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A vibrant field of sunflowers with bright yellow petals and dark brown centers, set against a background of green foliage and a clear blue sky. The sunflowers are in various stages of bloom, and the overall scene is bright and cheerful.

# Scleroderma

New Zealand support group

# Autumn 2014

It was good to see everyone again at our last meeting, which was a busy, well-attended affair.

Welcome to our new member Jo and good to see the Palmy ladies and husband also.

At our meeting we had guest speakers Delta and Melanie who are podiatrists.

They spoke to us about the care of our feet, the dos and don'ts of footwear and they brought along a variety of shoe inners, lotions and potions to use when caring for our feet.

They also spoke about what podiatrists do and the wide range of services that are available when you visit them.

In the newsletter this month we hear from the Palmy ladies who have been travelling abroad. You can read their adventures to England and Vietnam.

Yvonne has been walking the Queen Charlotte Walkway. You can see the beautiful scenery of our very own New Zealand in her story.



The podiatrist's tool kit. Part of the display that Delta and Melanie brought along to illustrate their talk

## News items

June 29th is World Scleroderma Day. Tell us what you have planned. Wellington group are having a photo shoot.

We will meet on the day and display our photos.

It will be a family day where family and friends come along to have a chat and morning tea and view all the photos.

Everyone is welcome.



# Best foot forward

May's meeting heard from two podiatrists who explained what foot problems you may encounter, how to alleviate some of the symptoms and what treatment is available when you need expert help

Delta and Melanie both work from the Avalon Podiatry Clinic in Lower Hutt's High Street but their advice is professional and would be available from podiatrists around the country.

Delta explained the effect that scleroderma may have on feet, caused by the way it over-produces collagen and constricts micro blood vessels, particularly in the cold.

She described how corns, which grow as a result of repetitive pressure on a point on the sole, can be alleviated and removed with skilled help and the aid of pressure-relieving gel pads and toe separators.

Her advice is to check your feet often and thoroughly for wounds or corns and don't delay seeking medical advice. She urged care when you cut your toenails to follow the curve of the toe when snipping and not to leave sharp edges.

Melanie spoke in detail on how careful choice of shoes can alleviate much foot discomfort. She says fat layers on the sole move with age and a good shoe coupled with an insole can mitigate that and retain a cushioning affect.

"It's all about taking pressure off," she says.

Melanie preferred leather shoes because they stretch. For socks, she had some tips: avoid socks with bulky seams as they press against the ankle or foot; diabetic socks that don't compress feet are available; try wearing long johns in winter to stay warm and avoid tight socks, even to the point of cutting a v from their tops to relieve their grip.

She described socks that include silver threads because the metal is a natural antibiotic and it retains heat. Suppliers may be found by Googling "silver thread socks".

Amongst a detailed explanation of foot problems and their treatment Melanie's thrust was: "Prevention is better than cure." Podiatrists are trained to help you and can do more the sooner you realise that there is a problem.

Delta and Melanie can be contacted at the Avalon Podiatry Clinic, 841 High Street, Lower Hutt or on 04 567 5918, [podiatry.avalon@gmail.com](mailto:podiatry.avalon@gmail.com)



Delta explained how nails can cause all sorts of problems if not cared for properly. Skin can retract from them and they become liable to infection. When cutting toe nails, follow the natural curve of the nail and don't leave ragged corners. Her advice is: if you have problems with your toes, seek help early.



Your foot has 26 bones, 33 joints and 100 muscles, tendons and ligaments. Together, they keep you upright and Melanie explains here how to look after them and deal with the effects of illness and age. Her aim as a podiatrist, she says is to align all these bones and muscles and remove the pressure points that damage you and cause pain



# The Palmerston crew prove that scleroderma isn't enough to slay the travel bug.

Linda from Palmerston North swaps her warm summer for the mid-winter chills of the UK.

In mid January I went to the UK. The trip over was 30 hours on planes and in airports.

I arrived in the morning so it was rather hard to stay awake for the day, but I managed after having the odd nap. Jet lag was not too bad. I wore thermals on the plane so I wasn't cold and got extra blankets. The food was OK though I did ask for and got lots to drink as I suffer from Sjogrens as well as Sclero.

You may ask why go to England in the middle of winter when I really feel the cold suffer and from raynauds badly? Our Daughter Joni, was having her second baby. A Caesar was planned for just a few days after I arrived. It was priceless to be there when little Anna was born safe and sound and Joni was good too. I spent hours having cuddles (making up for when I had to go home).

I also had 2-year-old grandson, Sam, to run about after. I did the early shift - getting up at 5am because that's when he woke. I have watched kids' movies like Cars 1 and 2 and Nemo and several Toy Stories so that I know them all thoroughly.. I've been to different toddler groups like Boogie Bunnies and church groups. I didn't do the swimming because it would be too cold for me (I was in bed exhausted most nights by about 8.30pm).

