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Scleroderma

New Zealand support group

Autumn 2016

Greetings to you all. We have a season change this month and autumn is here. Like they say on Game of Thrones: Winter is Coming.

What a fabulous summer we have had. Sore joints were at a minimum and I enjoyed a relatively pain-free season.

Let's hope that the first half of autumn is still warm and sunny so we can make the most of those lovely fine days.

In the newsletter this month, we have a report from the president. Dianne will keep you up to date with what's happening with Scleroderma Inc.

Rob tells us how he copes with his pain - he and his dog!

Adrienne tells us about her fabulous trip down the Danube, visiting the Christmas markets, and how she coped with her scleroderma.

There is also a pic of scleroderma ladies when South meets North for a lunch in Palmerston. Nice to see you ladies.

Let us know what you are doing to celebrate World Scleroderma Day so we can all share. We would like to hear from the area groups to find out what you are up to.

Items for the newsletter can be emailed to me at any time.



President's Report -

We have been extremely lucky with summer this year, it has been long and very warm and I'm sure it has given us all some relief in one way or another, but one of our biggest hurdles has been to keep cool, but not to get cold in the process.

The society is coming together quite well, our booklets will be printed and posted to all rheumatology services and GPs who are keen to learn some practical and basic knowledge of Scleroderma. We'll send the hospital check-list to those of you who want it with the help of an NZ Post Grant.

Maureen Kirby (Rheumatology Specialist Nurse from Invercargill) has worked hard to sell the calendars for the four charities she chose. Maureen has asked our committee to decide how we'll spend her donation. This has been a big task as Maureen works full time with a young family. We really appreciate her efforts and thoughts of kindness for all of us out there with our chronic condition.

We have just set up a Give a Little page for donations Give a Little: <http://givealittle.co.nz/org/sclerodermanz1/donate> you can donate through a link on our website or directly through Give A Little.

We have signed up to the Buzz the People: www.buzzthepeople.co.nz this is a company where, if you fill in surveys, you can donate your proceeds to your favourite charity.

KIWI KARMA: www.kiwikarma.co.nz (Accommodation booking service) is an easy way to support a charity, simply by doing what you were going to do anyway. Just use Kiwi Karma and at no extra cost to you and 5-8% of the room rate automatically goes to the charity of your choice.

Kiwi Karma's rates and availability should be the same as the overseas based sites. You get to support New Zealanders in need.

If any of you want to donate to Scleroderma NZ to help us raise the funds to print our booklets, it would be much appreciated. We will be asking for donations around World Scleroderma Day, 29th of June. We don't have an annual subscription so a donation around world Scleroderma Day could become a habit for those who can and would like to.

Our groups around the country will be looking at ways in which to take part in the International World Scleroderma Day.

You could do something you enjoy to mark the occasion or form a group and make it a special day out.

If you are thinking of exercising for personal fitness it is very important to wear orthotic inners in your runners or at least sheepskin inners, to spread the load on the soles of your feet to help prevent corns. Wear extra wide runners to avoid constricting your toes. It will help you enjoy your preferred exercise. It is important to wear orthotic day shoes



too. There is a wide range these days so you can still wear nice looking shoes in healthy comfort. Ziera nationwide www.zierashoes.com/Shoes/Orthotics have some good choices.

Winter will be on its way soon - my chance to have my rave about how important it is to keep your core warm. You'll help prevent internal Raynaud's to your major organs and help with your extremities too. Never let yourself get too cold. It is very difficult to recover. If you suddenly get cold hands, say, when getting food from the freezer, have a pair of pair of thick rubber gloves ready. Put the gloves on and run your hands under the hot tap. The water will warm your hands and return circulation. Be prepared: put your gloves on before you need them.

Merino leggings or stockings are now available at reasonable prices. Wear three layers of Merino around your core. And don't forget your hat.

All my best to you all out there, keeping warm is something you can all do for yourselves, to help prevent the vascular symptoms getting worse.

Dianne (a woolly by nature)



Golden Paste is a Golden Remedy

Wellington member, Rob Tomkies, picked up a really interesting tip at a recent support group meeting.

We learn something new every time we attend a Scleroderma meeting.

A couple of meetings ago a new attendee suggested that I could replace my paracetamol, which I was taking at 3-hourly intervals, with "golden paste". She said that she even gives it to her horses for arthritis, with excellent effect apart from leaving a yellow "smile" around their faces. She said the recipe could be found on the internet, the main ingredient being turmeric.

We bought turmeric from Commonsense Organics on the way home and Chris immediately made a batch.

The hope was that it would help me replace paracetamol and help Chris and our dog, Lucky, with their pain caused by arthritis in their hips. The concoction was a very bright yellow colour, the taste was rather challenging to start with!

