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# Scleroderma

support group

## *newsletter*

## Autumn Issue 2013

Happy New Year to you all and welcome to the first newsletter of the year. I trust you had a peaceful holiday break and are well into the New Year's work and leisure activities again. Remember if you did something exciting over the holidays let us know so we can all share your experiences.

Welcome to our new member Steve and his wife Bev, and also to Kokila, who was down here from Auckland where she lives.

At our meeting this time we had a guest speaker, Dr Giresh Kanji who is a musculoskeletal pain specialist. Dr Kanji has been doing this for 20yrs and specialises in finding the cause of people's pain, treating and alleviating the adverse effects pain has on its sufferers. He has some helpful hints in his report which is further on in the newsletter.

Barbara



### Relieving pain

It may look as though the February meeting brought along a jungle gym and hit the floor running, in fact it was our guest speaker, Dr Giresh Kanji, whose talk centred on alleviating stress, both physical and mental, as a way of combating the aches and pains that plague members. Pictured above, Dr Kanji shows a simple frame that relieves back stress and associated muscle pains. Read about his advice in detail on page three.



### Scleroderma Seminar - May

Come along and listen to a wide range of speakers on different aspects of Scleroderma at our special May meeting.

- When:** 4th of May 2013
- Time:** 9:30am-3:30pm
- Where:** Hutt Hospital Learning Centre, High Street, Lower Hutt
- Cost:** Free

See speaker bios, location map and registration requirements on page 4.

# Back and neck pain

## Some of the cure can be homemade

[www.sportsandpain.co.nz](http://www.sportsandpain.co.nz)



Dr Giresh Kanji

Pain and its avoidance occupied the February meeting as invited speaker, Dr Giresh Kanji, talked the group through ways to alleviate both the physical and mental stresses that often cause pain.

Dr Kanji runs Wellington-based Sports and Pain Clinic and he's a regular speaker at events, including seminars jointly staged with Arthritis New Zealand.

Straight down to business, he opened up on back pain, something that affected many of the members present. He ascribed 90% of back pain to discs. He says it's often misdiagnosed by GPs and misunderstood by patients.

Spinal pain, he says, results from a disc being compressed and as it's compressed, the disc's cushioning fluid is expressed and it the disc starts to grind against its neighbour. When the pressure is relieved, the fluid returns. That would be the case carrying something heavy for 20-minutes. But, when long-term pressure is applied, such as that resulting from poor posture, the pain can become chronic.

Dr Kanji described how pressure and injury generate electrical signals that travel to the brain and are perceived as pain. Some people, he says, have a lower pain threshold and amplify the pain, particularly those prone to migraines.

So the amount of pain that spinal compression generates depends on the damage to the disc and the person's sensitivity to pain. To start to reduce pain is to find how to reduce the pressure on discs in both the neck and the back. A good treatment for back pain is the couch potato's dream. While standing, everyone's

spine compresses, as it supports the weight of the body. Laid back in an armchair, it gets some respite. Dr Kanji says a night in bed may allow the spine to extend by a couple of centimetres as fluid is reabsorbed by discs that compress again during the day when the body is upright.

Neck pain usually results from the spinal discs trying to support the weight of the head. Those discs are compressed just the same as those in the lower back.

Short of lying in bed all day, there are ways to alleviate back and neck pain. The shape of a spine in someone standing upright resembles the letter 'c', although not as exaggerated. But it acts like a spring to support the back. Straightening the spine, by leaning forward slightly, means the springiness has gone and gravity presses down on the spine in full force.

A lumbar roll placed behind the back while seated is designed to retain this vague 'c' shape. Dr Kanji even suggests that when buying a recliner chair, you should take a book and sit in the chair for up to half-an-hour to ensure that your back pain doesn't increase. The book is probably optional but he stresses that each of us is different and what may provide rest and comfort for one body shape, might exacerbate pain for another.

Dr Kanji says the mis-diagnosis of damaged discs, written off, often by GPs, as age-related degeneration of the spine or muscular strain, causes many to suffer needlessly. He says the loss of fluid from discs caused by compression can be alleviated by stretching exercises. And lower back or neck muscular pain is almost always caused by compression to discs so treating the muscles without treating the cause will not bring long-term relief.

He didn't seem a fan either of prescribing

drugs, perhaps anti-depressants to treat back pain when the cause, compression, remains untreated.

"You can treat the brain (pills) or you can treat the cause," He says.

