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Scleroderma

New Zealand support group

Autumn 2019

Greetings to you all.

In the ten years since John and I started this newsletter, the support group has come a long way.

We started with just a few of us and now we have grown to encompass many regions to support each other in this scleroderma misadventure.

Along the way, some members have drifted in and out of the group, while others have stuck it out, turning up to meetings even when they really wanted to stay home and draw the curtains.

Through those years, we must have collectively spend thousands of hours waiting in doctors' and specialists' rooms, rehearsing lines to try to get through the frustration and pain we were experiencing.

Some visits struck gold while many left us feeling frustrated and misunderstood. Through it all, scleroderma, once it took hold, like rust, never slept.

Some members have succumbed to the disease, most recently Rob of the Wellington group.

But even through the sadness, the shared experience and support that group members offer each other still means we must plug away and persevere. Scleroderma has no self awareness. It just is, and through our group we have found another way to cope that doesn't involve injections, pills or potions.

Barbara



President's Report

March 21019

Welcome to the New Year every one, the weather is going well here in Wellington just the right temperature for us.

We had a sad farewell to Rob Tomkies in December 2018. Rob passed away on the 15th.

Rob will be greatly missed by us all here in Wellington and on our National committee. Rob had a positive attitude till the very end, always cheerful and he was always coming up with different ways of looking at things. Rob and his wife Chris gave great support to Scleroderma New Zealand as a whole and especially to us here in Wellington and Palmerston North,

I believe there was only one meeting that they missed in the three years.

Rob is survived by his lovely wife Chris and three children.

We also say farewell to Barbara and John Spavin as editors of this newsletter. We all owe them both a great deal of gratitude for their commitment to Scleroderma New Zealand over the last 10 years.

It is time for them both to enjoy their retirement together, but we will continue to appreciate them as members and I hope the committee too. Once again Barbara and John thank you both so much for all the great work you have done for us over the past years, it has been greatly appreciated, and has helped so many of us in many ways.



With the Nelson group:- From Left Gordon, Dianne, Lisa, Beth, Rosemary and Terry

Gordon and I recently took a trip down south to see family



and we were lucky enough to meet up with Heather and Graham, Jenny and Jeff from the Invercargill group and Beth and Ron, Rosemary, Terry and Lisa, and Lexus from the Nelson area.

It was a great pleasure seeing you all, we all had a great talk, and both Gordon and I valued your time and effort for coming out to meet us. Having these get togethers is valuable and we learn quite a bit from each other. We both wish you all the very best for the coming year.

We are currently working at putting a National Scleroderma seminar together here in Wellington for the 18th of May.

The programme is outlined later in the Newsletter.

I am looking forward to seeing as many of you as possible for the event, we have a great venue and a great line-up of speakers, and a great opportunity to catch up with friends and share information.

Take Care and keep warm with the change of temperature coming our way with the onset of Autumn.

All the Best **Dianne and Gordon**

Scleroderma NZ National Seminar 2019

It has become a biennial event and this year promises to be as interesting and informative as all the others

Date

18TH May

Venue

The Learning Centre
Hutt Hospital
High St
Lower Hutt.

Cost

Cost **\$25-00** for the Day. Pay at the Door on the Day.

Lunch, morning and afternoon teas included.