I can report that it does not enhance porridge, and tea with golden paste is no longer tea as we know it! We bought some empty gel caps, which Chris filled and put in the fridge. The next morning she found a pile of golden paste and partially dissolved caps. So caps were then filled at the time of taking - extremely inefficient use of time.

Time to man up, we thought. Chris and I now take half a teaspoon twice a day, straight from a teaspoon, followed by a drink of water and no longer notice the taste. Lucky has half a teaspoon mixed in with her food once a day, I've had no



Luck and Chris

feedback from her but she is a black lab and labs never turn their nose up at food. Incidentally, it does stain clothes- badly.

The result? Lucky bounds about like a puppy and has improved general health. Chris bounds about like a puppy and has greatly reduced her dependence on opiate-type drugs. She can walk for an hour most days and not suffer debilitating pain. I considered bounding about but have too much dignity, however I'm totally off paracetamol, and suffer only slight pain in my ankles first thing and when I get tired at the end of the day.

Would we recommend for joint pain? You betcha! Barking mad not to.



There and back again - Adrienne's trip

It's northern November, it's getting cold and days are shortening. The news talks of terrorist attacks in Paris. Europe's railway stations and border crossings are crowded with refugees. Who would want to go to Europe at this time of year. Well I did - and I went.

As part of my bucket list I wanted to do the Christmas Markets that are held throughout Europe in November and December. I'd combine it with a cruise along one of the major rivers. The desire culminated in four kiwis and three Americans joining the last Christmas Market cruise on the Danube for 2015. Great excitement: seven women; 12 days' shopping; luxury accommodation; nightly entertainment; local guides and delicious food. We were doing it in style.

Each day brought a different city or historic place to explore. At night we attended a concert or other entertainment on board after which we sailed off down the dark river through lakes and locks to our next day's destination.

We explored markets in the town squares and bought as many little treasures as we could safely carry home. We tasted a wide variety of dishes, local and classic. We knew nothing of the local languages but, wrapped in bundles of warm clothing, got ourselves about the city or town we were in, knowing we had to be back on the ship before the anchor weighed. Then it was ship ahoy to our next river port while we ate the chocolates on our pillows, sipped hot chocolates, remembered the spiced red wine we had enjoyed at markets, and then slept soundly as we travelled along the calm river.

I'm not very mobile as also are many of you with systemic sclerosis and polymyositis who read this. The trip had its challenges. I need a walking stick to get about and have two speeds - dead slow and stop. Both of these were in use each day. Some days were tougher than others so I would give myself a good talking to and decide what I really needed to do that day and still feel that I had accomplished something satisfying. I was determined to get as much as possible out of the trip, to enjoy myself, stay well and not be a burden on travelling companions, who were helpful and supportive throughout the trip. Here are some of the techniques I used.

- I carried my usual medications and spares, and took the recommended daily dose each day at the correct time
- I kept a full week's medications in one of those sectioned pill boxes and always had this box with me
- My doctor prescribed me different antibiotics, which I filled before I left NZ and which I needed to use twice during my travels
- I carried pain killers and used them to the limit some days so that I was able to do as many activities as I could



- I had a copy of the prescriptions for all the medications with me at all times and a separate copy in my suitcase along with phone and email contacts of my doctors in New Zealand. Luckily I didn't need to use them
- I showed my sister, my travelling companion where all of my medications were and what they were for, so, if I had a problem she had some of the information she would need
- Each day I chose my clothes carefully so I could add or remove layers to keep Reynaud's at bay and deal with the sweat attacks I am prone to, hot or cold weather
- When the main group went too fast during the walking tours or I was feeling more than a bit sore, I took a taxi to the walk's end and met them there.
- I used a good moisturiser and its contents were invaluable as my skin dries as quickly in the cold as it does in summer.

See next page

There and Back Again *contd.*

And what did I not do that I should have done?

- I forgot Imodium and when I needed it I had to put up with vomiting and diarrhoea. I now have TWO packets and will not move even in New Zealand without it.

Cruising is great when you have a challenge like scleroderma - plenty of room, the luxury of staying on board for the day if you don't feel up to it and making haste slowly. The downside: you have to get there. For me it has almost always been in cramped cattle-class in the back of a wide-bodied airliner.

There is the accompanying boxes of pills (1.5 kilos, in my case), the need to get up and stretch and the physical confinement. Is it 26 hours, or two stretches each of around 12-to-14 hours for the long flights? Everyone chooses what suits their budget.