Part of the cause is the way we stand, he says. For example, leaning forward but leaving the knees straight doubles the weight on the spine as it supports your trunk for each 20-degrees of lean. This leaning might be over plants in the garden, the sink bench or a craft table. It squashes the discs, forcing the cushioning fluid from them and exacerbating pain.

A simple way to give your spine a break (as in relief, not snap!) is to place one foot a little ahead of the other and bend slightly at the knees. This posture reduces the spinal curve and should let you stand for a lot longer with less pain.

Dr Kanji peppered his talk with tips on alleviating back pain. They ranged from the simple: sit with your back against the back of the chair to gain support, to how beneficial it is to hang upside down for a time to reduce gravity on the spine. That last one too tough? Try lying across a bed on your back with your neck hanging out over the edge. That will reduce downwards compression on the discs and let them rejuvenate their cushioning fluid. Both of these methods stretch the spine and let fluid back in.

After a detailed hour-and-a-half, Dr Kanji summed by saying that drugs and doctors and therapeutic massage can all get expensive and there's a lot that chronic back-pain sufferers can do for themselves.

"Say, there's ten out of ten pain level. Even with the worst we can usually reduce that to five out of ten," he says. And much of that the patient can be taught to do for him or herself.

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**"You can treat the brain with pills or you can treat the cause"**

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# Flight Path of Disability

## A support group member's experience with scleroderma

Palmeston North support group member, Catherine Thompson, has completed a series of paintings entitled "Flight Path of Disability", representing her journey with scleroderma and her my life over the past year. It also expresses grief and loss.

The first painting is called "Encased" with the hands encased in ice and the arctic owl encasing its prey and everything caught in the cold Arctic environment. It expresses lost circulation/feeling.

The second is called "Inflamed" Flamingo cupped in hands that are hot and burning – depicting pain.

The third painting is called "Interned" with the tern up against the glass, isolated behind the hands. Feeling alone, imprisoned and isolated.

The fourth painting is called "Enraged" with the fighting cocks and the fist. It depicts anger and frustration. The fifth painting is called "Engulfed" – with the seagull diving and the hand being pulled under, a feeling of being completely overwhelmed.

The sixth painting, "Ensnared" features a New Zealand falcon pulling back against the tether, caught in a cycle with little control and hands slowly tightening into the shape of a claw, feeling trapped.

The seventh painting is called "Enlightened" – moon rising and two doves meeting, finding peace, tranquillity and understanding/wisdom.

The final eighth painting is called "Interred" – depicting death with new life and freedom. It shows hands flying free with the cross, depicting death, and the Kiwi underground with its egg – new life.

The series took Catherine a year to paint and was also a struggle emotionally so there were times when she says she couldn't paint at all.

"I am a mainly self taught artist with a love of nature and New Zealand wildlife in particular. I am inspired by the New Zealand bush and coastline. I use large brushes and work with a free, loose style on the background of the pieces finishing the finer detail with smaller brushes and strokes," she says.

I express myself freely in my work and this series of birds "Flight Path of Disability" depicting my journey with Scleroderma, grief, loss and disability is an example of that.



Catherine with her collection. Catherine sells her work through the Taylor Jensen Gallery in Palmerston North. She is asking \$2,200 for it but wants to keep it as a set and not break it up into individual paintings.



The first painting in Catherine's series, called "Encased" with the hands encased in ice and the arctic owl encasing its prey and everything caught in the cold Arctic environment. It expresses lost circulation/feeling.



# Scleroderma Seminar - our May meeting

## Welcome to our May Scleroderma Meeting

Come and listen to a wide range of speakers for the day on different aspects of Scleroderma. Our Speakers are:



### Associate Professor Andrew Harrison

Andrew is a rheumatologist and Clinical Head of the Wellington Regional Rheumatology Unit, practicing at Hutt, Wellington, Kenepuru and Bowen Hospitals. He is coordinator of the rheumatology component of the 5th year Musculoskeletal Module at the University of Otago Wellington. His current research interests include gout genetics and pathophysiology, ankylosing spondylitis and barriers to access to rheumatology treatment.



### Dr Richard Steele

Clinical Immunologist and Immunopathologist at Aotea Pathology and Capital & Coast Health. Dr Steele has a special interest in autoimmune serology, particularly coeliac disease and connective tissue disease.



### Dr. Raj Anand

Senior Registrar at Hutt hospital, Wellington  
Dr. Anand is currently a senior registrar at Hutt hospital, (Wellington), specializing in rheumatology and Internal medicine. He brings a lot of his personal experience in sitting various medical & aptitude exams in USA, UK, India & Australia. He is also a national committee member of Art of Living Foundation, which helps people in managing stress.