I caught the flu about 10 days after I arrived and got pretty crook. (I do have the NZ flu injection), I have not had a flu since way before my diagnosis about 9 years ago and boy I was now well. During the 5 weeks I was in the UK I flew to Guernsey to have a few days with my sister. It was lovely to sleep in and recoup there.

The whole time I was there the temperature never got above 9. Most days it rained and blew, one day it snowed, rained, hailed blew and was sunny too. I did have 2 days when the sun shone all day.

While English houses have radiators throughout and they think



Linda, wrapped for the climate, holds baby Anna

they are warm they haven't lived in my house. Joni's partner Scott thought he had lived in a sauna for the time I was there because we had it a lot warmer than usual.

We weren't out in the weather too much - mostly it was getting Sam and Anna in and out of the car which was a mission sometimes as Joni could do no lifting. And, of course, I had to do some driving. Thank goodness, at least, it was the same side of the road as us but gee they have very busy narrow roads there. (The car I had was a large Audi station wagon).

Yes my raynauds was bad at times but I coped OK and wore several layers of Icebreaker thermals all the time. It was hard to wear gloves when we were out because I needed to be able to have a good grip on Sam and it was slippery when carrying the baby cube.

As usual it was a very sad trip to Heathrow when it was time to return. It was an awesome trip, I cant wait to do it again with my hubby Kevin next time. I will always treasure those early days with Anna. Even though I loved it there, there is no place like home. As the plane was coming into land in Palmerston North at 7pm the pilot announced that it was 29 degrees outside. I was the only person getting off with warm clothes and a coat on.

I had a few more days off work after I got home so had time to get back into the time zone. Once again jet lag was not a problem. I had a few sleepy moments a day or so after I got back but was generally pretty good.

# Leaflets from Scleroderma Victoria

Recently Robyn Sims the President of Scleroderma Australia very kindly sent Scleroderma NZ a number of leaflets free of charge which was very generous and much appreciated.

If you would like any of the following leaflets or a booklet on Understanding and Managing Scleroderma please contact Dianne Purdie:

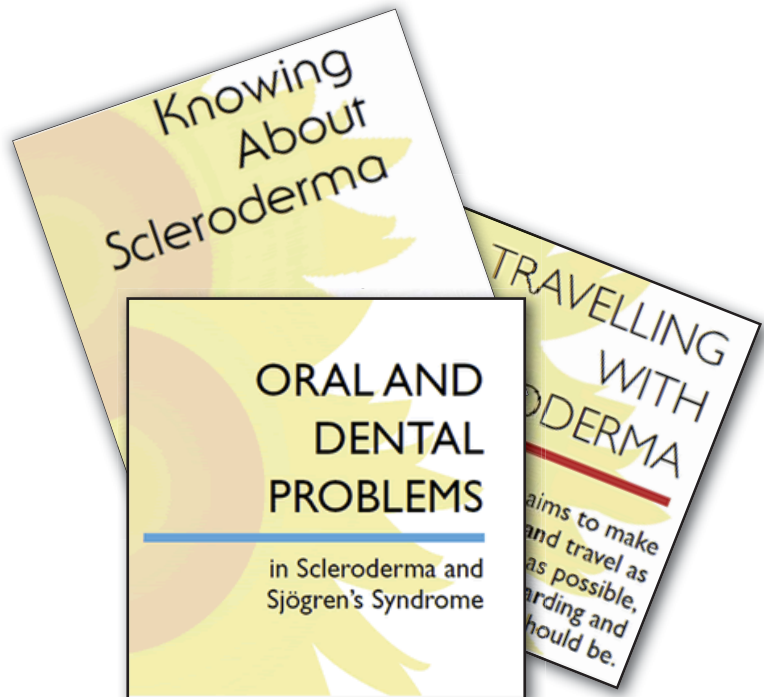
ph 04 479 5548 or

email [diannepurdie@xtra.co.nz](mailto:diannepurdie@xtra.co.nz)

and she will be very happy to send them out.

Leaflets available.

- Knowing About Scleroderma
- Travelling With Scleroderma
- Eating Well
- Dealing with Bladder and Bowel Problems in Scleroderma
- Oral and Dental Problems
- A Hospital Check list
- And the Booklet Understanding and Managing Scleroderma



## Advice from the US Scleroderma Foundation

There are a number of general common-sense measures that a person with scleroderma can take to enhance his/her well-being. These measures include:

- Avoid over-fatigue by taking it easy and getting sufficient rest. Knowing your own limits does not indicate you are lazy.
- Learn to control and minimize stress.
- Eat well-balanced meals and maintaining a sensible weight.
- Practice good hygiene habits, especially of the skin, teeth, gums and feet (including the wearing of cushioned and well-fitted shoes).
- Avoid smoking. The health risks of smoking are well known but frequently ignored. It is particularly dangerous to persons with scleroderma because it can have effects on blood circulation and lung function.

