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Scleroderma

support group

newsletter

Spring Issue 2012

Greetings everyone and welcome to another newsletter.

With winter in full force I hope that you are all keeping warm and not having too many problems with this cold. At our last meeting Dianne showed us an array of clothing that was inexpensive and warm enough to cover all winter conditions (excluding a trip to the polar regions).

Adrienne gave us a talk describing her trip to England and Europe,

taking her scleroderma with her, which was most interesting.

We have small sunflower badges available from Scleroderma Australia available. Cost is \$5 plus postage from Dianne.

The new website is up and running. However with the upgrade it will cost \$30 month to run. This is quite a lot of money but it's more intricate than the old site. We have been fortunate enough to gain sponsorship for the hosting from Modica Group.



Going Travelling

At the August meeting of the support group, member, Adrienne Burleigh described how she faced down being a scleroderma sufferer and became instead a defiant traveller, determined to see get to the other side of the world, have a holiday and return home. Read about her experience and you'll see that she triumphed.

Often we, as people with scleroderma and related conditions, limit ourselves in what we can do. Sometimes our own beliefs place limitations upon us and at other times, it's our friends and family who do if what we intend to do is a little challenging. Even health professionals will express doubt about what we might be thinking of doing. This is all legitimate given the nasty nature of scleroderma but at times it is really good to challenge ourselves, friends and family and our medical care-givers – after all it is our own life and we get only the one chance to live it. So what can we do?

Earlier this year I set off on a 10 week trip to England and Western Europe. I travelled by myself for 50% of the time and for the rest was with a friend as we went to our own friends either together or separately. I had a full 23kg suitcase and a backpack that often contained a further 7kg so at all times was fairly loaded. In my family we have always had a saying – those who go travelling, carry their own suitcases and this I had to do. I did it, but there were a number of precautions I took – not the least being carrying a walking stick, which attracted support when I needed to lift my gear on and off trains and stagger up staircases where there was not a lift available. Often, very helpful people, many much younger and fitter than me, made my day with the smiling assistance they gave me.

I have often heard people who have scleroderma say they could not travel because they would not be able to get insurance. However, I found that I could by booking and paying for my tickets through my National Bank Gold Card. To ensure I was covered for systemic sclerosis, I needed to declare this and to pay \$100.00 as cover. This was so much less that going through the standard insurance companies and was also a very painless process. I took part in a short telephone interview covering who I was, what I had, if I had had any unplanned hospitalisation because of the condition over the past two years, etc. I was then told I would be covered and was given a claims number to use if I needed it. I had cover for 90 days but the bank will reduce that to 40 days from September 1 this year as part of a tightening up of insurance. However, it is still an excellent cover, valid anywhere in the world and includes general travel cover, such as lost luggage etc, as well as health.

On the trip I ensured that I took all the medications I needed with me for the duration of the trip and for two extra weeks, in case of delays in returning home. I also carried a full list from my pharmacist of the medications and dosage I am currently on.

I also carried a letter from my GP outlining my medical conditions and giving contact details so that if I had need of medical help, my medicals details and the treatment I have been receiving would be immediately available. Beside phone numbers, I was given email addresses in the event I needed assistance out of NZ office hours.

I ensured that I had all the tests I needed before I left (both hospital and GP surgery based) and that these gave no

cause for concern. With my GP I discussed possible health issues I might face while away such as lung problems brought on by infections I could catch while on the plane and how I should deal with these before I needed to get further professional attention. I carried antibiotics for such an emergency. This proved very helpful in my case as after several drenchings in the almost constant rain I experienced throughout the trip, I was able to deal with the wracking cough I managed to develop.

I was meticulous about taking all the medication I had been prescribed at the correct times and in the correct dose and I kept warm and where possible dry. I had hoped for good weather, it did not happen and although I needed to buy some warmer cloths and some thermals, I was glad I did as this helped keep me healthy.



Adrienne displays mementos from her trip, that included getting close to the Queen on her Jubilee outing.

I got plenty of sleep. You can manage great things if you have had plenty of shut-eye although there were some days when I did not feel like pushing myself regardless of what had been planned so I said NO and meant both the N and the O. This ensured I was able to recover energy quickly and go on with the programme in good health.

