/Scl antibody. Although pathogenesis is unknown, there is evidence supporting local trauma, chronic inflammation, vascular hypoxia, and dysregulation of bone matrix proteins as potential mechanisms.

People with connective tissue diseases such as systemic scleroderma, dermatomyositis and cutaneous lupus erythematosus may also develop calcinosis. Excessive vitamin D intake may also cause calcinosis and so can taking calcium or phosphate.

How is calcinosis diagnosed?

No specific tests exist to diagnose calcinosis, though it is usually quite obvious on examination. In case of uncertainty, an X-ray can be used to diagnose the condition.

How is calcinosis treated?

If calcinosis deposits do not cause discomfort or impede function, they may not require treatment and can be left alone if the patient so desires. But some deposits can be annoying and painful. In some cases, they may break through the skin and lead to local secondary infections that require antibiotic treatment.

Calcinosis deposits occasionally resolve themselves spontaneously. Some patients find that a paraffin wax bath helps soften the deposits and discharge them.

If calcinosis deposits become very painful, cause recurrent secondary infections or impair function, a doctor may

recommend surgical removal. Unfortunately, these deposits usually come back after such surgery.





Gut feelings: How what you eat could be affecting your health - and what to do about it

How does our everyday diet influence how we feel, and could a few simple changes really make a difference?

Gastrointestinal (GI) involvement affects around 90% of people living with systemic sclerosis (SSc), and this can have a dramatic impact on quality of life. Symptoms vary from person-to-person, and if untreated, there may be long-term complications. The GI tract runs from the mouth all the way to the back passage and although treatment is crucial for controlling symptoms and slowing disease progression, there is also evidence that diet could play a role in managing symptoms and maintaining quality of life.

The human gut is a highly complex aspect of the body that has attracted growing interest in recent years, as we continue to realise the true scope of its role in keeping us well. Whilst nutrition is always important in a healthy lifestyle, when we think about GI tract involvement in SSc this becomes even more significant, because symptoms can affect what someone is able to eat and digest comfortably. There is also evidence to suggest that certain dietary changes may help to control symptoms, and many people (although by no means everyone) report that diet does indeed make a difference.

Keep a food diary

Just as scleroderma affects everyone differently, there is no 'one-size-fits-all' approach to dietary management. It is important therefore to start by looking closely at what you eat and trying to identify any possible reactions.

Keeping a food diary for at least four weeks will help you to understand the relationship between your body and the food you eat. It is not always easy to remember everything, so writing it all down may help to show how certain foods may be affecting how you feel, for better or for worse.

Start a new page each day and try to record how you feel whilst you eat, as well as afterwards and even a day or so later. Sometimes with scleroderma, foods may take longer to digest so any reactions may be delayed. Consider noting not only your GI symptoms, but also your energy and mood that day, along with how you slept during the night.

Balancing bacteria

Gut microbiota or gut flora refer to the trillions of bacteria that naturally live in the human gut. This is an area that has gained momentum over recent years, as we begin to better understand the possible role of gut flora in our health, including immune reactions.

This dense microbiome within the human digestive system has multiple functions, including the absorption of nutrients and preventing disease. 'Good bacteria' help to promote

health and wellbeing and reduce inflammation. There are also the unfriendly or 'bad' bacteria, that may actually promote inflammation within the bowel. In fact, the true significance of gut bacteria upon mental and physical health is still very much under investigation.

Dysbiosis means an imbalance amongst the gut bacteria, which can be an aggravating factor in autoimmune diseases, including SSc. This can cause digestive discomfort and even make symptoms worse. A study from the USA in 2016 found that patients with scleroderma had higher levels of the unfriendly bacteria that might promote inflammation, and lower levels of the good bacteria that could protect against this.

Bacteria are largely sustained by the food we eat and are maintained by prebiotic fibres. Diet can therefore affect the microbiota, which may then impact upon health and symptoms. To help maintain the good bacteria, think about what you eat. If you can tolerate them, a wide range of plant-based foods including fruits, vegetables and wholegrains will help to boost your intake of the prebiotic fibres that nourish healthy gut bacteria. There may be plenty of products on the market claiming to have similar effects, however, always talk to your doctor before introducing anything new.

Try to avoid foods that are overly processed, such as processed meats and ready meals. These contain higher levels of artificial additives, which are thought to suppress the good bacteria and even encourage their unfriendly counterparts, which in turn may lead to inflammation and feeling worse. Another American study from 2018 found that certain additives had a negative effect on microbiota balance, leading to issues including inflammation in study participants.

Leaky gut syndrome

Leaky gut syndrome means increased intestinal permeability; and once again there seems to be a growing interest surrounding this concept. The gut lining acts as a barrier that prevents harmful agents from entering the bloodstream. Leaky gut occurs when this barrier is compromised, allowing certain toxins to escape. This may cause inflammation, along with imbalances in gut bacteria, with some studies associating a leaky gut with certain autoimmune conditions. There is evidence to suggest that a change in diet may help a leaky gut, although these generally focus on healthy eating and reducing aspects such as alcohol, added sugar and processed foods.

This information is intended to serve as a general reference only. If you would like to explore any of these aspects further as they relate to your health, please talk to your doctor or visit [nhs.uk](https://www.nhs.uk).