### Adrienne Burleigh

Adrienne has conducted a survey looking at Scleroderma patients and their experience with the health system here in New Zealand. Adrienne released the survey to our members of Scleroderma NZ last year and will present the results at this meeting.



### Gordon Purdie

Senior Research Fellow Otago University Wellington  
Gordon is part of a team in the Department of Public Health that provides statistical consulting to health researchers. Within the Health Inequalities Research programme, he is involved in the Differential Colon Cancer Survival by Ethnicity in New Zealand project and works with Te Ropu Rangahau Hauora a Eru Pomare on several research projects, including Unequal Treatment: The Role of Health Services. His research interests include solvents and scleroderma.



### Dianne Purdie

Dianne has worked as a Medical Cytologist in Melbourne and New Zealand for 25 years and now has retrained in Vascular Diagnostic Medical Ultrasound. Dianne has a strong interest in the disparity of clinical health services in Australia and New Zealand and she also has a keen interest physiology.

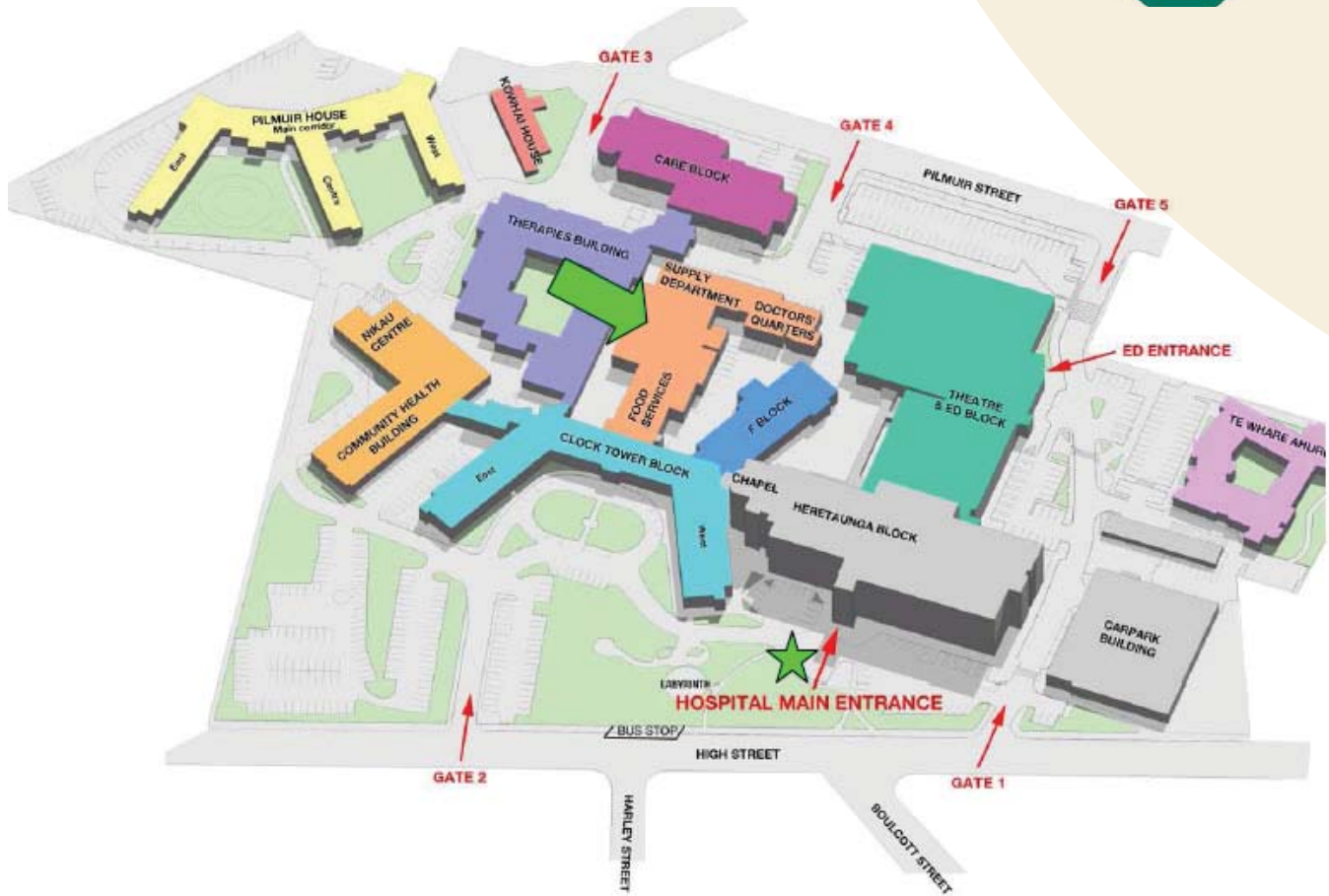
May 2013						
Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
			1	2	3	4
5	6	7	8	9	10	11
12	13	14	15	16	17	18
19	20	21	22	23	24	25
26	27	28	29	30	31	

