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○ SPRING | ○ 2009



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# Scleroderma *newsletter*

A SUPPORT GROUP BASED IN WELLINGTON FOR THOSE DEALING WITH SCLERODERMA

*This issue is the first and comes from a meeting held at Arthritis New Zealand's Hutt Valley rooms in July 2009. It's intended to publish it quarterly.*

## Welcome to you all in this first issue

Greetings to all and welcome to our first newsletter for 2009.

It was good to see everyone at the meeting and we hope that we continue to meet, share our experiences and overcome issues that are challenging us. This newsletter is a means of keeping in touch with each other and helping to manage our disease better. We hope to achieve this through your input and knowledge gained from guest

speakers, websites, books and any other medium we can find.

The newsletter is not supposed to be a solo effort and contributions are sought on any subject that you think might contribute to the interests and knowledge of members of the group.

The intention at the moment is to publish it quarterly. We're happy to publish more regularly but let's take it a step at a time.



## ARTICLES

We need items of interest to make this newsletter relevant and interesting to you all. Contribute news you have discovered or something you do that helps with your aches and pains and which you would like to share with the rest of us. Perhaps you have an interesting hobby or have read an enjoyable book or seen a great movie. Maybe even share stories about funny things that have happened to you. We need items like that to fill our newsletter to make it interesting and enjoyable each time we get a newsletter. It doesn't all need to be about Scleroderma.

# Meeting sets up activities

*At the meeting in July when we agreed there was enough enthusiasm to meet regularly and contribute help and knowledge to the group, we agreed on several steps we needed to take.*

*Here's a look at progress and a few 'wouldn't it be nice' items*



## Web site

Work has begun to design and building a web site to carry news of events and archived copies of the newsletter. Like the newsletter, the web site will probably evolve to encompass subjects and content that interests members.

## Newsletter

We also agreed we'd like a newsletter and you are reading the first issue. The circulation won't be huge but we hope the content will interest you and that you are enthused enough to contribute content of your own.

You don't need to be a polished writer (we can tidy up grammar and style). However, if you see even a line in an interesting and relevant article then sending in the link will be enough some times for us to chase up news of interest.

## Guest speakers

It would be good to have suggestions for guest speakers to come to a group meeting to talk on their area of expertise.

Experts might speak on topics relating to Scleroderma and Connective Tissue Disease. For example, they could talk to us about managing stress, managing pain and offer advice on living with a chronic disease.

## Topics

*Things you want to talk about.*

Tina had a magazine she subscribed to called Scleroderma VOICE. This is an American-based magazine, which has lots of helpful information in it. You can subscribe to this publication for \$35 USD and receive the magazine, or go to their website at [www.scleroderma.org](http://www.scleroderma.org). You can subscribe on line.

Work Bridge provides support for people with disabilities to stay in employment. However some people in the group were having difficulties getting their help or support!! This may need perseverance and persistence.

Someone at the meeting mentioned a shop in Petone, which provides aids for hands that don't bend as they should. Could that person find out the name of the shop, exactly where it is, and what exactly these aids are. Maybe someone from the shop could come and give us a talk and bring some aids along, or even write an article for the next newsletter. That has benefits on both sides.

Diana found great benefit from her wax hand bath. She

found this on Trademe at not too great expense.

Also dried celery was suggested as a good remedy for relieving the swelling in your hands. It comes in pill form.

Lobbying for easier access to the latest and improved, but expensive, pharmaceuticals and monitoring protocols may be one of the activities the group pursues.

National networking of Scleroderma groups around New Zealand and internationally is something we could work on. There is nothing like shared knowledge to show that your situation is similar to that of many others and that they may benefit from your experience and you from theirs.

Dianne mentioned solvent exposure, such as aromatic hydrocarbons, as a cause of SSc and CTD and the legal battle to have it recognised by ACC.

**NEXT  
MEETING**

November 2009

Date and venue to  
be advised

## Technology

Three women, two younger, and one old, were sitting naked in a sauna passing the time when there came a beeping sound. The young woman pressed her forearm and the beep stopped.

The others looked at her questioningly.

"That was my pager," she said, "I have a microchip under the skin of my arm."

A few minutes later, a phone rang. The second young woman lifted her palm to her ear.

When she finished, she explained, "That was my mobile phone. I have a microchip in my hand."

The old woman, not to be out done, stepped out of the sauna and went to the bathroom, returning with a piece of toilet paper hanging from her rear end.

The others raised their eyebrows and stared at her.

The old woman finally said, "Well, will you look at that, I'm getting a fax!"

## CONTACTS

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