Source: <https://www.sruk.co.uk/about-us/news/gut-feelings-how-what-we-eat-affects-our-wellbeing/>



Members Stories:

Betty Peck – Poem; Sjogrens (Show-grens) Syndrome...

Sjogrens is a syndrome
And not many folk have got it
But I'm glad I now know what it is
Because I thought I was neurotic

It started many years ago
With itching in my ears
I thought I had a bug in there
The itch was so severe

My legs were dry and flaky
And while there was nothing I could see
I itched in so many places
I thought that I had fleas.

And my scalp became so itchy
I checked myself for nits
And spent a fortune on medications
It really was the pits.

My eyes became so dry and sore
They were always tired and gritty
I thought cataracts were the cause of it
But they weren't – more's the pity.

My dry mouth made it hard to talk
And my voice would fade away
Life became quite difficult
Because I had so much to say.

I frequently had ulcers
Which I often carped about
Caused, no doubt, by the dryness
That I felt within my mouth

My voice became quite croaky
And I acquired a tickly cough
It sounded really irritating
As I tried to clear my throat.

And then one day I noticed
That my feet which once were cold
Were burning hot and stinging

Which was really rather odd.

I never took a hot water bottle
To keep me warm in bed
I had to take a pack of ice
To keep me cool instead.

One day I'd really had enough
And went to see my doctor
I said you've got to do something
I'm going off my rocker.

She had a think and then she said"
"Run that past me once again,"
And when she looked at all I had
Said: "It looks like you've got Sjogrens."

Not that there's a cure for it
You have to treat each symptom
But at least I know I'm not insane
It's just that I've got sjogren

A handy tip about Macleans "my Big teeth" toothpaste - if you have problems with food flavourings from Heather....

I have a problem with food which have chilli, curry, black pepper, mustard, mint flavourings burning my mouth. All fluoride toothpastes I have tried have mint flavouring. Macleans '**my Big teeth**', surprisingly it has the same fluoride as adult toothpaste, it does say fresh mint taste on the tube, but it does not burn my mouth!



Heather



Members Stories

continued:

Jane Sainsbury –

Cycling the Wilderness & Gibbston Trail for a day...

My husband John was turning 60 in February this year and we had always wanted to do a driving trip around parts of the South Island we hadn't visited before. We made a big circle from Picton and began by heading down the West Coast. Our intent was to get 2 cycle days in the 14 days we were away. The targets were the Wilderness Trail and the Gibbston Valley Trail. Although we have our own electric bikes at home, we decided to rent e-bikes rather than cart ours around on the back of the car. And to just clear up a misconception about e-bikes, you do actually work harder than what people think.

I struggle with extensive calcinosis on both hands. Cycling brings its own challenges. Braking and changing gears is not easy for the sore joints in my hands and the overly tender calcium deposits under my skin. We rented our e-bikes from a place in Hokitika and cycled from town to pick up the Wilderness Trail. The destination was the Treetop Walkway and Café. A distance of 15 km one way. It was the journey there that was amazing and challenging all in the same breath. I found the dense rainforest made for beautiful cycling under its canopy, but the downhill tight switchbacks in the dense forest found me getting off my bike to make the tight turn. The marshland although holding its own beauty had a fairly narrow wooden structure over it to walk or ride. I wondered what I would do if I met another cyclist or walker coming the other way. Heading into the watery marsh wasn't an option! I had to really concentrate and hoped the end was near. Then voila, our reward the Treetops Walkway and the café for a yummy lunch.

Our second cycle trip was the Gibbston Valley Trail from Arrowtown. Again, we rented our e-bikes from town and hit the trail immediately along the Arrow and Kawarau Rivers. It was a beautiful sunny day riding over gorges and through country lanes. Although relatively easy cycling the 5 swing bridges are a challenge for anyone with a fear of heights. A few years ago, I would have ridden my bike over them, but found myself walking over a majority of them not having the confidence to cycle over them. I loved this cycle ride,

but once we got to our destination, Kinross Winery for lunch, I made the decision to be picked up by the van from the bike rental place. I'd had a little run in with a bridge. My elbow clipped the side and was feeling quite sore. We had ridden 15 km in quite warm temperatures, and I had to pace myself so I wasn't completely shattered for the rest of the day.

A few years ago, I never would have doubted any ability I had cycling. I would cycle 3 consecutive days for 35-40km a day. Unfortunately, with this disease all the things that were easy for me have become harder. I question myself more and talk myself into safer options. But the most wonderful part is that I can still get on a bike and that hasn't been taken away from me yet.



Members Stories

continued:

Erena Bruce — Shoulders; Investigation & Physiotherapy...

Kia Ora koutou.

It's been a year now that I have had shoulder niggles. After a great session at the pool the pain was too much. I suppose I was lucky to get an ACC claim approved and began treatment with an Xray and then MRI. Both came back with a picture of calcification, (a build-up of calcium in areas, that contributed to limited ability for joint, tendon movement). Not uncommon for those who repeatedly use same muscles for extensive periods over years. For example this could have been there 20 years ago whilst playing a lot of squash and now triggered by another exercise or Scleroderma bringing the injury to the fore.