It was a great trip, encompassing England, France, The Netherlands, Belgium and Hong Kong. and I proved to myself, my family and friends and my medical support people that it was all possible.

Go ahead and challenge yourself. You will be surprised what you can achieve if you have done all your homework beforehand. You will be able to walk on water (because you will know where the stepping stones are!!)

Adrienne Burleigh
Paraparaumu

Scleroderma Patients: Call For Better Monitoring, Treatment

Thursday, 28 June 2012

Press Release: New Zealand Scleroderma Group

Call For Better A Monitoring And Treatment Programme For Scleroderma Patients

The New Zealand Scleroderma Group is calling for the introduction of a monitoring and treatment programme for New Zealanders with scleroderma to mark World Scleroderma Day on June 29.

Scleroderma is an autoimmune connective tissue disease that can affect many organs of the body. It is associated with excessive inflammation, fibrosis and vascular disease and causes hardening and restriction of the skin and internal organs such as the lungs and kidneys, sometimes progressing rapidly to death. It affects people of all ages.

It is likely that about 1,000 people in New Zealand have scleroderma with most of these patients being cared for by rheumatologists.

In 1994 the National Advisory Committee on Core Health and Disability Services considered that there should be one rheumatologist per 100,000 people. A 2004 study found that rather than improving, the provision of rheumatologists was worse with one rheumatologist per 251,211 people.

The study suggested inadequate funding and now the New Zealand Scleroderma Group calls on the Government to adequately fund rheumatological and other related services.

In 2007 a study of scleroderma patients at Middlemore Hospital in Auckland was published showing they were poorly monitored.

Although there is no cure for scleroderma, early detection and treatment of failing organs in scleroderma can improve quality and extend people's lives.

There are monitoring programmes in centres around the world. In Australia 12 centres are involved in the Australian Scleroderma Screening Program. Three centres in New Zealand are members of a Europe based programme.

World Scleroderma Day marks the death of leading Swiss expressionist artist Paul Klee who died on this day in 1940 of scleroderma. He was diagnosed in 1935. Paul's production slowed noticeably as scleroderma took hold. His artwork began to transform from light and joyful to murky and echoing. en.wikipedia.org/wiki/Paul_Klee

The New Zealand Scleroderma Group is joining with other scleroderma groups around the world to raise awareness and improve health care for this potentially serious condition.

New Zealand Scleroderma

Dianne and Gordon organised a press release to mark World Scleroderma Day in June. As is often the case, it was difficult to gain the attention of mainstream media but it is up on Scoop.co.nz and with the website, Google is gradually beginning a store of scleroderma-related links in New Zealand



Mind your beeswax

Everyone at August's meeting sampled a trial batch of healing-moisturising cream from a Fox Glacier farmer who is experimenting with natural products to develop a cream that helps ulcerated skin soften



Barbara takes her turn to sample the beeswax balm.

and heal.

Val brought the sample jar and it was passed around and enthusiastically applied. It contains a beeswax base to which is added jojoba oil, New Zealand palm oil and aloe vera.

It is not yet a commercial product but may be one day if it proves effective. It has an odd smell but the maker has assured Val that the addition of lavender oil should overcome this in the final product.

Web site sponsorship and system upgrade

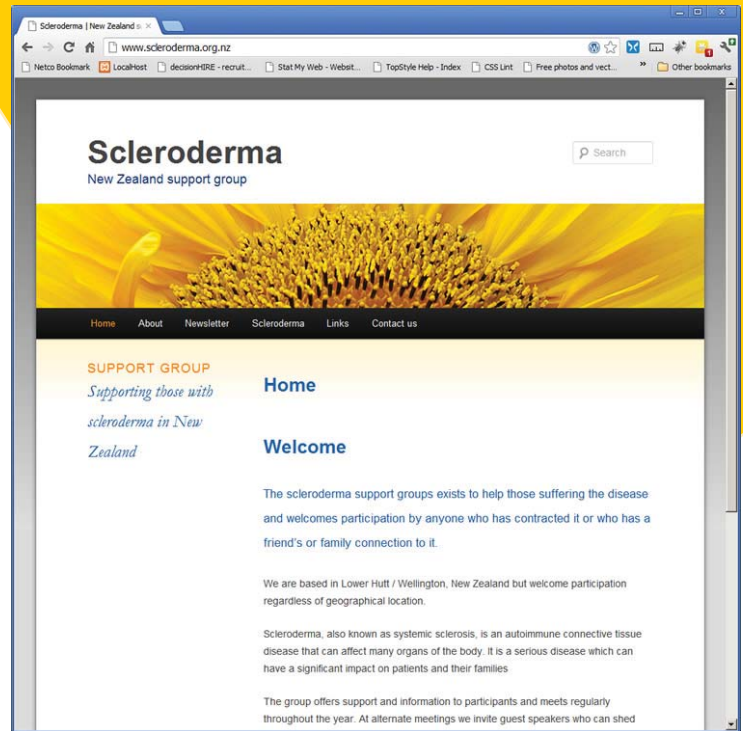
The website has had an upgrade and now sits on a content management system for easier maintenance.

