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Scleroderma
New Zealand support group

Summer 2018

Greetings to you all.

Welcome to the last newsletter for the year.

In this issue we have the President's report. Dianne will keep you up-to-date with happenings around the country and other news.

There is an online test for Raynaud's phenomenon, so you can test yourself, although you already know if you have this or not. Still worth a go.

We also have an interesting article on Pernicious Anaemia especially for those of you who have this autoimmune affliction (me). It is much misunderstood, and I even had to educate my practice nurse that it was no good me eating foods rich in Vitamin B12 because I can't absorb it: hence the reason she was giving me the injection.

Dianne wrote about the success of the Hamilton seminar. Many thanks Dianne and to Linda. Kim has an excellent story about the saying "There is no such thing as can't". I think we can all relate to this one.

We have snippets of news from people with scleroderma that are outside the scleroderma world. Tell me your story so we can share with others. That's what the Southland group (thanks to Jenny and Heather) and Beth Richards have done.

Last there is a delicious recipe from Chelsea Winter, with some Christmas cooking. Looks really enticing to make Chelsea.

President's Report

December 2018

Hello everyone, well where did that year go to?

First of all a huge thank you to the Scleroderma NZ committee, they have had their work cut out for them this year, they have been a huge support and I would like very much to show my appreciation, it has been truly valued.

A big thank you also to Barbara and John Spavin who have worked hard on these wonderful newsletters, apart from their continued support on the committee, coming up ten years now. Their work has been a big asset to Scleroderma NZ.

Also a big thank you to all of you who have made some very much appreciated donations to Scleroderma New Zealand this year. Your donations are greatly appreciated and will be used for the good of the whole society throughout New Zealand.

By now most of us would have had our Christmas get-togethers. We have one last one to attend in Palmerston North. Chris Carlyon has very kindly invited the Wellington group to meet up with her Palmerston North group to enjoy a high tea at her home, which we are very much looking forward to.

In October Gordon and I had the pleasure of attending Linda Bell's Hamilton scleroderma seminar, it was terrific, we personally learnt a lot and enjoyed ourselves. A nice pleasure to attend someone else's seminar, and we greatly respected the amount of work that Linda and her family put in, to produce such a wonderful day. I have a write up later in the newsletter.

Medical Advisory Board

A big landmark for us this year is that Scleroderma New Zealand now has a Medical Advisory Board. We have rheumatologists from Auckland, Dr Kristine Ng, Wellington, Dr Rebecca Grainger, Christchurch, Professor Lisa Stamp, also President of the New Zealand Rheumatology Association, Dunedin, Associate Professor Simon Stebbings, along with two keen specialist rheumatology nurses, from Greymouth, nurse Maureen Anderson, and from Hamilton, nurse Anna Schollum. We are currently awaiting a reply from one other doctor, but we are very optimistic.

The objective of the Medical Advisory Board is to provide clinical and scientific advice of a medical nature to Scleroderma New Zealand. Scleroderma New Zealand's responsibilities will be to notify the Medical Advisory Board of any academic publications produced by Scleroderma New Zealand. Scleroderma New Zealand will seek advice from the Medical

Advisory Board when lobbying Government for any health services. The Medical Advisory Board's responsibility will be to report to Scleroderma NZ.

A more detailed outline of the Medical Advisory Board will be in the next newsletter.

In February 2019 Julius Ikitogia has offered to run a half marathon around the bays in Wellington to fund-raise and to raise awareness for Scleroderma New Zealand. A walking group from Island Bay will be joining in the fun, to support us too. We hope to have a few of us at the finish line to welcome in our supporters. So a huge thank you to Julius and the Island Bay Walking Group for their support.

We hope to have seminars in Wellington, Auckland, Christchurch and Southland/Dunedin next year.

We are also looking at starting up a few more coffee groups around the country in the regional areas along with a few in Auckland City, as travel can be difficult.

We hope you all have a safe and enjoyable Festive Season, and we look forward to catching you all up in the New Year.

All the best,

Dianne

Online test for Raynaud's

Scleroderma and Raynaud's UK (SRUK) has started an online test to help diagnose Raynaud's

The test is to raise awareness of Raynaud's phenomenon (RP) and to encourage individuals to be actively involved in their own health care

The test is not designed to substitute for a doctor's diagnosis.

Raynaud's manifests itself as the sudden constriction of arteries in the hands and feet, following their exposure to the cold.