Injury identified, Investigations complete now treatment with Physio. I chose Cambridge Physiotherapy, a young Lacrosse player. We developed an awesome rapport and any and all questions regarding recovery was never a problem. I got to know much more about the intricacies of the upper body. Shoulders like all muscles and tendons respond and need movement. What going to a Physio taught me was, it is the specific types of movement for your need that is what will aide recovery. I began to focus on exercising the surrounding tissue, by strengthening and stretching so the damaged areas could be utilised without the excessive pain and need for Panadol. This took a long, long, long time.

I changed my Physiotherapist to an experienced, knowledgeable Englishman who had background in auto immune conditions, as my lady was taking maternity leave. Sessions are short but I still come out satisfied I am listened to, small increments of progress is made, I am not judged and Yippee progress. My recovery has been about my new friend 'the stretchy band ', it's all about the use of these small but brilliant inventions. Can be used in the car, on holiday, I have three at home in different locations (doorknob, couch leg (for knee) and the other for free arm use).



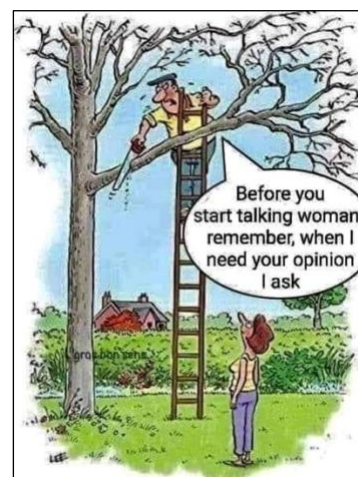
I guess I feel more empowered to look after my shoulders now with the use of exercise, my Physio believes I can get back on the squash court and doing yoga, balance again will be doable. My next challenge is being able to get up and off the floor with grace and curtesy, because it's not happening right now.....anyhow folks we are what we set our minds to do, physio's are able to aide with tendon, muscle recovery. The complexities of the body are not as daunting as they were a year ago and I am fortunate to have found good physio's who are genuinely interested in people and the role they play in keeping us scleroderma folk active and mobile.

Regards Erena

Carolyn Barkhausen — Dry Mouth ; Asking if anyone has any ideas...

Is there anyone who has Scleroderma, Sjogren's and MDS Syndrome? I am struggling with such a dry mouth and my tongue feels like it has ulcers on it? This has been going on now for about 18 months. There are times when I cannot eat much, apart from jelly. Continual oral thrush, also in the throat is another issue. I am on antibiotics so much. I know the MDS Syndrome is a complication. My Haematologist is fantastic, just a phone call away. Does anyone have any ideas? Would love to hear from anyone who may be suffering the same.

Best wishes
Carolyn

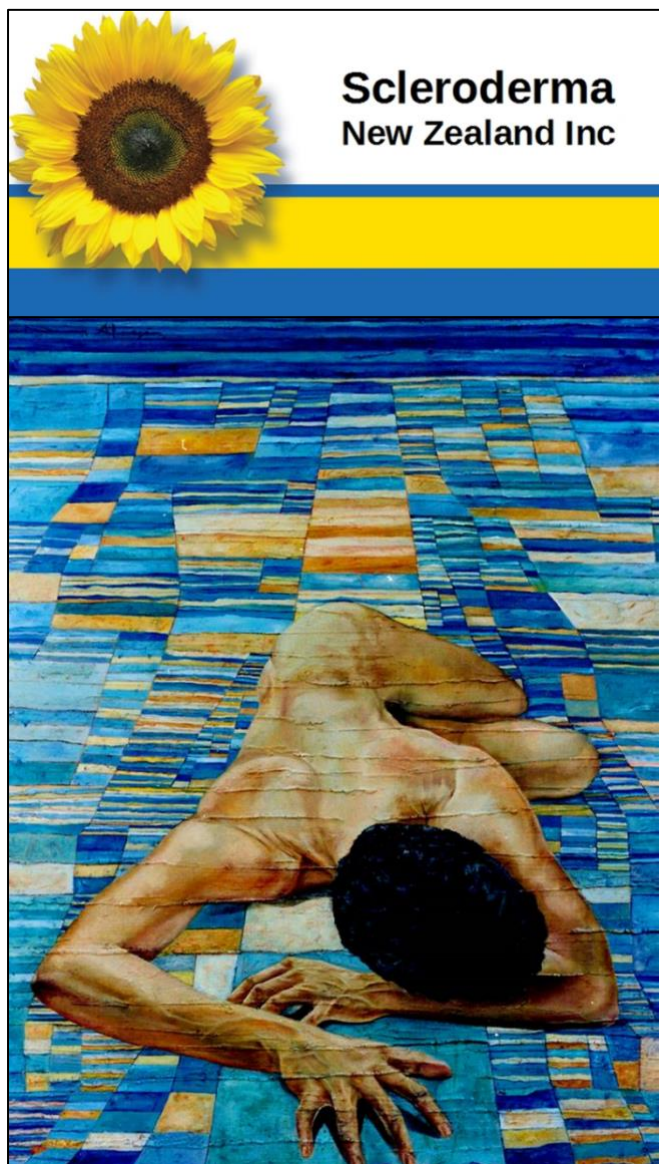


World Scleroderma Day:

29th June 2021...