## Programme

Time	Event
9:30am	Registration
9:45am	Introductions
10:00am	Morning Tea
10:20am	<b>Dr Andrew Harrison: "Optimising your outcome in the health system"</b>  Factors that matter to patients with scleroderma (iloprost, lung function, echocardiography) and the likely effects of budget restrictions, pulmonary screening, the newly announced funding of sildenafil for Raynaud's phenomenon). Dr Harrison will also discuss how avoid of slipping through the cracks and will encourage patients to take charge of their own monitoring.
11:10am	<b>Dr Richard Steele: Scleroderma a laboratory perspective</b>
12:00pm	Lunch
1:00pm	<b>Dr Raj Anand: Stress and Scleroderma (related immunology)</b>
1:40pm	<b>Mrs Adrienne Burleigh: Overview of our recent Scleroderma Patient Survey</b>
2:00pm	<b>Gordon Purdie: Solvents and Scleroderma</b>
2:40pm	<b>Dianne Purdie: The importance of keeping warm with related vascular physiology</b>
3:00pm	Afternoon Tea
3:30pm	A General discussion, for those who want to stay back and chat for a while.

# Scleroderma Seminar

Hutt Hospital Learning Centre



## Seminar directions

### From the main entrance

- Walk past the volunteers desk, ATM and florist
- Turn left at the hospital directory board
- Walk down the corridor past the chapel entrance into the clock tower building
- After ENT (ear, nose and throat) go up the stairs to your left
- Turn left at the top of the stairs
- Down the corridor, the library and learning entrance is to your right
- The visitors' parking building is easiest to reach from gate 1 off High Street.

## To register:

Deadline: 22nd April

Dianne Purdie on 04 479 5548

[diannepurdie@xtra.co.nz](mailto:diannepurdie@xtra.co.nz)

## Sjögren's Syndrome

### Managing Dryness

Venue C C S Disability Action  
17 Claudelands Road  
Hamilton

Time 2 pm - 4pm  
Wednesday March 20th

Presenters D. Koppenâ's Paterson Burn Optometrist  
Talking about managing dry eyes.  
Karen, Dental Hygienist, Wide Smile  
Talking about dry mouth

### Sjögrens Support group

Sandra Forsyth 021024765595

[sjogrens.sandra@gmail.com](mailto:sjogrens.sandra@gmail.com)

# Palmerston North Group establishes itself

"For the past year a small group of Palmerston North women, members of the Wellington Support Group, have been meeting at each other's homes for a catch-up and a good laugh and chat.

There are times when we just can't make it to the Wellington meetings with the four hours of travel but we do enjoy the meetings when we get there.

Catherine, Maree and Chris have a lot in common but the talk is rarely about Scleroderma. Conversations are usually bright and cheerful and the odd time when support is needed we are there for each other.

We decided that Christmas deserved a trip out to celebrate the year's end and to plan for 2013. We will meet at Chris' home when she gets back from holiday up North. We are hoping to get down to Wellington for the Pain Management talk on 2 February but we have learned from experience that you just shouldn't count your chickens with this condition and with the surprises life throws at you.



One of the benefits of the small group is that we do encourage each other to seek extra help outside of our specialist visits, which are not always very helpful. Catherine sought a referral from her GP to the hand therapist at the hospital and came back with some great tips and encouraged us to do the same and go and see her. She advises on the creams to use, utensils and other helpful hints and exercises. A gentle stretching is much better than trying to force fingers, apparently.

We would like to thank all the Wellington members for their support and encouragement over the past year and wish you all a happy and healthy 2013.

Take Care

Catherine

## Results of scleroderma survey due soon

The results of a survey distributed late last year on scleroderma sufferers' experience with health professional will be released shortly.

