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# Scleroderma

## New Zealand support group

## Spring has sprung!

Greetings everyone. Summer is almost upon us, and aren't we very happy to see the end of that very cold winter. I hope you all survived the cold and the rain. Your joints will be happier with summer sun on its way. It's good to see spring blossom and the noisy tuis diving on any blackbird that happened to land on his kowhai tree. We have been out in the garden planting lettuce, tomatoes, beans etc so wishing now for warm sunny days ahead.

In this newsletter we hear from Amanda Johnson, a hand therapist who talked to us about how to get the best use from our hands. She explained when to exercise, when was enough, using aids to get the most from our strength, and to use other muscles to manipulate rather than all the pressure coming straight from our hands. Read her story further on.

You can read about Catherine's success here and in Australia from her paintings. Just click the link on her story in this issue.

Fundraising for Scleroderma: A calendar is out now for you to purchase. Maureen from Southland has organised this and part of the sale proceeds go to Scleroderma NZ Inc. So let's get behind this and help make it a success. The calendars cost \$12.50 each and make great Christmas gifts.

We are close to our next meeting and you can read about the guest speaker. Maree is a natural health practitioner with a wealth of knowledge of plants and their medicinal qualities. Maree is likely to have a remedy for your skin and health woes. Join us for that meeting on November 7th.

You can read a report from the Hamilton seminar held last July and also a message from the President of Scleroderma Inc Dianne Purdie.





# Respect pain - it's your body talking

Wrist and hand therapy specialist, Amanda Johnson, talked at the winter meeting about wrist and arm pain - she said pain is your body telling you to ease off.

Amanda says movement that exacerbates an ailment causes swelling and that worsens symptoms. It can lead to more degenerative damages in the joints.

Easing back when an activity or exercise causes pain makes more sense than pushing on. She says the "use it or lose it" attitude in fact, is not a black and white rule. "It's a kind of a balance," she says.

So rather than pushing on, Amanda advises that you monitor the pace of how you go about things. If the going gets tough, sit back for an hour or so. There's no set time to have a breather - 10 minutes or an hour - you will work out what suits you best. It might turn out to be a 2-hour break.

She says strengthening muscles, without overdoing it, means you can use them to help take pressure off joints when you're using your arms and hands. Beyond that, Amanda described the aids that can be strapped to arms, wrists and fingers to help with household activity like gardening. Aids can take over some of the work. These are things like a household key turner, kitchen utensils and the like.



She showed how simple aids can be by giving attendees an example each of some insulating tube. She places these over cutlery and pens to give something more substantial to grip. Grips let you use a bigger shoulder muscle to manipulate things, rather than placing all the stress on fingers and wrists.



Amanda Johnson has been a physiotherapist for 18 years and has specialised in hand therapy for 15 years - that's from the elbow to the fingertips.

Amanda had detailed advice for the hand problems that affect scleroderma sufferers and for those with Raynaud's.

Amanda's clinic is in New Town, Wellington.

[www.workinghands.co.nz](http://www.workinghands.co.nz) | [amanda@workinghands.co.nz](mailto:amanda@workinghands.co.nz) |

## Ways to protect your joints

Avoid tiredness

- Pacing
- Plan ahead and set priorities

Maintain muscle strength & joint range of motion

Use larger muscle groups

Adaptive aids

Splints



# President's Report

It has been a busy year, and now Spring is just around the corner which is a big relief to us all.

Our Society is coming along nicely; we are now a registered Charity along with our incorporated status and a bank account, so we are now fully operational.

On the 1st of August Scleroderma NZ was very busy with both a seminar held in Hamilton organised by Linda Bell, with a very interesting programme and the Wellington group held their normal August meeting with a very interesting Speaker Amanda Johnston from working Hands, a great turn out all round.

We have great news that Scleroderma NZ was granted permission from the Scleroderma Foundation USA and Scleroderma Australia to reprint the booklets on Managing and Understanding Scleroderma. This way we will be able to put the contents of the booklet in a New Zealand context.

Australia is currently doing their own rewrite as we speak, so we are waiting to look at their new information before going ahead. Gordon and I are currently working away at the contents. We have had great input from Maureen Kirby from Invercargill and Jan Ipenburg from Christchurch. Both are our hard-working and dedicated scleroderma specialist nurses who we are very lucky to have.

We are also working on a hospital check list for Scleroderma patients to take with them to hospital should an occasion arise. Maureen has put a lot of effort into this project also.

This brings me to the next piece of news that Maureen has produced a calendar to sell to raise funds for Scleroderma NZ Inc, Arthritis NZ, Crohn's and Colitis NZ and Psoriasis Southland.

We need all your help and support with this one, it is such a lovely idea to be able to help other conditions as well as our own so please buy a few and sell them on to help us all out. We need funds for the reprinting and postage of our booklets and leaflets. We need to help ourselves and any new people coming along the way with this condition.