ART EXHIBITION 2021 NZ

Check out our Facebook Page for our **2021 Art Exhibition** for all those with Scleroderma.



We would love you to share something that you have done that makes you proud. At the moment we have photography, cross stitch, paintings and a jigsaw.

Take a photo of your knitting, crochet, your garden, anything, don't be shy. There is no judgement here, only encouragement. 😊

It is always great to see what others are doing with their time.

Link to our Face book Page:

<https://www.facebook.com/Scleroderma.org.nz>

SAFE AT HOME BLANKET:

Adrienne Burleigh creates a masterpiece – a blanket that is both warm and beautiful...

You too can do this

Last winter we were all in lockdown, enjoying a slower pace of life and looking for something to do. Added to this I had a spell in hospital and enforced rest when I returned home. Boring, you could well have said. One day I was cruising on my computer and I came across a knitting pattern (there is one in crochet as well) that fascinated me. Wow, I just had to have that one.

Margaret Holzmann, who lives in America developed the pattern in recognition of the needs we have under Covid19 to keep away from others for our own and their health. She has called the pattern "Safe at Home" and it consists of rows of houses, all the same but with different colours. I got the pattern and got stuck in. The pattern is worked all in garter stitch with each house ending up as a square. I used up so many small balls of wool that were left over from other projects plus a number of balls of new wool to make the 100 houses for my blanket. Margaret's original blanket had 81, but you can make the blanket as small or large as you like.

To strengthen the blanket and make it less scratchy on sensitive skin, I lined it with a very fine knitted fabric. To anchor the lining in place I stitched 100 tiny buttons on the front as door knobs. Lots of fun. If you would like the pattern and to see a whole range of blankets, just search the net for "safe at home blanket".

So, what is the take away message? Get out your wool, pick up your needles, be kind to yourself and stay safe, warm and secure at home to beat winter ills and chills.

Adrienne Burleigh



Adrienne's
lovely
blanket

World Scleroderma Day:

29th June 2021...

Scleroderma Awareness Day...

Having a disease that nobody has heard of is a lonely business. When even the doctors cannot recognise 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 recognise the bravery of those who live with scleroderma, and to demand equal treatment and equal care for people with scleroderma across Europe.

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.

Paul Klee died June 29, 1940



Paul Klee (1879. – 1940.), Swiss painter

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.

Scleroderma Awareness Day

On June 29 we celebrate the life and death of Paul Klee and all those who struggle with scleroderma. We campaign for a world in which equal rights, treatments, and care are offered to people with scleroderma, and in which such rare diseases are not forgotten, but afforded the consideration and attention of other more common diseases.



Scleroderma New Zealand Inc. Annual Appeal Day 29th June (World Scleroderma Day)

*We would greatly appreciate your donation to
Scleroderma New Zealand Inc.*

Your Society is fully run by volunteers but we would appreciate your donation to help cover costs for regional seminars, and for the **Understanding and Managing Scleroderma** Booklets. We hope to have them updated and reprinted soon. We also need to run a website which has annual hosting costs.

*Your Donation would be much appreciated as it
goes to help people with Scleroderma in
New Zealand.*

**You can donate online with this bank account
number: 38-9017-0107454-00
Or go to Give a little**



<https://givealittle.co.nz/donate/org/sclerodermanz1>

Thanks a Bunch in advance Dianne



Members News:

Southland Scleroderma Group

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

Southland Lunch Get Together February 2021

I did enjoy having a catching up with my fellow Southlanders on a lovely summers day.

We don't usually acknowledge birthdays, but Jenny and Kimberley were both celebrating their 50th within days of each other, that did need recognition.

Thank you to Jenny for organising us in amongst your own 50th celebrations and work commitments.

Looking forward to seeing everyone in May.

Heather Milligan



Southland Group



Jenny & Kimberley celebrate their 50th birthdays

Nelson Scleroderma Group

Beth Richards bring us up-to-date with happenings from Nelson...

Hello to our Scleroderma friends throughout NZ.

Early march Jenna, Lisa & Beth met at Alberta's cafe in Mapua for a coffee and a snack. Unfortunately Michele was unwell and couldn't be with us.

Rosemary one of our regular group members is unable to attend our meetings because of ongoing health issues.

We miss not seeing her and wish her well in her battle for better health.



Jenna, Lisa & Beth

It was a stunning sunny day at the Mapua Wharf with many people enjoyed the beautiful weather and cafes. We can highly recommend a visit to this beautiful part of the South Island.

2 weeks ago we decided to meet again in Richmond at the Wooden Spoon cafe. Unfortunately Jenna and Michele couldn't make it because health issues.



Lisa & Beth

We certainly missed them both and also Rosemary.

Lisa and I got together for a wee catch up where Lisa took a selfie of us both. The date scones are delicious and we enjoyed chatting together.

I hope you are all doing okay and coping with life as best you can. Best wishes from our small Nelson group. Cheers everyone.

Beth Richards ❤️🌻



Members News:

Wellington Scleroderma Group

Our Wellington group met up on January 16th at the Hardwick Rooms in Lower Hutt...

It was a very warm January afternoon when we last met here in Wellington.

It was lovely to catch up with everyone again, we sat round and had a great chat about how we were going, had a few good laughs and shared some good helpful information between us all.