Registrations to Dianne Purdie as of now. Email diannepurdie@xtra.co.nz

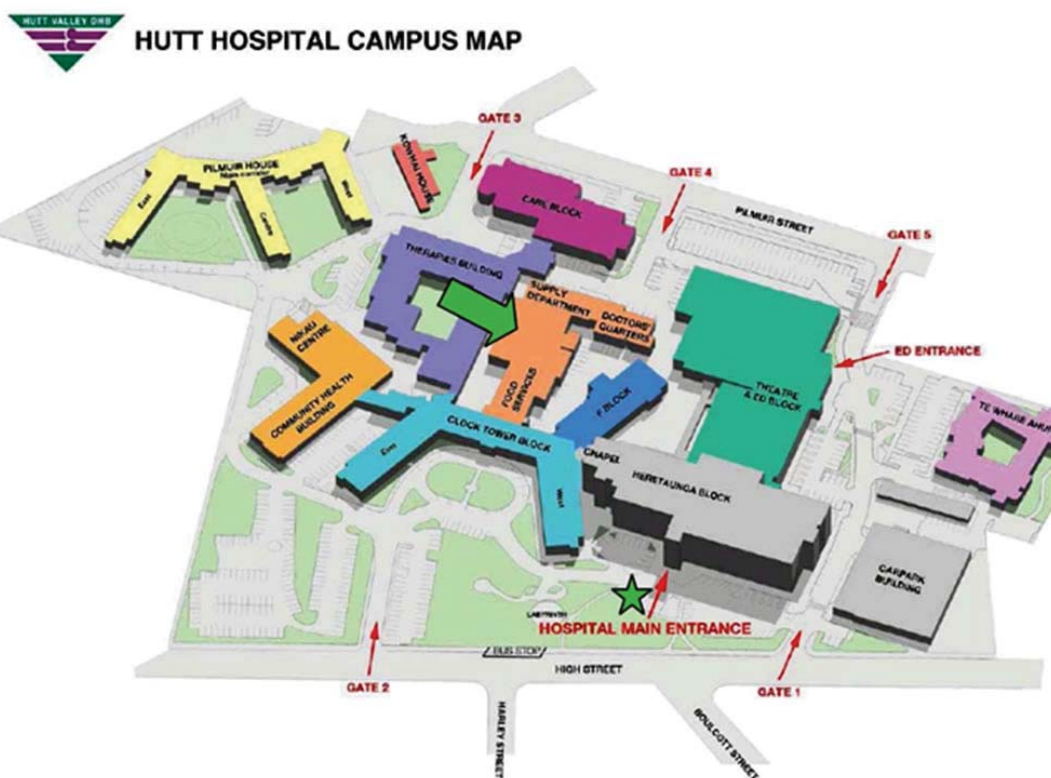
Programme

8:20am	Registration
8:50am	Welcome
9:00am- 10:00am	Possible Dentistry talk
10:00am- 10:20am	Morning Tea
10:25am-10:55am	Jarred Wake Podiatry and Scleroderma
	5min stretch
11:00am- 11:45pm	Dr Rebecca Grainger Rheumatologist
12:00 - 1:00pm	Lunch
1:05- 2:05pm	Amanda Johnson and Theresa Working Hands. (Hand care/ support and exercises).
	5 minute stretch
2:10-3:10 pm	Possible Respiratory Specialist.
	Afternoon Tea and chat- Finish around 4:00pm

The Learning Centre at the Hutt Hospital, High Street Lower Hutt.

From the main entrance:

- Walk past the volunteers' desk, ATM and florist
- Turn left at the hospital directory board
- Walk down the corridor past the chapel entrance to the clock tower building
- After ENT (ear nose and throat) go up the stairs on your left
- At the top of the stairs, turn left
- Down the corridor, the library and learning entrance is on your right.