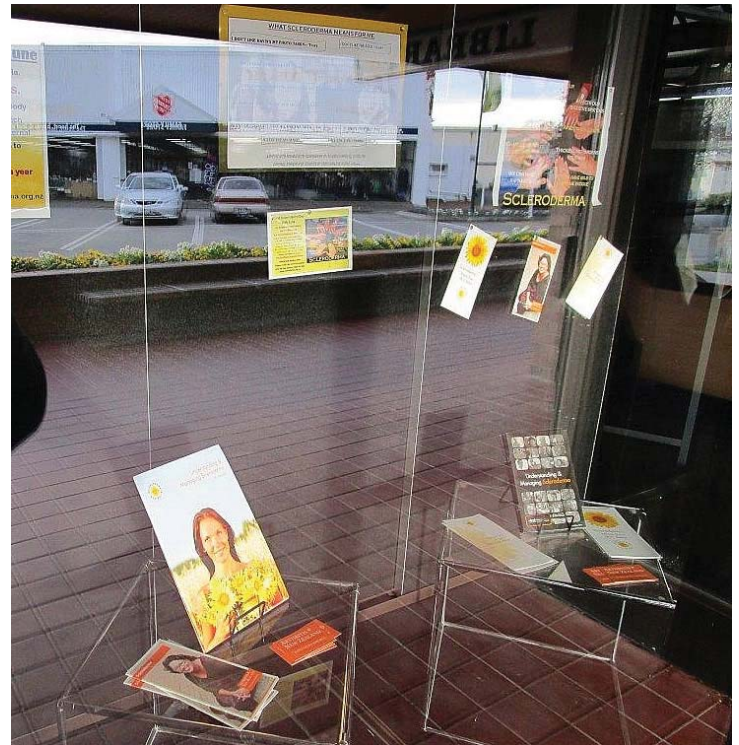
I would like to thank all of you for your ongoing support it will help us all in the long run and a big thank you to all of our committee and especially Barbara and John for putting us out there with their great newsletters and website.

Take Care Keep Well and Warm

**Dianne**

# Southland's Display

## Highlights World Scleroderma Day





## How to cope with pain: relaxation exercises

The US Scleroderma Foundation has published a series recently about coping with pain.

The Foundation links to a variety of sources for both exercises and information dealing with pain.

The quote a complementary health organisation's estimate that just over 11% of Americans suffer chronic pain.

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**"Living with chronic pain can be difficult and have negative consequences on your life, including your ability to work and your relationships with family and friends. But, there are coping mechanisms that you can employ to help alleviate these challenges."**

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'How to cope with pain' offers a variety of plans and exercises to help you cope with pain, relieve anxiety and reduce stress.

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



The National Center for Complementary and Integrative Health, a US-government-funded body that researches the usefulness and safety of complementary medicines, has studied the incidence of pain in America,

It's a big country with a vast population compared with New Zealand but it also has a western lifestyle similar to ours and may offer an insight to conditions here.

<https://nccih.nih.gov/research/blog/analysis-pain?nav=fb>

The Americans are using the survey results to build better national data on the nature and extent of the problems that chronic pain causes. They have published the report online.

<https://nccih.nih.gov/research/statistics/NHIS/2012/pain/severity>

## Communications help offered

A communications specialist looking for a good cause has offered to help Scleroderma New Zealand spread word about the disease and help fundraise.

Michelle Hunter, from the Kapiti Coast, has worked out a long-term plan for the group covering the next two years.



Michelle introduced herself at the Winter meeting. She wants to take the ideas from the brochures and checklists a step further to make a public awareness campaign. She has already written up a brief on that.

Her plan is to publicise the group through community papers by placing articles and some advertising. Michelle hopes the publicity she generates will expand the support group's recognition and reach to other sufferers.

Michelle will research what government help is available for sufferers with, say, lung problems and heating during winter. She says there is government help but little research that says it applies to those with scleroderma.

"If it's not currently available, then how do we go to that government organisation and include scleroderma?"

She says there's a whole raft of private funders who would help with booklet publication and printing costs and to distribute them to doctors and hospitals.

Michelle's first task was to be a draft of the public awareness campaign and a 2-year plan. She says she has the skills and if we need them, she's here to help.



## Brushing up on leaf and beak - Catherine's trans-Tasman bid

Palmerston North member, Catherine Thompson is forging ahead with her art, opening a website to display her paintings.

Catherine works with acrylic on stretched canvas she says New Zealand's wildlife and natural bush and coastline inspires her.

Catherine sells her paintings privately and accepts commissions. She has paintings for sale through the Seaside Artists Gallery, Redcliffe, Queensland, Australia, Majoh's Cafe, Clontarf, Queensland, Australia and the Taylor Jensen Gallery, Palmerston North, New Zealand.

<http://cathtomo.wix.com/artist-painter>



## Lotions and potions - natural November. Our speaker for the November meeting is Maree Murphy



Maree is a natural health practitioner and medical herbalist. Maree lives with her husband and children in Fairfield, Lower Hutt.

They have a large organic garden where Maree grows a big variety of herbs and vegetables.