Read more from the well resourced Foundation's website:

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



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



# Queen Charlotte Walkway

## Yvonne finds you don't have to do the (too) hard yards

The Queen Charlotte Walkway is good for those unable to do the tough stuff anymore - it's fairly easy walking: no really steep hills, and it can be done over 5, mostly easy days.

We were dropped off by ferry at Ship's Cove, walked to Furneaux Lodge on Endeavour Inlet and the next day we went on to Punga Cove. Each day took about 4-5 hours walking. The third day, from Punga Cove to Portage is an 8-9 hour walk, which can't be shortened easily but there the water taxi if you don't feel like walking!.

The last 2 days, from Portage to Te Mahia and then on to Anakiwa were another 4-5 hours easy walking each day.

On the first and last days we moved through beautiful bush. The middle day brought stunning views from the top of the ridge. A water taxi carried our packs to our accommodation each day; this meant we only carried light days packs making it much easier.

There are some really nice places to stay along the way, making it a really nice trip altogether.



Colin and Yvonne beneath the waterfall at Ship's Cove



Trekking to Portage





# Palmerston has the travel bug again - this time, Vietnam

Everyone was asking "are you excited", in the weeks and days leading up to the BIG trip and my answer was a disappointing "not really", spoken with undertones of dread.

I am not a very brave person, never have been really. I have lived quite a *careful* life, with only trips to Aussie, so definitely not a "worldly" gal!

So you can imagine the culture shock, to be in a country of 90 or so million people, all on a mission to get somewhere on their motor scooters and trying to cross the roads, oh what a nightmare. The markets were a classic experience - talk about coercion, at its extreme. My very worldly daughter taught me the art of haggling and I, more often than not, passed my wallet to her as she had the currency sorted, having been in Vietnam for 2 weeks.

Highlights of the trip - NOT the 10-hour overnight train trip, sitting in a broken seat and arriving in Nha Trang with the worst motion sickness, no sleep and a room on the 10th floor. That building was fair moving about! But around the corner was the divine beach of Nha Trang where we spent 3 glorious days, soaking up the spring sunshine and enjoying the celebrations of New Year.

It was all beautiful (in hind sight, if not a little overwhelming at the time) and amazing to see how advanced the country is and the people so happy, despite having been in war, not so long ago. I must say, it was good to be able to say I was a Kiwi, when asked. Not so comfy being an American or Australian tourist in Vietnam, I wouldn't think.

We dined out on beautiful, cheap food, twice-daily and I learned quickly to steer clear of the hot stuff, after a couple of days of suffering and having to stay pretty close to the loo.

The temples were lovely but I would have loved to have visited some out in the countryside where there was some peace and not so many tourists.

Singapore was amazing, we had 3 days there. Our elderly airport taxi driver asked if we had visited Singapore before and when we answered no, he so eloquently suggested that next time we could choose a nicer area to stay, this being the red light area. The zoo was fab and very hot, trudging around on a 36 deg day however it was so worth it!

Now at the other end I find myself feeling much braver and confident, that despite my health issues, I CAN travel, just perhaps at a slightly more relaxed pace, like most things. And so now I find myself searching for trips to Europe, cruises around the Med on the net. This time I will be taking Jack!!

[www.facebook.com/maree.drogemuller](http://www.facebook.com/maree.drogemuller)

Maree Drogemuller



Maree and daughter under the bright lights of Asia



# A day at the hospital...

The local hospital, feeling it was time for a shakeup, hired a new CEO.

The new boss was determined to rid the hospital of all slackers.

On a tour of the facilities, the CEO noticed a guy leaning against a wall.

The room was full of staff and he wanted to let them know that he meant business

He asked the guy, "How much money do you make a week?"

A little surprised, the young man looked at him and said, "I make \$400 a week. Why?"

The CEO said, "Wait right here."

He walked back to his office, came back in two minutes, and handed the guy \$1,600 in cash and said, "Here's four weeks' pay."

"Now GET OUT and don't come back."

Feeling pretty good about himself the CEO looked around the room and asked, "Does anyone want to tell me what that goof-ball did here?"

From across the room a voice said, "Pizza delivery guy from Domino's."

## Noticeboard



Next meeting is  
2nd August  
2014

World  
Scleroderma  
day  
29th June

Send your news items  
to be included in the  
newsletter to:  
[Barbara@netco.co.nz](mailto:Barbara@netco.co.nz)

Coping with scleroderma?

Share your tips

[barbara@netco.co.nz](mailto:barbara@netco.co.nz)