We had a lovely shared afternoon tea, contributed by everyone, it was a great relaxing time held by all.

We have recently secured a nice venue at Belmont Domain in Lower Hutt, hired from the Hutt City Council. The venue has good access on the flat with plenty of parking and the rooms are set in park like grounds. Plenty of room for the children to run around.

We also have a great little kitchen where we can heat up food and make a lovely cup of coffee.

We also have the added bonus of a BBQ outside if we would like an outside shared lunch sometime in the future.

We are very much looking forward to our next meeting this coming weekend where Lori Davis from Arthritis NZ will be coming along to talk to us about how to cope with a chronic condition. We welcome anyone passing through Wellington to our meetings.



Hardwick Smith Lounge



Park Grounds surrounding the venue

Christchurch Scleroderma Group

Carolyn talks to us about their catch up in Christchurch...

The Christchurch ladies met at Burwood Hospital cafe at the end of March. We all wore our sunflower headbands, and a couple of visitors in the cafe commented on them so we told them about Scleroderma. We gave a Hospital patient a copy of the last newsletter! People are starting to notice us!

Chris and Carolyn have sunflower shirts which we bought from Hallensteins!

We look forward to our next catch up at the end of May.

Cambridge Trio Get Together

Erena Bruce bring us up-to-date with happenings from Cambridge...

I am part of a little coffee group in Cambridge. We usually meet on a Thursday, a couple of times a month to catch up and chat about various ups and downs. We have found this beneficial as we all have such different home lives but share similar symptoms and our needs and past woes have been the same. Currently one of us is trialling a zinc supplement and is finding this very useful (a test at Health 2000 found she was short zinc in mineral and vitamins). Another finds her electric throw the best way for her to keep warm and relaxed, also not having processed sugars and eating gluten free foods in her day to day intake, such great discipline. Another has found the opossum gloves to be the warmest gloves of all the options and also attending an Aqua aerobics class at least once a week soooo beneficial. It's being weightless and no incumbents to move and stretch. Anybody interested in coming along you are most welcome. **Erena**



Members News cont:

National Zoom Meeting

Our latest Zoom Meetings were on April 17th an informative one on the morning and a chat in the afternoon....

The talk covered the normal Physiology of body thermal regulation, in relation to how the body keeps warm in the absence of Scleroderma.

It was then discussed what happens from the vascular point of view with Scleroderma. Starting with what normal blood vessels look like and comparing them with Scleroderma effected blood vessels.

Raynaud's was covered in some depth along with general non drug management and then information on the drug therapy's available here in New Zealand. This included the mechanisms of the drugs.

Prevention of Raynaud's was discussed along with lots of helpful information from a practical point of view. This included clothing, how to keep warm in bed, exercise, how to bring back your Raynaud effected hands to normal as quick as possible. Keeping your home environment as warm as possible.

Some useful Websites:

Readers you are welcome to submit a link of useful website links that you may want to share with other members here.

I was visiting these websites and thought our members may want to read:

Smiling Mind – Mindfulness



A useful insight into mindfulness. Learn how to:

- Reduce worry, anxiety and distress
- Create a sense of calm
- Improve your concentration and increase productivity
- Relax and regulate your emotions
- Develop a sense of empathy and connectedness
- Enjoy better health and sleep

By paying attention to the present moment and cultivating an attitude in which we pay attention, mindfulness has been shown to positively affect both our physical and mental wellbeing. Give it a try!

Smiling Mind Website:

<https://www.smilingmind.com.au/>

Laughter Yoga is good for you:

At our recent Wellington Scleroderma group meeting, one of our members Temu mentioned that she had been to a Laughter Yoga course. We were all very interested to know about it, so Temu has sent me their link below: -

<https://laughteryoga.org/club-profile/upper-hutt-laughter-yoga/>



Entertainment Fundraising Booklet in support for Scleroderma

I hope you are all keeping well there and sorting out your warm woollies for these cool autumn mornings.

Linda Bell's Family through their **Target** Business has very kindly set up some fundraising for **Scleroderma NZ** through the Entertainment booklets which is done through your Phone. Please see the attached information.

Link below: -

<https://www.entertainmentbook.co.nz/orderbooks/935q727>



Many Thanks again Linda and Family for your on-going support, it is much appreciated.

Dianne Purdie



2021 Virtual National Scleroderma Conference

Save the Date: July 17 & 18, 2021, for the "Virtual" National Scleroderma Conference

Dianne reminds us that there is a National Scleroderma Foundation Virtual conference in July



As the COVID-19 pandemic continues, a virtual conference is the best option to provide access to vital scleroderma information and experts, and at the same time protect the health of individuals who have the

disease and of all those who attend and support the National Scleroderma Conference.

Details about registration and programming will be published on this page as we plan the event. Please check back from time to time and [submit your email here](#) to stay up to date.

Programming for children who have scleroderma and their adult caregivers will take place later in the year. To receive email updates when **Kids Get Scleroderma, Too!** Information is available, please [enter your email address here](#).

The Foundation continues to be the best resource for **information** about scleroderma. A wealth of information can be found on scleroderma.org. Information requests can also be submitted by email, SFinfo@scleroderma.org, or by calling the **Hope** line, (800) 722-4673.