Maree makes herbal teas, natural creams (without chemicals) and health tonics.

Maree also works in a clinic where she sees clients who want natural help for common health problems e.g. skin conditions, high cholesterol, high blood pressure, constipation, gout, menstrual and menopause problems, arthritis, weight issues, cancer, infertility, indigestion, stress, insomnia etc.

Dianne Purdie can personally recommend Maree's hand cream.

"It works quickly, makes my hands soft and moist and a pot lasts for a very long time", Dianne says.

Maree will have some hand creams and other products for sale if you wish to buy any of them at the meeting.

Dianne says Maree has a wealth of knowledge and a zest for life and is a very entertaining speaker.



*Lemon balm - a de-stress tea favourite*



# Fundraising For Scleroderma NZ Inc and Other Good Causes.

Maureen Kirby, our Southland Rheumatology nurse, has put together a calender for 2016 for a big fundraising effort for Scleroderma NZ Inc, Arthritis NZ, Crohns and Colitis NZ and Psoriasis Southland

Maureen has sold 250 and she needs to sell another 250.

If you could buy a few calenders at \$12.50 each (there could be postage costs for some, please inquire) you would not only be helping us, but some other great causes too, and it's a good feeling to be helping others. So please feel free to pass this request on to your contacts.

If you send your order to Dianne Purdie email: [diannepurdie@xtra.co.nz](mailto:diannepurdie@xtra.co.nz) with payment via direct debit through the following bank account and add details of your name,how many calendars you want. In the reference put "fundraising calendar".

ANZ account number 060501 0016449 00

The accompanying image is the calender that Maureen has put together, it is a very real, heartfelt effort to show life in all its stages from good beginnings and difficult trails along the way, a terrific effort.

So please could you too have a big heart and help support us.

The funds that we will raise for Scleroderma NZ Inc will go towards the printing and distribution of our New Zealand Edition of the Booklet: Understanding and Managing Scleroderma for the New Zealand audience.



## Website Visits

Interest in our website varies from month-to=month, with some months being very busy. Our busiest this year was September when visitors viewed just under 26,000 pages. Out lightest month was August when only a tenth of that number were viewed.

Best month: September 25,998 pages viewed

Year-to-date  
115,422  
pages viewed

### What they searched for

1.	scleroderma blood test
2.	blood tests for scleroderma
3.	scleroderma nz
4.	scleroderma blood tests
5.	blood test for scleroderma

# Waikato Seminar

## Waikato has staged another successful scleroderma seminar

Attendees came from Kaitaia, Auckland, Rotorua, Matamata, Tokoroa, Whangamata and there was a good turnout from Hamilton.

Many had not attended a seminar before and had just been diagnosed.

As we had become incorporated I was able to raise funds to cover the seminar costs involved. I thought the day went very well, I had family and friends doing the catering and there was plenty to eat. There were excellent speakers: registrar, podiatrist, occupational therapist optometrist and a respiratory physician.

We also watched the DVD Documentary "Beneath the Surface". With the help of social media outlets Christy Caffrey connects to scleroderma patients all over the world offering them a voice in this film. The film is an intimate look into the everyday struggles and painful setbacks of scleroderma patients, blended with highly educational details about the disease from leading doctors and researchers.

I was able to do raffles this year and would like to thank Feel Good Pharmacy, Dinsdale Hamilton, for the lovely gift basket donated, Hoyts cinema for movie passes and Centre place for gift card.

Also I wish to thank Francesca Holloway, Regional Manager and Trevor Fredericks, Arthritis Educator for Hamilton. A special thank you to Sandy and Allan Edmondson for all your help with seminar and you're continuing support is very much appreciated by me.

Yes, I do have Facebook please join me on Scleroderma Waikato which has interesting articles and up to date news an what is going on in Hamilton for Scleroderma members. If you do live in Hamilton and wish to join our coffee/tea group, we meet once a month at Westfield Chartwell, Robert Harris Café. Please contact me [linda.bell@hotmail.co.nz](mailto:linda.bell@hotmail.co.nz) .

Thank you all for your support and attending the seminar - very much appreciated and hope to do it again next year.

Many thanks take care,

**Linda Bell**

**Scleroderma Waikato Inc**



Armies and seminars alike march on their stomachs and Linda had family and friends to look after that.



Linda Bell welcomes another attendee at the Waikato seminar.

# Take as directed

An artist asked the gallery owner if there had been any real interest in his paintings which had been on display for the previous few weeks.

'I have good news and bad news,' the owner replied.

'The good news is that a gentleman inquired about your work and wondered if it would appreciate in value after your death. When I told him it would, he bought all 17 of your paintings.'

'That's wonderful, absolutely marvellous,' the artist exclaimed. 'What's the bad news?'

'The buyer was your doctor.'



# Noticeboard



**Next Meeting:**  
**November 7** see  
you there

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

has a section for those  
newly diagnosed with  
scleroderma -

[learn more here](#)

## Your News

We're keen to include news  
from: Auckland, Hamilton,  
Palmerston North and  
Southland groups

