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Scleroderma

New Zealand support group

Summer 2014

Greetings everyone. Happy New Year to you all.

This is the first issue for the year and we are off to a good start.

The fine weather will be great for your joints and your Raynauds: long may it last.

We have a lot to cover in this issue. The talk from Zoe on pain and fatigue went very well and we have the main points from her talk in an article.

We all got something special out of it to help us cope with these problems. They affect us all in our daily life so learning strategies to cope is invaluable.

Adrienne talked at this month's support group meeting about her trip to Atlanta, Georgia for the Scleroderma Foundation Patient Education Conference last year. It's an annual event and attracted more than 500 people this time as well as a bevy of medical and associated experts in the fields of diagnosis, treatment and research and producers of physical aids.

And we have a bit from those Palmy ladies and their antics as two branches of the group met for a cuppa and a chat..

The statistics for our web page make very interesting reading. We have a selection of statistics for 2013 from the web site visits logs.

Who would think that so many people from the Czech Republic would be interested in our Website? It can only mean that there is an ongoing need for information about Scleroderma, it's sufferers and how to cope with different symptoms and situations.

Sharing our experiences is an important part of realising that each of us is not alone in facing down scleroderma and learning to live with it.

News items

Because support group members are spread throughout New Zealand (just like scleroderma, as it happens), a newsletter seems useful to keep us all in touch.

It can be a little daunting trying to find material that is topical and current to keep a newsletter full, relevant and interesting.

To that end, we want your group news items about shared events, triumphs and adventures. Why not also share your hobbies, travel adventures, garden tips etc.

Most of all, tell us about your experiences with scleroderma, interesting Internet finds and news of relevant events and products that make life easier.



Managing Pain and Fatigue

An overview of January's seminar presented by Zoe McGavock, an arthritis educator with Arthritis New Zealand.

Pain is:

- A sensation
- Any unpleasant sensory or emotional experience
- A sign of actual or potential damage
- A subjective experience – both for the person and the observer
- Very real

Factors that influence pain:

- Psychological
 - stress, attitude, understanding etc
- Physical
 - age, health, fatigue etc
- Social
 - supports, role models etc
- Cultural
 - treatment, religious beliefs etc
- Situation
 - control, duration, environment etc

Relieving Pain

Use heat:

- Keep joints warm (gloves & socks)
- Direct heat: wheat-bag / hot water bottle / heat pads – caution with Raynaud's
- Hot shower / bath / sauna

Creams / Gels & Massage

- Capsaicin
- Anti-flamme
- Rheumon Gel
- Voltaren

Combating Fatigue

Pacing

- Activity – rest – activity – rest

- Build activity levels up slowly
- Be aware of the BOOM-BUST!

Prioritising

- What tasks are my priority today?
- What is the worst thing that can happen?

Planning

- Spread the 'heavy' tasks throughout the day
- Plan rest periods
- Be flexible: allow for changes due to pain

Posture

- Good posture conserves energy
- Adapt activities: e.g., sitting to garden
- Keep things within reach

References (and more details than space allows here)

Arthritis New Zealand www.arthritis.org.nz

Arthritis Research UK www.arthritisresearchuk.org

NIAMS..... www.niams.nih.gov

Every Body NZ..... www.everybody.co.nz

How to cope with pain www.howtocopewithpain.org

Pain explained..... faculty.washington.edu/chudler/pain.

[Download](#) a copy of Zoe's PowerPoint from the website



Best wishes from 'Palmy'

We Palmy girls got together for a pre-Christmas BBQ at Linda's house.

We are: Chris Carlyon, Catherine Thompson, front Maree Drogemuller and Linda Waters. We had a great night and hope all the members had a wonderful Christmas and New Year.



Had an event or spotted something relevant to the group in your region? We are keen to feature you in the newsletter.

And speaking of Palmerston North, Catherine has completed more paintings of the type that we featured in a previous issue.

We have loaded them to the gallery page of the scleroderma website (where there is virtually unlimited space to display content)

You can go directly to the site to view them at this link:

www.scleroderma.org.nz/about/gallery/

Meantime, here are two examples of Catherine's paintings to give a preview of their style and colour.

All feature native New Zealand wildlife or rural scenes.



...and just when you thought you'd heard the last of Palmy for a while:

It was billed as a get together, a chance to bond two branches of the Scleroderma Support Group.

Some Wellington members would travel to Palmerston North to have lunch with the local support group's members.

After all, the Palmy people frequently make the 2-hour trip south to Lower Hutt to attend the quarterly meeting. What could go wrong?

In fact, in Palmerston North, nothing went wrong; quite the opposite. They all enjoyed the lunch, the company and the swapping of experiences and trials and triumphs.

There was just a small sense of foreboding in the mind of Barbara's husband when he saw on his driveway, after Dianne had departed with Barbara for the drive to Palmerston North, quite a few drops of liquid,. They may have been brake fluid, maybe oil, maybe water, dripping from beneath the white Subaru onto the asphalt.

However, they made it to Palmerston North and, lunch over, Dianne motored south for home with her southern co-members on board. All went well until a tiny dot on the map, called Shannon and the cause of the drip, drip drip.