The National Conference is a special experience, particularly for first-time attendees, but also for those who return every year. The Scleroderma Foundation staff and Board of Directors values each of you very highly, and we look forward to the next opportunity to share time together in person. Thank you for your understanding.

Video recordings of presentations by scleroderma experts at prior Foundation national conferences can be posted at www.YouTube.com/sclerodermaUS.

[COVID-19 information and recommendations](#) from the Medical & Scientific Advisory Board of the Scleroderma Foundation.

About the National Conference

The annual National Scleroderma Conference offers educational and networking opportunities for people living with scleroderma, their caregivers, family members and friends.

Workshops, panel discussions and other educational sessions are led by leading scleroderma researchers and healthcare professionals. Whether you are newly diagnosed or have had scleroderma for many years, the National Conference is a great way to learn about the disease and become connected with others that are dealing with scleroderma.

With more than 60 workshops, dozens of exhibitors and the chance to meet other patients and caregivers, the weekend's activities offer an excellent opportunity for attendees.

Did you know that the actual per person cost of hosting the conference is more than \$700? We would like to thank our corporate sponsors and donors for helping to reduce the cost for participants.

Name Change. The conference name has changed from *National Patient Education Conference* to **National Scleroderma Conference** for two main reasons. The first is that the Foundation is changing the way it refers to individuals who have scleroderma because that's what they are, individuals; their identity is not "patient." Secondly, the conference is so much more than education, as vital as that is to attendees, the conference is also an essential opportunity to connect with others who have the disease. We hope that you understand and appreciate the decision to change the conference name for these reasons.

Source:

https://www.scleroderma.org/site/SPageServer/?page_name=national_conference_home



Useful Hints: Gardening Gloves:

We have some useful information regarding garden gloves from Jane and Tina...

Amazon Garden Gloves:

Below are gloves that Jane ordered off from **Amazon** to garden in.



Jane says "They are great! Very warm and waterproof Soft inside to pad the sore hands and any fingers."

Amount shown below is in US\$ 12.99

DS Safety Men's Waterproof Thermal Winter Work Gloves Size Medium.

Kind Regards, Jane

Bunnings Garden Gloves:



I too have bought some gloves for gardening.

I saw them at **Bunnings** for \$2.99 and checked them out

I put them on to try them out. They felt so lovely and warm. Very fluffy inside, good for the cold autumn days for those of us who are still keen on going outside to tend to their plants on these cold Autumn days.

I had to double check the price with my husband and asked him to tell me if I was seeing it correctly! He confirmed the price was \$2.99

Well, I had to grab 2 pairs for Hubby, and 2 pairs for myself :<)

Happy Gardening everyone,
Tina



Can anyone explain this?



This has got to be the photo of the year.



Today's Recipes:

Readers you are welcome to submit your favourite recipes, ideas, suggestions, hints...

I love this recipe. So easy to make and can have it as a dessert or a slice. My kids always made it for shared lunches at school. Jenny

Goosey Raspberry Brownie (Sauté Pan)



THE INGREDIENTS

- 180g butter
- 1 cup caster sugar
- 3/4 cup good quality cocoa
- 3 lightly beaten eggs
- 1 1/2 cups self-rising flour
- 1 tsp. vanilla essence
- 250g good quality chocolate (milk, dark, or both)
- 1 1/4 cups frozen raspberries
- Icing sugar for dusting

THE FUN

1. Preheat oven (fan-forced) to 170°
2. Melt butter in Sauté Pan over low-medium heat, remove pan from heat
3. Stir in sugar, cocoa, eggs, flour and vanilla, mix well
4. Stir through chocolate pieces and raspberries, spread mixture evenly over pan
5. Bake for 25 minutes (no lid). Brownie will seem quite soft but will firm on cooling
6. Remove from oven and cool 5 minutes. Run spatula around edge, invert onto a Splatter Guard and allow to cool a further 5 minutes on Cooling Racks
7. Cut into pieces, lightly dust with icing sugar and serve warm with vanilla ice-cream

Joke of the day:



THE HAIRCUT



"Blessed are those that can give without remembering, and take without forgetting."



One day a florist went to a barber for a haircut. After the cut, she asked about her bill, and the barber replied, 'I cannot accept money from you, I'm doing community service this week.' The florist was pleased and left the shop.

When the barber went to open his shop the next morning, there was a 'thank you' card and a dozen roses waiting for him at his door.



Later, a cop comes in for a haircut, and when he tries to pay his bill, the barber again replied, 'I cannot accept money from you, I'm doing community service this week.' The cop was happy and left the shop.

The next morning when the barber went to open up, there was a 'thank you' card and a dozen donuts waiting for him at his door.



Then a MP came in for a haircut, and when he went to pay his bill, the barber again replied, 'I cannot accept money from you. I'm doing community service this week.' The MP was very happy and left the shop.

The next morning, when the barber went to open up, there were a dozen MPs lined up waiting for a free haircut.

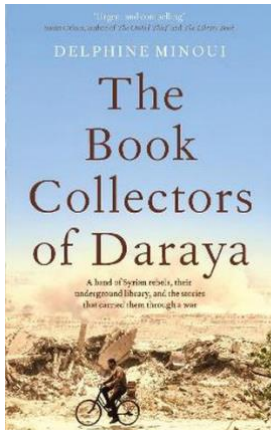


Book Club:

Welcome to a new section of the newsletter we have added. Readers are welcome to submit their favourite book, video or film...