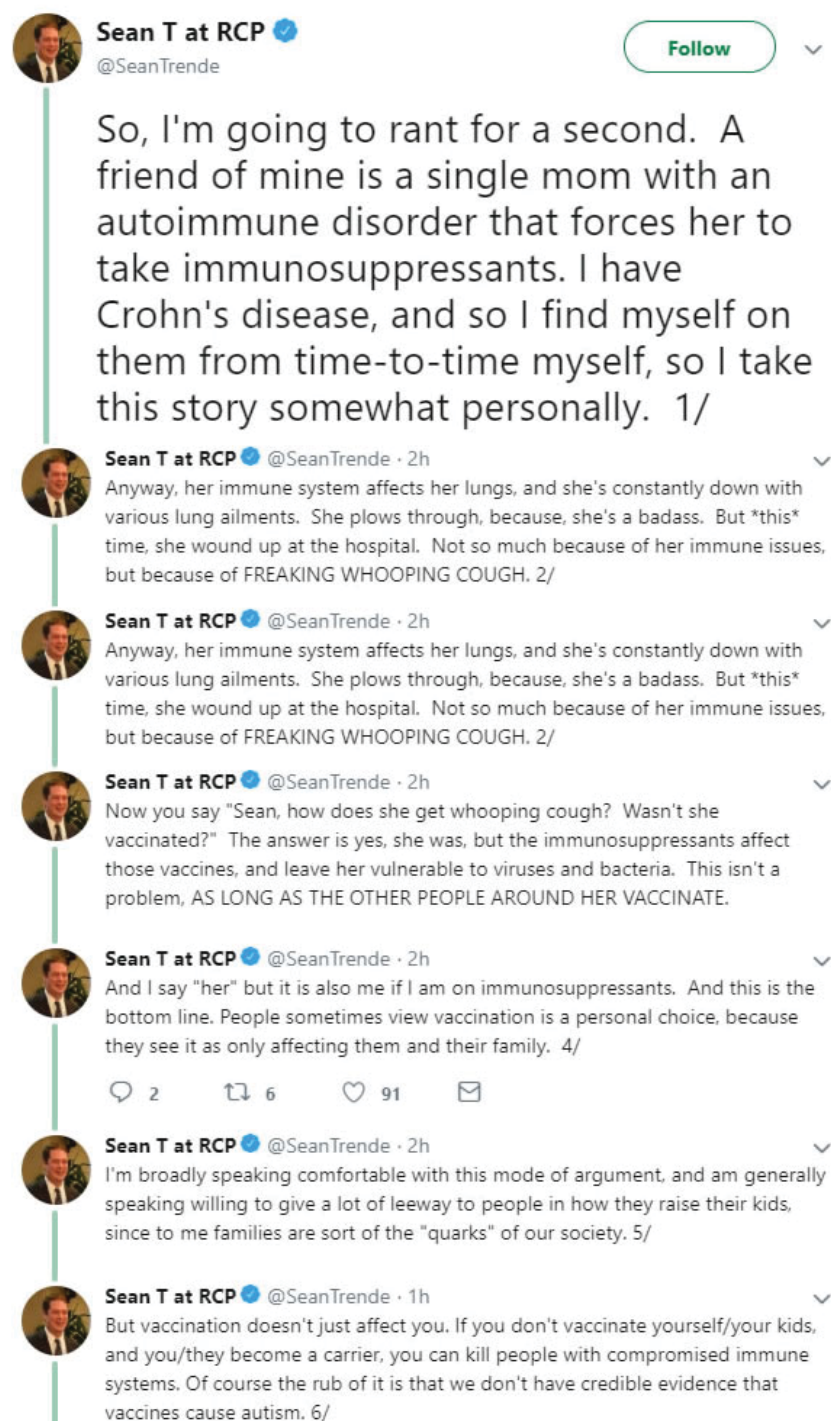


Best access to the parking building is from gate 1 on High Street.

Vaccination and the Internet's biggest time-waster

Twitter is an Internet message system in which people trade ideas and insults. Mostly insults.

But every now and then someone puts up a series of "tweets", as Twitter contributions are called, that make sense amongst all the other angry and credulous rubbish that normally clutters it. Here is one, spotted recently, relevant to anyone living with an auto-immune disease, particularly since the measles outbreak in Christchurch.



Southland Group finds thing to be glad about

Thanks again Jenny for organising us to meet in Gore in January.

It was delightful to catch up with everyone.

Jenny had us thinking as she asked us to say one thing we are 'glad' about. Among the responses were Jenny's delight that their 16 year-old son had gained his restricted driver's licence and was out looking for after-school work.

Another member had just received word that he had a job promotion, another was they had attended a 90th birthday for their uncle and had a great family catch up.

The most practical was Beverly whose husband had made her a sewing table she can use in the warm lounge in the winter for her beloved sewing.