Sudden changes in skin colour often accompany Raynaud's attacks. The colour changes range from white, blue/purple, and then red. It causes pain, numbness, impaired function and reduced quality of life.

The presence of Raynaud's can be primary or secondary due to underlying disease such as systemic sclerosis.

There is a delay in the diagnosis of secondary Raynaud's generally because the time between the onset of Raynaud's and the emergence of the first non-RP symptom can be more than 5 years. Scleroderma and Raynaud's UK says that makes it a critical, un-met need that must be addressed.

The online test comprises questions derived from existing RP criteria to determine if RP is likely and whether further assessment is needed.

Feedback is provided to respondents in the form of statements, such as "This is unlikely to be Raynaud's" or "You may have Raynaud's".

They advise participants to seek medical advice if they experience painful or frequent symptoms, or if they say yes to developing sores or ulcers on their fingers and toes, regardless of their responses to other questions.

From June 2017 to June 2018, nearly 19 thousand people completed the test on the website. SRUK says that highlights the large number of people visiting patient organisation websites for information. It sees the potential of patient organisations to encourage patients to take more responsibility for their own health care.

It says collaboration between health professionals, patient organisations and the public is crucial to raise awareness around the importance of early diagnosis and to increase the profile of RP.

Table 1 The questions and responses comprising the online SRUK 'Raynaud's Test'

Questions (Q) comprising the Raynaud's Test	
Question 1	Are your fingers sensitive to the cold?
Question 2	Do your fingers change colour in response to temperature change or stressful situations? (white, blue, red and purple)
Question 3	Do you get numbness or pain in the affected area when they change colour?
Question 4	Do you feel stinging or throbbing when the affected area warms up?
Question 5	Have you ever developed any sores/ulcers on your fingers or toes?
Responses provided to visitors depending on their answers to questions 1–5	
No to Q1-5 OR Yes to Q1 but no to Q2-5	**This is unlikely to be Raynaud's, however if you experience painful or frequent symptoms, or are concerned, then it may be worthwhile visiting a GP** You may be oversensitive to the cold and so to reduce your symptoms try to keep warm. Take a look at our information below to support you with keeping warm and avoiding smoking. If you would like to know more information about Raynaud's then why not have a look at the further information below. Raynaud's is a common condition affecting around 1 in 6 people. In people who have Raynaud's, the small blood vessels in the extremities are oversensitive to changes in temperature or stress causing a Raynaud's attack. Raynaud's symptoms generally affect the fingers and toes, but all extremities can be involved, including the ears.
Yes to Q1, Yes to one of Q2-4, and No to Q5	**You may have Raynaud's** Raynaud's is a common condition affecting around 1 in 6 people. In people who have Raynaud's, the small blood vessels in the extremities are oversensitive to changes in temperature or stress. This causes a Raynaud's attack where the fingers change colour typically white, blue or red. Raynaud's symptoms generally affect the fingers and toes, but all extremities can be involved, including the ears, nose, lips, tongue and nipples. If you are experiencing painful or frequent symptoms then it is worthwhile visiting your GP to discuss the situation, including management techniques and possible treatment options.
Yes to Q5, irrespective of the answers provided to Q1-4	**You may have Raynaud's** Raynaud's is a common condition affecting around 1 in 6 people. In people who have Raynaud's, the small blood vessels in the extremities are oversensitive to changes in temperature or stress. This causes a Raynaud's attack where the fingers change colour typically white, blue or red. Raynaud's symptoms generally affect the fingers and toes, but all extremities can be involved, including the ears, nose, lips, tongue and nipples.

Take the test here »»

Pernicious Anaemia

Oh, the delights of auto-immune diseases

Some members of the support group have the aptly named pernicious anaemia

Pernicious anaemia is a type of vitamin B12 deficiency. People who have it can't absorb the vitamin through their food like most of us do. It's caused by the lack of a substance known as intrinsic factor (IF) produced by the stomach lining. It was once a fatal condition - hence the 'pernicious' label..

Vitamin B12 helps the body make healthy red blood cells and helps keep nerve cells healthy. It is found in animal foods, including meat, fish, eggs, milk, and other dairy products.

The most common cause of pernicious anaemia is the loss of stomach cells that make intrinsic factor. Intrinsic factor helps the body absorb vitamin B12 in the intestine. The loss may be due to destruction by the body's own immune system.