It's the first change to the site, which went live about two-and-a-half years ago. Because it is stored in a database it means that at some time in the future we can set up a members' section to store documents and add some automation to storing member details. None of that is in place or planned yet but it might be useful some day and now it's possible.



Barbara and John have paid for hosting and maintenance of the site until now. However, Modica Group, a Wellington-based website hosting and infrastructure company have agreed to sponsor the increased cost of having a content management system hosted. Modica Group will cover all hosting costs while John continues to update and maintain the site.

www.scleroderma.org.nz



We are on Facebook!

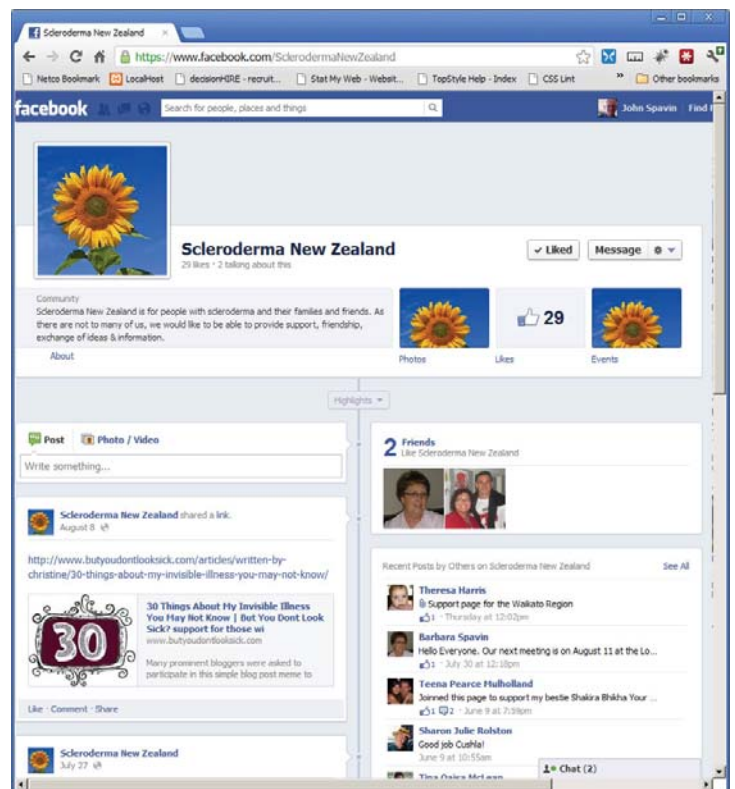
Yes, there's something to do on Facebook now instead of playing Bejewelled, Farmville or looking at cat pictures from school friends you haven't met in 20 years.

Cushla set the page up and at the time of writing it had more than 30 "likes". Gaining more "likes" unlocks new functions on the site so do take the time to "like" our group and convince your friends and families to do it too.

Once you are connected you will begin to see Cushla's contributions and you can comment and link back.

It's not the biggest community on Facebook but it's an easy way to get the scleroderma name mentioned and perhaps get a few more people to understand the implications of the disease. When you "like" it on your page the link becomes visible to anyone who is connected to you on Facebook.