It can be exhausting and unpleasant but a budget is a budget and I stuck to it. I fantasise that one day I will be fed into a fax machine, to appear in some other place, to enjoy myself without the uncomfortable journey - dream on Adrienne!!

Most of the trip was in economy. Both my sister and I have mobility difficulties and we booked to have wheelchair assistance at all the airports, to be whizzed across long distances. It's a free service for everyone with mobility difficulties. Ask for it when you book.

BUT, sometimes miracles happen. We were waiting in our wheelchairs in Amsterdam for our Malaysian Airlines flight. A uniformed Malaysian Airlines official asked for our boarding passes. We gave them and he returned a few minutes later with new ones. He had upgraded us to business class. WOW, we had full-length beds, plenty of room and superior service throughout the 14-hour flight.

Malaysian Airlines has had a bad rap, a really bad rap after it lost a plane in the Indian Ocean and kind of lost its way heading out of Auckland recently. But we were treated like

royalty in seats that were probably three times the cost of the cabin class ones we had purchased. The expense of buying business class was beyond our budgets but we really appreciated this wonderful Christmas present to each of us.

And then there is a second plaudit for Malaysian Airlines. I mentioned earlier that I had need for Imodium during my travels. This was on the long flight from Kuala Lumpur to Auckland, back in cabin class. Twenty minutes into the flight, the chicken I had eaten in Prague caught up with me and from then on for the next 10 hours I was a real mess. Again I can only praise the crew. The cabin attendant kept bringing me cold sparkling water, face cloths, various containers to fill up and was so concerned with my welfare throughout the trip. I survived this lengthy experience, I suspect, in far better condition because of the care and support he provided.

When we landed in Auckland to be greeted by a very large bus complete with several paramedics. Cabin crew asked my sister and me to accompany them. We made our slow way down and climbed aboard the bus. The plane disappeared and we and one other miserable looking younger woman who had the same problems as me, went off through customs and immigration at what felt like lightning speed. Auckland Airport staff were marvellous, organising shower and access to clothes from my bag. I felt human again. Not the best of homecomings but one handled very compassionately and gracefully. Thank you Malaysian Airlines.

The experience was very unpleasant and took ten days to get over yet I have no fears about flying again, with or without scleroderma. The cabin crews are well trained and do their very best in conditions which are just as bad for them as they are for you. Smile and say thanks was all I was able to do, but I am grateful to them for making the end of my lovely holiday so much better than it could have been. By the way, my sister says that they must have had a good air conditioning system on the plane as she was not able to smell anything. I relaxed.



Lunch in Palmerston North



It might not be John Cleese's cup of tea but some Wellington members enjoyed a jaunt to Palmerston North to have lunch with local members this month.

Advice for those newly diagnosed with scleroderma

Feeling scared upon diagnosis of scleroderma is natural and, as tempting as it may be, don't randomly roam the Internet for information.

You will encounter worst-case scenarios, as well as incorrect information. If you do search for and find scary information, don't panic.

Instead look for a doctor who has expertise and experience dealing with scleroderma. Many GPs seldom encounter it and it's usually

a rheumatologist who can provide comprehensive management for your illness.

Your GP and specialist can work together to devise a care plan.

After you have had an initial consultation with an expert on scleroderma, spend time learning about the disease and your specific situation by consulting reliable sources. The following patient-oriented websites provide good overviews of the

illness:

- rheumatology.org
- my.clevelandclinic.org
- mayoclinic.org
- scleroderma.org

When you return to a specialist write down questions you want answers to, such as short and long-term expectations; the impact on your personal and professional life.

Eat a healthy diet; try walking

or chair exercise—whatever you can manage. Rest when you need to.

Remember that you are a person who happens to have scleroderma; the disease need not define you. Take control. Choose to live the best life you can imagine.

This is an extract from a most helpful article at:

<http://awomanshealth.com/when-the-diagnosis-is-scleroderma/>

Hic

A woman burst out of the examining room screaming after her young doctor told her she was pregnant.

The director of the clinic stopped her and asked what the problem was. She told him what happened and the doctor sat her down to relax in another room.

He marched down the hallway where the woman's doctor was and demanded, "What is wrong with you? Mrs. Miller is 60 years old, has 6 grown children and 9 grandchildren, and you told her she was pregnant?"

The young physician continued to write his notes and without looking up at his superior, asked, "Does she still have the hiccups?"

Find a Scleroderma support group near You

Auckland: 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: Maureen Kirby-
Maureen.Kirby@southerndhb.govt.nz

Christchurch: Kim Tocker-
akaroakim@gmail.com

Wellington: 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.

Noticeboard



Next Wgtn
Meeting:
Saturday, May 7

World
Scleroderma
Day
June 29th

Contacts

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