Pernicious anaemia can cause permanent damage to nerves and other organs if it goes on for a long time without being treated. It also raises the risk of developing stomach cancer.

Common signs and symptoms of vitamin B12 deficiency, seen in pernicious anaemia include:

- Feeling tired and weak;
- Tingling and numbness in hands and feet; and
- A bright-red, smooth tongue.

Pernicious anaemia is easy to treat with vitamin B12 pills or injections as well as diet changes. The treatment is needed life-long.

Complications caused by untreated pernicious anaemia may be reversible with treatment.

Doctors don't know how to prevent pernicious anaemia. Eating foods high in vitamin B12 and folic acid can help prevent vitamin B12 deficiency caused by a poor diet.

Humans get vitamin B12 from animal products; both meat and dairy. The body is able to store vitamin B12 for a long time, so an inadequate diet must persist for years before a true deficiency of vitamin B12 is reached. Therefore, the symptoms of pernicious anaemia usually do not appear for years. It is most commonly diagnosed in adults with an average age of 60.

Pernicious anaemia is more common in Caucasians of northern European ancestry than in other racial groups. Pernicious anaemia also is termed Biermer's or Addison's anaemia.

When lunch tastes just offal!

In 1920 a researchers discovered that eating about 2 kilograms of minced, raw bullock's liver daily stopped pernicious anaemia in its tracks and allowed the absorption of B12. They won the Nobel prize for it. Anyone with pernicious anaemia who refused to eat the raw liver died.

A few years later a bright spark synthesised the liver extract and now an injection did the same things and saved lives

Group member, Barbara, who has pernicious anaemia, was telling a friend about it and she exclaimed that her grandfather had been one of those who'd had to eat the raw liver every day to survive.

Hamilton Seminar October 2018

On a rather fresh, early start on Saturday the 27th of October Gordon and I arrived at the seminar venue in Hamilton, along with a woolly hand warmer!!

As we walked in there was a hive of activity.

Linda was organising the helpers with setting-up and her beautiful family was flat-out in the kitchen getting all the food ready for the day.

The day started with a lovely welcome from Linda. There were well over 50 people who attended the seminar all the way from, Auckland, Taranaki, Hamilton and regional Waikato, and Gordon and me from Wellington.

The first speaker was Dr Kamal Solanki who talked about scleroderma from a newly diagnosed perspective. I learnt a lot as there have been some advances over the years.

Next we had Dr Kennedy, a rheumatology registrar from Waikato Hospital, who gave a very good talk on gastrointestinal problems and scleroderma, which was very interesting and informative.

Next up they had a very good physiotherapist from Waikato Hospital who spoke about how we can look after ourselves, with exercise at our level. At midday we enjoyed the most wonderful lunch provided by Linda's family. It was delicious and most filling.

First up for the afternoon was me talking about Scleroderma New Zealand, outlining our history and what our society provides for its members. I added a quick outline of the results for our three surveys this year.

Last we had a very interesting talk from our vice-president Allan Edmondson. Allan talked about how we can look after ourselves by keeping good medical records and keeping our details on a USB stick, so that if we end up in hospital for some reason all our medical information is at the medical personals' fingertips. Allan also had a great line-up of useful appliances, including arctic sheets and heated blankets for keeping us warm over the colder months.

The seminar was enjoyed by all, I have received lots of positive comments from the people who attended. A huge thank-you to Linda and her family for an exceptional seminar. We are looking forward to the next one.

Dianne

Linda attracted more than 50 attendees to her latest seminar

When it is OK to say, "I can't"

Kim Tocker, Scleroderma Support Group member, writes a regular column for an online site, sclerodermanews.com Here is a recent column by Kim.

There is a phrase that gets me going every time it is offered up to me. It drives me nuts.

It usually happens when I am trying to explain why I cannot do something that entails using a part of my body that scleroderma has permanently damaged. This explanation could be anything from why I can't pour water from a heavy jug to why my heart doesn't cope with strenuous forms of exercise.

It's that old line, everyone's favourite: "There's no such thing as can't."

My feeling about that particular expression is that it is far too broad, contains aspects of foolishness, and also is rather whimsical. Perhaps it is offered because I am perceived as lazy, unmotivated, or possessing a negative attitude. I lack hope and self-belief.

Or maybe it is a thoughtless attempt to encourage me in some way.