Adrienne Burleigh, support group member and diagnosed with systemic sclerosis in 2008 organised its distribution and analysis.

Adrienne had tired of the lack of knowledge of those charged with medical care and of how the health system reacted to her disease.

She says she has come to live with scleroderma's many and varying challenges since being diagnosed with it. She has made great efforts to learn as much as she can find out about the disease and she would like many more of our health professionals to make the effort to be similarly informed. Her reasons are straightforward:

"So that we who live with it as a daily reality can have the most up to date treatment and not be regarded as oddities that are a puzzle to the health system," she says

Adrienne says from her many years of working at head office level in a number of government departments that she is aware that the policy makers and the bean counters who control the finances only act when they have data to examine and a good case to support any requests.

"If we are to get continuing support plus access to the latest drugs and treatment regimes we need to be noticed. This was the driver for me to begin gathering information via the survey," Adrienne says.

So Watch your mail box! The survey was



Adrienne Burleigh,

distributed with this newsletter late last year.

Adrienne says while the response wasn't large, she has collated the results, which will be distributed shortly. She is happy to receive comments on the results.



# Point Howard to bus barn challenge

## Dianne's big adventure

You might have heard of the Mt Lowry Challenge on the Eastbourne hills on the east side of Wellington harbour. My husband Gordon and I invented our own version: "The Bus Barn Challenge," traversing the Eastbourne ridge to the big bus parking shed.

We set out on a Sunday a couple of weeks ago. It was a toasty 25 degrees so I took plenty of extra clothes in case I got a little damp with the climb up Lowry.

We met people coming down towards us, capturing the sites and listening to the tuis. It was nice to see their happy smiles and chat, a chance to cool down every so often. One was elderly, he must have been in his 80s. He had a wealth of information about the trek ahead but he thought we should have made it a round trip, not one way. He did have a little sparkle in his eye though, so I didn't feel too lazy.

The abundant flora was regenerative manuka, kanuka, mahoe, mamaku, ponga, kawkawa, fivefinger, cabbage trees, rangiroa and numerous ground ferns. There was also the odd gorse bush until the track gave way to beech and the odd rimu and rata, as noted by the elderly gentleman earlier on.

We made the summit of Mt Lowey, thankfully before lunch, knowing that it was a slow decline to the bus barn a few hours ahead, with its ups and downs along the way. We'd planned our lunch seat as on our previous visits it had always been deserted but, alas, it was nicked by another couple who were having second thoughts about continuing in the heat. So we trundled on down into the bush for some cooling shade. Gordon found a wide, comfy seat in a twisted tree trunk and we happily waved the other trampers off.

Next, the lovely main ridge walk in open beach forest to Day's Bay. We met a man with three identical dogs. He'd found them as pups on the roadside in the Wairarapa. He didn't know the breed but he adopted them. By chance, a year later, he met a woman with identical dogs and asked her, "Do you know the breed?" She didn't, she said, because she'd found them on the roadside Wairarapa at around the same time as he had. Well how's that for a coincidence.



Gordon and I got covered in big sloppy kisses from each one of them incidentally.

We reached the Days Bay turn off and arrived at the old bait trap track (which has now been blessed, according to the old gentleman we met earlier). It took me back to my old tramping trips: twisted roots, narrow paths, thick, tangled semi rainforest and tree orchids. The hair do definitely took a turn for the worse in that section.

Once again we had our seat planned and, yes, you can guess, it was a busy day in those hills, so we sat in a cutting on the side of the track and fed on pre-cut and sun-warmed oranges.

We went down next into Butterfly Creek, a humid valley that gave way to rain forest with nikau, tree ferns the odd beech, rata and rimu and numerous vines. Just like the West Coast.

The next planned stop was vacant, shared only with biting mosquitoes and as we set out again I could hear younger, fitter people coming up the rear, laughing and jabbering as they trotted up the hill. My ego got into first gear and we tore off ahead to be first to the top, puffing. We left the seat to the younger ones and headed along the last part and there was our destination: the bus barns.

Our adventure was graced with glimpses of Wellington Harbour through the beech trees and beautiful views of distant, bush-covered hills. We seemed to be in the middle of nowhere and wondered who needed to cross the straight to the Marlborough Sounds when we have it all here. But we will soon, to collect a few more stories and pictures on the way.

It took us 5 ½ hours so we were thrilled and we thought of that elderly gentleman with a sparkle in his eye. Another day, we thought, we might do the return trip, with a sparkle in our eyes. We had a wonderful time!



### 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)