At a recent zoom meeting, members mentioned books/videos/films they wanted to share with other members. The titles are listed below:

The Book Collectors of Daraya Written By Delphine Minoui



It begins with a photograph posted to the “Humans of Syria” Facebook account in 2015 – an image of two young men (one in a hoodie, one in a baseball cap) standing in a windowless room, surrounded by stacks of books. The caption reads: “The secret library of Daraya”. When she encounters it, Istanbul-based journalist Delphine Minoui is transfixed by the sight of this “fragile parenthesis in the midst of war”. Who were these young

men? What is it that they were seeking?

This book was given to me to read by one of my weaving friends Trudi, “Here you might like to read this, but it is a library book which has to be back by the 3rd of May” Thank you I said transfixed by the cover!! I thought heck, that’s not much time for me, so I better get cracking, I had it finished in three days, it’s not a large book, but one that is very hard to put down. I have little knowledge of the Middle East conflicts, we don’t really get told the whole story!

Well this book sent me on another tac of feeling extremely lucky of where and how we live, and we really do not have anything to complain about generally.



I acknowledge and empathize that we all have our personal trauma of coping with some really difficult circumstances. I have been through some myself over my life time. What the people of Syria have to cope with, is a different level, I came away feeling like I should be able to cope with anything sent my way after reading this book. It inspires, the up most determination, strength, humanity, courage just to name a few.

The brave young men went around collecting books from the bombed remains every chance they had, they repaired the books, and put the owners’ names on the books so they could return them to the owners once the war was over. They kept the books in an underground library safe from harm’s way, the library became a sanctuary for the people of Daraya especially for learning, which gave them hope and took them away mentally from where they were physically, living in so much terror.

A confronting well worth read. Thank you to Delphine Minoui for her depth of concern for these people and my friend Trudi for sharing.

Dianne Purdie

Author Biography



Delphine Minoui, a recipient of the Albert Londres Prize for her reporting on Iraq and Iran, is a Middle East correspondent for Le Figaro. Born in Paris in 1974 to a French mother and an Iranian father, she now lives in Istanbul. She is the author of I’m Writing You from Tehran and The Book Collectors of Daraya.



Upcoming Events:

Southland

Is there anyone in the Otago Area who would like to join our group until we can get one up and running in Dunedin? If so please get in touch with either Heather or Jenny.

Heather: milliganseeds@xtra.co.nz

Jenny: jennyred@xtra.co.nz

Waipa

Looking for fellow Scleroderma folk who live in Cambridge, Te Awamutu or even Morrinsville to come and join Susil and I once or twice a month. Just the two of us. We meet lunch times but are open to meet Saturday afternoons. Depends on what suits really. We chat, share resources, ideas, networks anything really. Open to zoom as well. Let's endeavour to support each other as best we can.

If you would like to join in with the **Waipa** Group, please contact **Erena Bruce**, all welcome.

Email: glenanderena@xtra.co.nz

Mobile: 021 186 9680

Waikato

We normally meet every second month at **Robert Harris Café, Chartwell Hamilton** but to recognise International Scleroderma Day we are having a luncheon on

26th June Saturday 11.30am at St. Andrews Golf Club.

Linda will be contacting the group.

Please email linda.bell@hotmail.co.nz to confirm.

Phone: 07 8535434

Mobile: 027 548 1214

Christchurch

Our hard core group of ladies still meet every couple of months in Christchurch in the cafe on the ground floor at the **Burwood Hospital**. 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.

Please contact Carolyn **Barkhausen** if you would like to join in with the **Christchurch** Group, you would be most welcome.

Email: barkman@xnet.co.nz

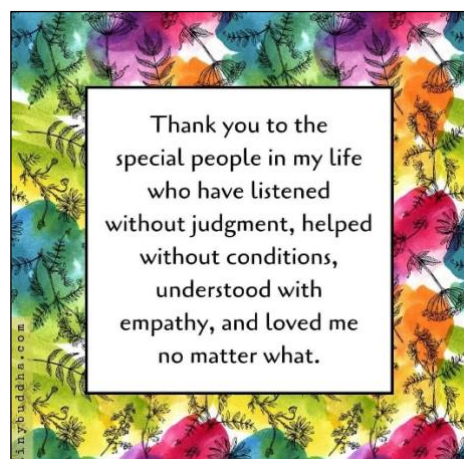
Wellington

Please contact **Dianne Purdie** if you would like to join in, you would be most welcome.

Email: diannepurdie@xtra.co.nz



Thought for the day:



Events & Happenings:

All Welcome To Scleroderma Wellingtons Support Meeting

15th May 2021

1:30pm Hardwick Smith Lounge Belmont Domain
Lower Hutt.

We are very fortunate to have Lori Davis from
Arthritis New Zealand



Topic:- Coping with a Chronic Condition.

Enjoy a lovely afternoon tea and chat after the presentation.