Facebook's share price may have tanked and denied multi-millionaire status to a lot of US geeks, but it's still one of the handiest ways around to get news out to the world, as it approaches one thousand million members.



www.facebook.com/SclerodermaNewZealand

Survey planned on scleroderma

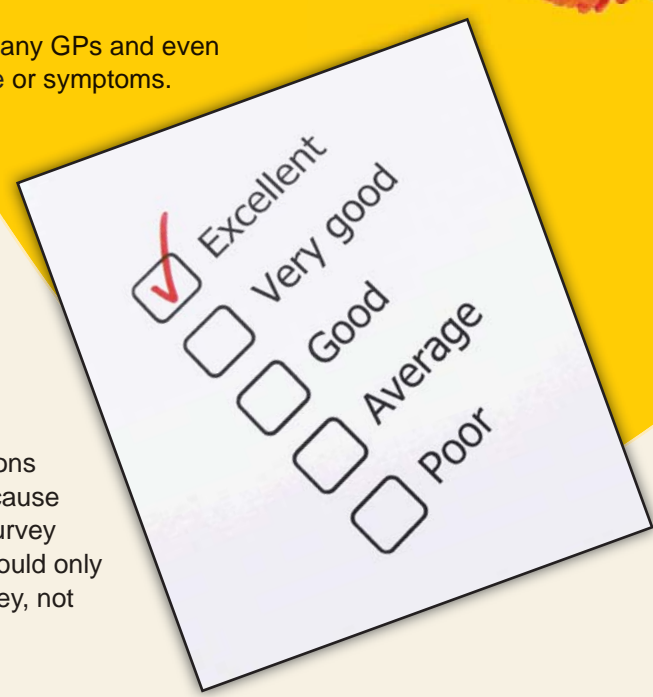


Anyone with even a slight familiarity with scleroderma will know that many GPs and even various medical specialists have little idea about the disease, its cause or symptoms.

There may be 1,000 New Zealanders suffering from the disease. Australia has a database that tracks 1,250 people with scleroderma, which tracks treatment, problems and needs common to sufferers. There is no such coordinated effort here in New Zealand.

Scleroderma Support Group member, Adrienne Burleigh wants to conduct a survey of sufferers to establish what is needed to advance options for treatment here. Adrienne says the survey would also help inform policy makers and health funders.

Adrienne, with the help of Dianne and Gordon has finalised the questions and wants to survey members. Your responses will be anonymous. Because so many people are on the Internet these days we will also offer the survey online. Note that when it arrives, should you wish to participate, you would only need to fill out either the paper-based questionnaire OR the online survey, not both.



Support group for Hamilton

A scleroderma support group may start in Hamilton, with a seminar: 'Living with scleroderma', according to Linda Bell, one of our members.

Linda says she developed scleroderma in the eighties and the only information she had available was a medical book with four sentences.

She says she developed Raynaud's then heart failure followed by surgery and then the scleroderma diagnosis.

"By then my hands already had formed the claw-like position, she says."

From four sentences of information she now has the internet.

"Information is at your

fingertips but too much information can also be confusing as no two people with scleroderma have the same symptoms," Linda says

Each year, Linda says, she approached either her GP, rheumatologist or the local Arthritis Foundation asking for more help and a support group in the Waikato area.

This year with the help from Catherine Swift of Hamilton Arthritis the seminar is planned:

Living with Scleroderma

Linda hopes that in June every other year that supporters could hold a formal meeting to coincide with World Scleroderma

Month.

In the meantime, she wants other sufferers who live in or near Hamilton to meet regularly.

"It is important to make the effort to attend as scleroderma and auto immune diseases can be very lonely condition and sharing with others helps," Linda says.

Linda says for those newly diagnosed, the staff at the rheumatology clinic at Waikato Hospital will help but sufferers must also help themselves to become independent and not let scleroderma run their lives.

Linda has started a Facebook page:

Scleroderma Waikato and she welcomes participants.

linda.bell@hotmail.co.nz

SEMINAR:

LIVING WITH SCLERODERMA

Date: 17th October

Time: 10am - 2 pm

Venue: C C S Disability Action Hamilton
17 Claudelands Road Hamilton.

Presenters: Dr Kamal Solanki and other guests.

All welcome.

CONTACTS

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Links: www.arthritis.org.nz | www.scleroderma.org.nz | www.sjogrensnewzealand.co.nz