The fact is that there are fundamental parts of my body that physically don't work anymore because I have systemic scleroderma. It isn't rocket science, really.

Now, I appreciate the fact that the mind and body are often intertwined. I know only too well that sometimes physical possibilities are achievable even when they feel impossible.

Those additional three bench presses during a workout, jogging that extra mile when you thought your body had nothing more to give, hauling yourself out of bed to get to the gym in the mornings. Those types of things.

I remember working hard to overcome my mental blocks when I trained, competed, and was placed in a body-shaping contest years ago, before I got scleroderma.

It's called extending yourself. It is very effective when you have something to work with — something to actually extend in the first place.

However, the crunch comes when people and patients alike do not understand that there are, in fact, times when the

body and the mind are separate entities, and they cannot work together as a team. In these cases, mantras such as, "It's all in the mind," or "There's no such thing as can't," are not appropriate.

If my body is irreparably broken because of scleroderma and it stops me from doing some things, then this is the truth of my situation.

It is hard enough for me to accept that my mind will not fix my fingers that cannot grip things or my heart that will never have enough oxygen because of scarred vessels. I don't have the energy to convince others that is the case.

So, to those who really believe my mind can overcome the permanent damage resulting from my disease, I say this:

"Enjoy your healthy life and all the things you can do. Have fun pushing yourself and mentally overcoming your pain threshold and physical endurance capabilities. I'm genuinely pleased that you can.

"But please: If you don't care to take the time to get to know me, or to understand systemic scleroderma, then check your privilege.

Especially before suggesting that the power of the mind will overcome my permanent physical limitations because of this wretched disease."

Scooting about the place

Beth Richards takes to the road in Nelson

Hello to my scleroderma friends. My name is Beth Richards. I live in Ruby Bay near Nelson. I'm 66yrs old

I was diagnosed with scleroderma CREST syndrome in 1997.

Since then I have had at least 20 operations for broken bones, hip and shoulder replacements, plus fingertip amputation and removal of calcinosis ulcers.

I am generally well but my muscles are weak and I cant walk far.

I decided that I would buy a mobility scooter to expand my horizons and get me out of the house.

It was the best decision I've made. It has changed my life.

I go down to Mapua, which is a 45-minute ride to see my friends and my young granddaughters go bike riding with me.

Its so much fun.

My scooter has larger all-terrain tyres and suspension to tackle the bicycle tracks.

If any of you had thought about it and hesitated please try one to see if it is for you.

They can be hired from a shop. There are many second-hand scooters around.

We live on a hill with a steep gravel drive and it tackles it easily.

Anyway dear friends I hope you enjoy my story and here's to happy scootering.

On the pointy end of a plant habit

Dianne and Gordon Purdie, effective founders of the Scleroderma Support Group have another life: they are mad about cactuses

At the recent Hutt Horticultural Society's show, the pair were at work selling a variety of their plants, as they have been for many years. Dianne is recently retired as secretary of the society.

Incidentally, if you are pedantic about the plural being cacti instead of cactuses, the Oxford has a bob each way, accepting either form.

There is life outside scleroderma, even it if can be a bit prickly

Southland Scleroderma get-together

We met in late November in Invercargill,

Thanks so much to Jenny for organising as well as setting out our get-togethers for next year!!! It's always great to meet like-minded people and their partners.

One of the main topics for discussion was that the Southern DHB was developing setting up a dedicated clinic for scleroderma to run across their region. It covers Waitaki River south down to Southland and Central Otago.

We will let you know more when the process is underway. I do wish it was a New Zealand-wide initiative.

At my last appointment with my GP for a repeat medication (they come around too quickly) she commented that she recently had a visit from a representative of the rheumatology service based in Dunedin Hospital to discuss how GP's felt they were achieving (which she thinks is very good).

The representative, without prompting, commented on the 'large' number of those with scleroderma in Central Southland as well as the other areas of Southland.

Good to know we are not forgotten.

At the last count from Jenny's data base there are 5 of us in Central Southland, 9 in Invercargill and 10 in Eastern Southland and we are sure there are a few more out there not drawn to joining us.

Heather

Scleroderma registry launched

The George Washington University School of Medicine and Health Sciences is one of 12 top US medical research centers to collaborate with the Scleroderma Research Foundation (SRF) to launch CONQUER: the first-ever national, longitudinal patient registry for those suffering from scleroderma.