Gold coin Koha

Please let Dianne know if you plan to attend by 13th May

diannepurdie@xtra.co.nz



SPECIAL ANNOUNCEMENT:



Scleroderma NZ AGM Notice 2021

Tuesday: 29th June 10am – 6pm
Via Email

Nominations to: [The Secretary Jane Sainsbury](#)
Email: jsainsbury@xtra.co.nz
Email by: [June 22nd](#).

President
Vice President
Secretary
Treasurer

Committee



NOTICE BOARD...



"Virtual" National
Scleroderma
Conference
Starts on
17th & 18th July
2021

Scleroderma
Wellington Support
15th May 2021

Scleroderma
Christchurch Support
29th May 2021

Scleroderma
Southland Support
16th May 2021

Scleroderma
Waikato Support
26th June 2021

Next Zoom
Meeting
Saturday
26th June 2021
From 2.00pm



Noticeboard:

Wellington support group meets:

Saturday 15th May 2021 1.30pm to 4.00pm
Saturday 21st Aug 2021 1.30pm to 4.00pm
Saturday 20th Nov 2021 1.30pm to 4.00pm

Venue:

Hardwick Smith Lounge, Belmont Domain, Lower Hutt

Christchurch support group meets:

Saturday 29th May 2021 2:00pm to 4:00pm
Saturday 31st July 2021 Lunch at the Garden Restaurant
Saturday 25th Sept 2021 2:00pm to 4:00pm
Saturday 27th Nov 2021 2:00pm to 4:00pm

Venue:

Café, ground floor at Burwood Hospital

Auckland Respiratory support group meets:

Venue:

327a Whangarata Road, Taukau Auckland 2694

Southland support group meets 12pm:

Sunday 16th May 2021	Buster Crabb	In'gill
Sunday 22nd Aug 2021	TBA	Gore
Sunday 28th Nov 2021	TBA	Invercargill

Waikato support group meets:

Scleroderma Waikato coffee group is having our World Scleroderma Day luncheon on 26th June Saturday 11.30am at St. Andrews Golf Club. Linda will be contacting the group.

If you would like to join in with the Hamilton Group, please contact Linda Bell.

Please email linda.bell@hotmail.co.nz to confirm.

Phone: 07 8535434

Mobile: 027 548 1214

We normally meet every second month at Robert Harris Café, Chartwell Hamilton.

Date: TBA

Place: Robert Harris

Time: 10.00am

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 she will be happy to help you set one up.

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

www.scleroderma.org.nz/calendar/

Contacts:

Find a Scleroderma a Support Group near You:

Auckland Respiratory: Allan Edmondson, Email: alsand327a@gmail.com

Waikato: Linda Bell, Email: linda.bell@hotmail.co.nz

Hawkes Bay: Jane Sainsbury, Email: jsainsbury@xtra.co.nz

Waipa: Erena Bruce, Email: glenanderena@xtra.co.nz

Palmerston North: Dianne Purdie, Email: diannepurdie@xtra.co.nz

Wellington: Dianne Purdie, Email: diannepurdie@xtra.co.nz

Nelson: Beth Richards, Email: ronbethrichards3@gmail.com

Christchurch: Carolyn Barkhausen, Email: barkman@xnet.co.nz

Southland: Heather Milligan, Email: milliganseeds@xtra.co.nz



Scleroderma New Zealand Inc.

President: Dianne Purdie
diannepurdie@xtra.co.nz

Vice President: Jenny Andrews
jennyred@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



Welcome to Scleroderma New Zealand Inc.

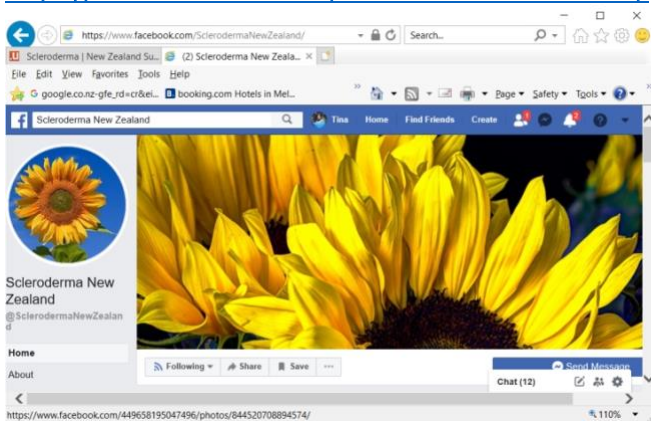
To all our new members, who have recently joined us – Welcome....

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

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



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



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



Virtual Support Group Meetings

Due to the uncertainty of things with Covid-19 we are still offering Virtual Zoom Meetings for those who do not wish to attend a meeting in person, or if we are unable to hold them in person. This keeps us involved and in touch with each other.

Remember to keep your activity levels up, there are gentle exercises you can do in your own home. Even if it is walking around your garden a few times.

Due to Covid-19 Virus, we are still offering Zoom meetings....



NEXT ZOOM MEETING:

Topic: **Scleroderma NZ Meeting**

Date: **Saturday 26th of June 2021**

Time: **2.00pm**

Join: **From PC, Mac, iOS or Android**

<https://otago.zoom.us/j/91580109817?pwd=YnNqQTgwVnl oM2YwR1puMFhqSTBNQT09>

Password: **022056**

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