The car died, just stopped and refused to go. It didn't help that on a scale of zero to ten, the temperature gauge showed 15.

There was nothing for it but to retire to the pub to think things over, call for a ride and sweet talk the local garage owner to rattle his dags and fix it. The first two parts of the plan worked out well.

A bunch of local yokels gazed in amazement as the ladies waltzed into the public bar and bought large, frothy handles of - ginger beer? The hairy farming lads hadn't seen this before.

Barbara's husband meantime motored up the highway for an hour and a half and escorted them from the bar and drove them back home. Dianne's car was the only fizzer. That would have to wait for some intensive work on the cooling system and be picked up the next week.

All in all though, it was a pretty good way to spend a day with friends.



South meets north. Wellington and Lower Hutt members mingle with the Palmy crew for some pleasant food and conversation.



Blast, looks like we're stuck in this Shannon pub for the afternoon. Cheers!



US Scleroderma Foundation National Conference 2013

Adrienne Burleigh travelled to Atlanta, Georgia last year for the US Scleroderma Foundations 2013 patient education conference.

At February's meeting Adrienne described a large conference at which more than 500 attendees (about half of whom were scleroderma patients) each paid \$US300 to learn about coping with and treating scleroderma. Adrienne was the only southern hemisphere attendee but there were others from the UK and Canada attending the weekend-long event.

The annual event presents lectures, with 7 or 8 running simultaneously, so Adrienne says it's wise to read the programme and check your preferences before you arrive. There were also workshops and question-and-answer sessions with medical experts who specialised in treating scleroderma and related conditions.

In all, 57 forum facilitators and speakers presented information on all aspects of scleroderma.

One particular session that Adrienne liked was Scleroderma 101 in which Maureen Mayes, author of *The Scleroderma Book*, covered the disease and its implications for those newly diagnosed.

Another highlight amongst the lectures for Adrienne was one delivered by a New York surgeon whose speciality was hand surgery. He was able to surgically straighten bent fingers. He had started on this technique when confronted with a patient whose referring doctor had recommended finger amputation. Thinking there had to be a better alternative, he developed a technique to save and straighten distorted fingers.

Adrienne says a woman from the audience suffering bent fingers approached the surgeon after the lecture. She was a music teacher and was having to relearn how to play and teach with bent fingers.

The surgeon examined her bent fingers and casually remarked that he could fix them.

"Well, the look on her face was incredible." Adrienne says. The surgeon instructed the music teacher to come and see him later and Adrienne says it was almost as if a miracle was happening for the woman.

Carrying on a theme raised at our own seminar last year



One of the convention halls at the Atlanta Hyatt Regency hums into life for another session.

by Andrew Harrison, the American event highlighted in a workshop the fact that GPs know little about scleroderma, either diagnosing or treating it.

Adrienne says a workshop canvassed experiences from people with scleroderma about what questions their doctors asked them.

The facilitator recorded the sorts of questions that attendees' doctors had asked them when they were trying to diagnose them. The point was that if doctors don't know the right questions to ask they won't get the right answer. For example, they may diagnose reflux problems incorrectly as stomach ulcers without looking any further.

The workshop's aim was to gather a range of questions that doctors could ask if a patient presented with scleroderma-related symptoms. Adrienne says the gist of the workshop was that so little has been done to raise awareness of scleroderma in universities and teaching hospitals that graduate doctors don't know the questions to ask to diagnose scleroderma.











This year's conference is in Los Angeles in July, a stone's throw from Disneyland. Adrienne is interested in hearing from anyone who thinks that the conference might be of benefit to them to get in touch with her (you can make contact through Dianne or Barbara). She thinks the flights and hotel for a small group may well be affordable and that the event would certainly be of benefit.

Website interest

The amazing thing about websites is that people peek in from around the world to see what's going on.

Some arrive by accident, some after a long search and still others because of a keyword search in Google.

Here are the countries (in descending order) from which people have looked in on scleroderma.org.nz during all of 2013.

Countries	Pages viewed
 Czech Republic	30,433
 Germany	12,078
 New Zealand	10,918
 Russian Federation	5,459
 United States	4,898
 Spain	4,869
 Ukraine	4,834
 Canada	3,298
 France	2,428
 Japan	2,237

What visitors were searching for that led them to the site:



Search term	No.	%
scleroderma	326	28.9 %
scleroderma nz	95	8.4 %
scleroderma blood test	17	1.5 %
blood test for scleroderma	14	1.2 %
blood tests for scleroderma	13	1.1 %
scleroderma new zealand	10	0.8 %
scleroderma blood tests	9	0.8 %
scleroderma.org.nz	9	0.8 %
scleroderma blood test results	8	0.7 %
www.scleroderma.org	7	0.6 %

Noticeboard



Tell us your plans for this year: Auckland group; Hamilton group and Southland group.

We want suggestions for what to do on

World Scleroderma day 29th June

A New Zealand autoimmune support site has been upgraded and can be found here:

www.autoimmune.org.nz

Next Meeting

3rd May 2014