CONQUER will collect a detailed clinical data set and blood from thousands of early-stage patients. It will follow each patient over several years.

The School says the data gathered will help advance current research and improve patient care.

George Washington University (GW) will join other leading scleroderma centres across the country, to follow patients. It hopes that collecting this type of longitudinal data will help to understand the disease better and ultimately to find a cure.

In addition to GW, the CONQUER consortium consists of universities and hospitals, including Johns Hopkins University, Stanford University and the University of Texas Health Science Centre at Houston.

Cooking for Christmas

Chelsea Winter has a new cookbook and a recipe that is a bit Christmassy.

It's tangy cranberries, crunchy macadamia and pistachio nuts with a creamy white chocolate and cream cheese icing. Finish it off with freeze-dried mandarins. It's a homemade Christmas gift – or keep it in the fridge to enjoy FOR GLUTEN FREE: Use gluten-free flour mix in place of standard flour and 1/2 cup coconut in place of the rolled oats.

Ingredients

200g butter
½ cup caster sugar
1tsp pure vanilla essence or paste
Zest of 1 large lemon
1 large free-range egg
1 ¼ cups flour
½ tsp baking powder
150g good-quality white chocolate, chopped
1 cup dried cranberries
½ cup rolled oats
¾ cup roughly chopped nuts (macadamia, pistachio, almond, cashew)

Extra nuts and dried cranberries, to decorate. Freeze-fried mandarin segments, to serve (optional)

Icing

100g good-quality white chocolate
25g butter
150g cream cheese, at room temperature
½ cup icing sugar
1 tsp lemon juice

Method

Preheat the oven to 180c conventional bake and line a slice tin (say, 24cm) with baking paper.

Place the butter, sugar, vanilla and lemon zest in a medium saucepan and melt over a low heat, stirring. When just melted, remove from the heat and cool for a few minutes.

Sift the flour and baking powder into a bowl and stir to combine evenly.

Add the egg to the butter mixture and whisk to combine. Add the white chocolate, cranberries, rolled oats and pistachios, and stir.

Sift the flour mixture in and stir to combine evenly.

Scrape into the lined tin and press out into an even layer with clean damp fingers (or you can lay a sheet of cling film on top and press out on top of that).

Bake in the oven for about 17 minutes or until just starting to go golden. Cool in the tin.

Icing

Break the chocolate into pieces and add to a heat-proof bowl with the butter. Fit over a saucepan of gently simmering water (don't let the water touch the bowl). Let it melt, stirring every now and then, until smooth. Remove from the heat. (If the chocolate seizes and goes grainy, try adding 2tsp of rice bran oil and stirring).

Beat the cream cheese in a smallish bowl until smooth. Sift in the icing sugar and add the lemon juice, and beat until smooth.

Add a spoonful of the white chocolate, beat to combine, then repeat until all is combined. Spread on the cooled slice, sprinkle with the extra chopped pistachios, cranberries and crushed freeze-dried mandarins (if using). Refrigerate for an hour to set then slice with a hot knife.

See chelseawinter.co.nz/cranberry-slice/

Noticeboard

Wellington meets:

Saturday 16 Feb 2019 1:30 pm to 4:00 pm

Saturday 18 May 2019 1:30 pm to 4:00 pm

Saturday 17 Aug 2019 1:30 pm to 4:00 pm

Saturday 16 Nov 2019 1:30 pm to 4:00 pm

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

Christchurch meets:

Saturday 26th January 2-4pm

Saturday 23rd March 2-4pm

Saturday 25th May 2-4pm

Saturday 27th July 2-4pm

Saturday 28th September 2-4pm

Saturday 23 November 2-4pm

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

Respiratory support group meets:

327a Whangarata Road, Tuakau, Auckland 2694

Southland meets:

January: Sunday 27th 12.00pm Gore

April: Sunday 14th 12.00pm Invercargill

June: Saturday 29th 12.00pm Gore (Scleroderma Day)

September: Sunday 15th 12.00pm Winton

November: Sunday 24th 12.00pm Invercargill

Contacts

Find a Scleroderma support group near You

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

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

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

Invercargill: Heather Milligan 03 248 5147

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

New Support Groups

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

Scleroderma New Zealand Inc.

President: Dianne Purdie

diannepurdie@xtra.co.nz

Newsletter: Barbara Spavin

barbara@spavin.com

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

www.scleroderma.org.nz/calendar/