Good man Gerry!

A member had also heard a whisper that one of the visiting rheumatologists was hoping to start a study on why there are so many with scleroderma in the south, we hope this comes to fruition.

Thanks so much to Dianne and Gordon for their resolve to improve and educate us in all things scleroderma (hopefully there will a sprinkling of Southlanders at the seminar in May). Thanks Barbara and John for producing an excellent newsletter, it's great to see what is happening in the rest of New Zealand.

Again, thank you Jenny and looking forward to meeting up again in April.



Kim Tocker tackles boredom (and wins)

Kim's column from sclerodermanews.com

The chronically unwell face daily challenges, some big, and some small. But my latest battle was brought to my attention by binge-watching a TV series.

I am a huge [Grace and Frankie](#) fan and have suddenly found my life much more interesting since the new series came out. However, aside from all of the episodes being totally fabulous, the show has brought something to my attention.

I realized after watching the current season to its end that I'm back to my "old life". Without distractions. I realise that prior to the series being released, I had been horribly bored.

Because my body cannot cope with actively doing very much, exhaustion traps me in my recliner. Scleroderma has created a great big boredom bubble that confines me.

Reading, doing online jigsaw puzzles, and watching reruns all become tedious after months of the same thing every day. The worst part of this situation is that I end up overthinking everything because I have little else to occupy my thoughts. Small problems become unnecessarily bigger and seemingly unmanageable.

Boredom coupled with too much time to overanalyze things can lead to [depression or anxiety](#), and in turn, to a lack of motivation and chronic sadness.

I was discussing this with one of my dearest friends, who shared how he deals with his boredom. His grandchildren. He is one of the wisest people I know, so my ears pricked up when he explained his theory about boredom and bringing up kids.

He explained that he believes that if children are continually offered something to entertain them (TV, computers, etc.) then they may not learn to become creative by inventing entertaining things to do. He pointed out that creativity is learned and borne out of boredom, as long as the children are allowed to experience it and not offered easy fixes all of the time.

So, I took this little gem of insight, and on further examination, I think he is right.

I have actually been finding ways to live with this disease that have required my creativity and ingenuity for quite some time. For example, I use a height-adjustable computer chair on wheels when I'm too exhausted to bend down and complete



low-to-the-ground tasks, such as using a brush and shovel to clean up a spill.

Some of you may know I love to paint rocks, but setting up my paints and actually sitting on a chair at the table to do it had become too exhausting. I made a trolley on wheels with my supplies ready to go so that I can easily access it from my recliner.

Looking back, when things became too hard, I managed to use my creativity to come up with ways to improve the situation. Fabulously, this means that my creative juices must still be flowing.

I have decided that boredom isn't going to beat me, either. If I can come up with ways to get my bra on in the morning with [sore, stiff, and swollen fingers](#), then surely I can find creative approaches to get on top of the monotony that [living with scleroderma](#) brings.

I have made a "boredom buster" list of things I want to do during the day.

Currently, none of them are possible as I don't have the energy or physical ability. But I decided to figure out creative ways to get around them. Already in my mind, I am devising ways that I can start crocheting again.

Isn't this the way the world changes? Someone decides to solve a problem or issue, switches on their creative flow, and eventually, an item, event, or process is produced that makes our lives better and provides change and growth for the world.

Perhaps that same process is occurring within me in my single life, and while my creativity may not inspire and change all lives at a global level, it certainly does change and improve my world. I'm so glad I've found it again.

Turning 50 in Rarotonga

Cushla took time out from from looking after the support group's Facebook page to celebrate her 50th in Raratonga. That's Cushla with the big smile, 3rd from right.



Kia Orana. On the 27th February I turned 50 (gasp), so to celebrate this "milestone" sixty of my friends and family headed to paradise, Rarotonga for fun, frivolity and fifty celebrations.

Most of us stayed at The Edgewater Resort, we loved it, there was a pool, there was the beach, fabulous food, the staff were full of smiles and couldn't do enough for us. We couldn't be happier. Wait, yes we could, everyday at 5.00 as it was Happy Hour!

