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# Scleroderma

support group

## *newsletter*

### Summer Issue 2012

Welcome to the last newsletter for the year.

I wish to thank all who have contributed to the newsletter in any way. Without your contributions it would not be the success that it is.

It is those individual and personal stories that give the rest of us the courage to try something new and push the boundaries that we would not

otherwise have done.

Please continue to send these stories in and attach a photo. Also if you do something exciting or different over the holidays let us know so we can all share.

Wishing you all a very happy Christmas and look forward to seeing you again in the New Year.



A small, enthusiastic group met for the last time this year in Lower Hutt and exchanged small gifts, experiences and banter

# Scleroderma seminar

## Hamilton seminar a great success and may be repeated next year

**The recent seminar on scleroderma held in Hamilton was so well attended that plans are already underway to repeat it next year.**

The 59 attendees far exceeded organisers' expectations and they have marked 29 June 2013 to stage it again.

Many of the audience left comments on a supplied form and they generally welcomed the event, seeing it as a chance to discuss the disease and its effects on others and to learn more about treatment.

For future events, attendees suggested information session on:

- the digestive tract and diet,
- living with chronic illness and pain,
- coping when symptoms are distressing and
- lung and PAH.

Some would like to see group workshops on specific aspects of scleroderma and its symptoms.

They were also interested in having medical specialists attend a question and answer session for attendees.

Satisfaction ratings, garnered from those who filled out the seminar's survey form, showed that 64% of attendees were Very satisfied and 36% were satisfied with the seminar, its presentation and information imparted.



At the seminar, from left Dr Kamal Solanki Waikato Hospital, seminar organiser, Linda Bell, Hamilton and Adrienne Burleigh, Wellington

Featured speakers included:

<b>Kamal Solanki</b>	Waikato Hospital
<b>Mammoood Al Mujeui</b>	Clinical Features
<b>Biddy Robb</b>	Speech Language Therapist
<b>Anna Schollum</b>	Role of Nursing in Scleroderma
<b>Sally Hollinshead</b>	Role of Occupational Therapy in Scleroderma

## 24 years of frustration led to seminar

Linda Bell of Hamilton got the seminar rolling after feeling alone with her illness for 24 years. Linda says she never met anyone else with the disease and felt that there was little help or information for her and others like her to cope and seek treatment.

She says she rang Arthritis New Zealand over the years without much result until, this year, a new, enthusiastic educator answered her call and it all snowballed into the seminar. She bought herself a laptop computer and learned how to use it so that she could communicate properly and things just took off.

"Instead of talking about it we felt it was time to do something about it." Linda says. "I want to help the up-and-coming diagnosed, I'm not so worried about me, after 24 years."

Linda has struck up ties with Scleroderma Australia's president, whom she met in a trip to Melbourne and has received a lot of advice and printed resources from her.

Next year Linda plans to repeat the seminar and attract more attendees by advertising it better. She says she has been told by Hamilton medical staff that there may be 70 people in her region suffering from scleroderma. Despite the good attendance, she knows of around 25 who were prevented from attending by their illness and she is keen to see events held around New Zealand rather than in just one centre to reduce the need for travel.

While she might be keen to reduce travel for others, Linda is off to a seminar on scleroderma in Australia next March. She is motivated more each day, she says, and was overwhelmed to be in a room full of people who share her disease and to swap experiences. . There is little chance of her stopping now.

# Website referers

The Scleroderma Support Group's contact information is now up and available on two additional websites.



First is the web site of the New Zealand Organisation for rare Disorders.

[www.nzord.org.nz](http://www.nzord.org.nz) is the site of the registered charitable trust that was established in 2000 following a conference of more than 30, rare disease groups.

The site offers a link to our web site and contacts for Dianne



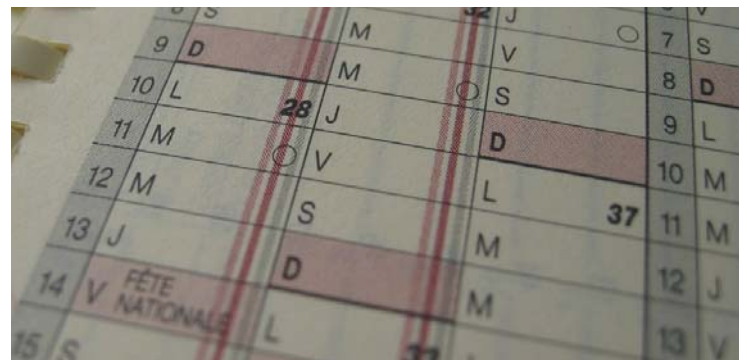
[www.everybody.co.nz](http://www.everybody.co.nz) has also linked to the group.

Everybody is a site published by UBM Media, a health and drug information publisher.

It also carries a link to our website and contact information for Dianne.



## Meeting dates 2013



February 2

May 4

August 3

November 2

Note that all of these meeting dates have been transferred from the second weekend of those months to the first weekend.



Palmerston North member, Chris Carlyon, and her secret weapon against Reynauds: merino wool mittens. They're light, they fold up into next to nothing and - so warm.



The Lower Hutt Citizen's Advice Bureau rooms, which have proved to be ideal for the support group's quarterly meetings. Meetings will continue here next year.

# Web site statistics show international flavour during 2012

The support group's website has attracted interest from many different countries over 2012.

All web servers capture the country of origin of visitors, what browser they use, how long they stay on the site and so on.











Over 2012, here are some points of interest for [www.scleroderma.org.nz](http://www.scleroderma.org.nz)

By month visitors and the number of pages that they viewed 2012

Month	Page views	No. of visits
January	452	185
February	451	198
March	701	255
April	423	154
May	740	250
June	713	327
July	538	243
August	1336	264
September	868	209
October	1688	257
November*	411	190

\* not full month

Top countries 2012

Country	Page views
 New Zealand	4140
 United States	1014
 Russian Federation	989
 Kazakhstan	364
 Japan	332
 Great Britain	182
 Australia	166
 Germany	166
 Ukraine	107
 France	135



Barbara Quickenden scored well in the Secret Santa gifts at November's meeting. Gifts ranged from chocolates to bag sealers to hand moisturiser to wheat bags.



Alastair and wee Ian found that no-one at the Christmas meeting went away without something new to enjoy

# Forget the Boxing day sales

## Look ahead to winter

ARTHRITIS NEW ZEALAND



**While shops push the latest and most expensive goods to prime display spots for the Christmas rush, don't forget that winter is coming (to borrow the gloomy phrase from the TV series, Game of Thrones).**

Dianne recently showed a support group meeting how out-of-season shopping can produce some real bargains.

When the sun's shining, think of winter and see that shops are still, even this late stage, eager to get rid of the fleecies to make room for the latest flimsies and there are bargains to be had for those who think ahead.

Dianne found fleecy gloves, thick, quilted jackets and scarves all for much, much less than their normal retail prices.

This type of stock will be back in numbers in shops at the end of the first quarter next year but prices will be back at a premium.



The booty from Dianne's out-of-season shopping expedition

## Merry Christmas!



Santa, for 2012 all I want for christmas is a fat bank account and a skinny body.

Please try not to mix them up like you did last year. OK!!!

I love it when



My pills kick in

### CONTACTS

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

Links: [www.arthritis.org.nz](http://www.arthritis.org.nz) | [www.scleroderma.org.nz](http://www.scleroderma.org.nz) | [www.sjogrensnewzealand.co.nz](http://www.sjogrensnewzealand.co.nz)