I am part Cook Island, my Father is Cook Island and the Marsters family is large and huge. It has a very interesting history to it (Google it). It is always lovely to go back and live as a local and a tourist, when they find out that my last name is Marsters they always say "Welcome Home", which it feels like it is and always with a big beautiful smile.

My dad's cousin and her husband hosted my party for me, with a lot of effort and love from my parents. Where Auntie Anne and Uncle Brent live, is in Nikao and right on the runway, they have a fabulous home and opened it up to all of us from

NZ. We had a pig on the spit and so much other yummy food with, of course, the local favourites: chop suey, mainise (potato salad), ika mata (raw, marinated fish). My birthday cake was something to behold and taste.

The party was such fun, there was so much laughter, drinkies, new friendships made and reformed between everyone. I danced (hulaed) with my female cousins. Another surprise came after dinner, a fire dancing troupe. They made the evening, especially when my youngest nephew, Tom stepped forward like the man he is when they invited volunteers.

Two more cousins arrived late on the Friday night. We are right on the runway so when their plane landed there was much whooping and yelling, honestly you wouldn't think that the majority of us live near Wellington airport and planes landing don't normally push our buttons. In our defence though, we don't see them that close and there may have been a few more drinks had by then. I had the best night, with the best friends and family.

After the party I still had a week in paradise and some of my guests were going to start leaving on the Tuesday onwards. Which meant there was lots of relaxation, eating divine food at different places all round the island. There's nothing like lounging, watching the gorgeous coloured sea crash over the

Cushla *contd.*

reef. It was very, very hot. The best time to go to Raro is in our winter, as it is the rainy, cyclone season in summer and it can be stinking hot. We went to the markets on Saturday but the heat was so oppressive that I could barely string two words together. When I was back at the resort the words began to form again.....can I please have a Pina Colada?

Everybody took full advantage of everything that was offered, some went fishing and managed to catch a Marlin. The Captain Tama's tour is always a highlight and my peeps had a blast and the bonus was that my middle nephew Sam was pulled out of the crowd for some fun and harmless ribbing.

Some of the fitter and more energetic ones got up early and did some walks, go you!! As we know preserving energy is a bit of a mainstay of us Sclerodermaites, especially in the heat. I had been luckily enough to do Captain Tama's before so I felt like I hadn't missed out on anything and sometimes a bit of a rest bounced me back and I am also so fortunate that my friends and family are understanding of my condition and so very supportive.

I had the grand thought to get a tattoo in Rarotonga for my 50th. I was very excited and had picked out my design, yep it was all go. Mum said you have to check with your medical people, sure I said thinking that I will get the all clear. I rang Liz, the rheumatologist nurse, and left a message. I told her my plan, asking to tell me if there were any problems with it. Under an hour later Liz called. I had never heard NO said so often in about ten minutes and some other words but at least she finished with have a good time.



I was very disappointed, then when I thought about it, I was silly to think this could happen when I have to take four antibiotics just to go to the hygienist.

One day we were having lunch at the stunning Little Polynesia, when my friend Aidsey said she would get my tattoo for me, I would choose the design and she would wear them for me. I couldn't believe it. The next day we went to the tattoo shop and I now have the most beautiful tattoo of Cook Island



turtles, you have ever seen. People have always said that getting a tattoo can be painful, not for me didn't even flinch once! My friends are my family and they are the best.

I am now home after the most wonderful time. Life can be up and down, some days and nights harder than others, but for me no matter what, I have the love, support and friendship of my posse and they know who they are and hopefully know how much I appreciate them.

I got diagnosed with scleroderma nine years ago this month, it has been the help and support of the Scleroderma Support Group that has made a confusing, hard time a bit easier and I thank you all for the friendship and support.

**Kia Manuia
Cushla**

Noticeboard

Wellington meets:

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 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:

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/

www.scleroderma.org.nz

