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Scleroderma

support group

newsletter

Another year, here's to the next

Greetings everyone and welcome to our last newsletter for the year.

Our latest meeting was fairly informal with not much business being discussed.

Everyone enjoyed chatting over a cup of tea and some very scrumptious food. It was good to see Tina and Alastair and their new addition, Ian, to the group. It was Ian's first public outing so how appropriate to go to his mother's scleroderma group meeting. We hope to see you a lot more Ian.

The new meeting premises are

proving most suitable for our group and we have pretty much settled in now.

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

Remember, if you have some adventures between now and then, or reach a health milestone, be sure to let us know so the group can share your achievement with you.

Our next meeting is in February 2012. The date will be confirmed in January and we'll let you all know.



Hutt Valley DHB combines rheumatology and cardiac wards

The Hutt Valley DHB writes to arthritis patients who use its facilities

Dear Rheumatology patients,

We are writing to let you know about some changes occurring in the Rheumatology Ward and Coronary Care Unit at Hutt Hospital.

Due to ongoing improvements in the treatment of patients with arthritic conditions, fewer patients are being admitted to hospital for treatment. Most rheumatology drug treatments can be given at home or through a short 'day stay' in hospital.

The Coronary Care Unit, who are on the same floor, have also had a reduction in patients admitted overnight and we have decided to combine the two units to allow more focus on managing our patients in the community.

From late September 2011, rheumatology patients who require an overnight stay will be admitted to the combined Coronary Care/Rheumatology Unit which will be located at the Coronary Care end of the 6th floor.

Please be reassured that you will continue to be admitted under the same Rheumatologist and a Rheumatology house surgeon and/or registrar will be providing your medical care as usual. We are not closing any services, just changing the way these are delivered.

If you are coming into the Rheumatology Ward for 'day stay' treatments, such as blood transfusions or some medication infusions please continue to come to the same Rheumatology area on the 6th floor of Hutt Hospital.

In July 2012, we are opening a new Endoscopy/Medical day stay unit on the ground floor, where the old Emergency Department (ED) used to be. Once this is open, all medical treatments (including rheumatology treatments) that can be delivered by a short 'day stay' in hospital will occur in this area from that time. Again, we would like to reassure you that your care will still be managed by the same clinicians you are used to; you will just be in a different area.

If you have any concerns please do not hesitate to speak to any of our Rheumatology staff.

Regards

Andrew Harrison
Clinical Head of Department

Lindsay Wilde
Medical Services Manager



Don't forget to look at Arthritis New Zealand's web site. They have lots of helpful information. For an example, go to 'about arthritis' and then treatment options and you will find some very good advice.
www.arthritis.org.nz

Correspondence

Members want to be able to email each other.

We need you, Scleroderma Support Group member, to email back so that we can draw up a list for others to contact you by email.

Your email will not be passed on if you do not email back or do not want to correspond with others.

You may want to share topics in addition to scleroderma, such as other interests or hobbies you may have in common.

Donations

Many thanks to Jocelyn Logie from Dunedin for her generous donation towards the ongoing costs of the website. It is most appreciated.

Next Meeting is February 2012. Date will be confirmed in January.

Enquiry

I have been asked if any of you have:-

1. A j-tube for feeding.
2. Incontinence or bowel trouble leading to bowel incontinence.

If any of you have either of these conditions could you please email me at Barbara@netco.co.nz so that I can pass the information on.

Thanks, Barbara.

Christmas meeting

As mentioned above, we had a successful end-of-year meeting, with food, chat and even secret Santa gifts.

The most precious gift stole the show, Alastair and Tina's new baby, Ian.

Ian came into the world after 29 weeks - 11 weeks early.

He's 3 months old now and the meeting was his first public outing.



Secret Santa for a day, Gordon grew a beard especially for the event, handing out gifts to those at the Christmas meeting.

Cushla and her Mum fish through goodies to choose as interesting looking one.



Shakira went for the girlie present.



Tackling the Bucket List.

Val Smith writes of her southern adventure

Time was running out for me to tackle the long list in my overflowing bucket. Too late to swim Cook Strait, climb Everest, or even finish my book. But this past year I've spent several days re-exploring historic Akaroa, Pipriki, Whangamomona, Lewis and Arthur's Pass, and haunting Deniston, all first hitchhiked as a student in 1951, then on my push bike in 1998.



Last July urgent eye surgery forced the "Milford Wanderer" to sail around Fiordland without me. This year she was in dry dock. So this July my daughter Dianne and I embarked on a 4 day adventure on the much smaller "Affinity". We almost didn't make it. Not through a medical emergency this time, but Nature. After a week of uncertainty, three days before we were meant to be in Te Anau, the Chilean ash cloud blocked our flight to Dunedin, so we booked on the night ferry and extra accommodation for 2 long days of driving. Mid-morning a crew shortage caused the crossing to be cancelled. The weather forecast was grim, I'd been denied travel insurance thanks to scleroderma, and though my brother bravely offered to fly us, he was naturally relieved that we plus all our adventure gear would not fit in his Cessna. Tears and tantrums in vain; once again my much-wanted trip was doomed.

Then, four hours before our 9pm non-sailing, a phone call; they'd found a master, we'd almost unpacked, and Dianne was a 2-hour drive away. Oh the joy and relief which gave us wings of our own, and by 9pm we were on board. Mentally and physically exhausted over all the drama, (Dianne had been working all day), we paid for a first-time luxury: a cabin! With a steward to fix the duvets and offer to wake us.

First stop after Picton and picnic breakfast was Kaikoura for the first of many magic moments over the next week. We scrambled up the track alongside the Kowhai Stream at Ohau and the first rapture. About a hundred baby seals



leaping and playing the in pool, diving from the rocks, cavorting around the pool, frisking near our feet. We could have stayed all day in that wonderland. We spent the night in a cute little Geraldine motel whose cheerful owner belied its name: "Grumpy's Place." He warned us about severe frost forecast for the Lindis Pass that night, an understatement, for next morning even the car doors were frozen solid, and the frost as thick as snow.

Conditions were marginal so progress slow, but who would want to speed through that magnificent country under a cloak of frost and sunshine and a backdrop of snowy peaks. Tekapo, the Passes and lakes, grand McKenzie Country, Whakatipu, the Kingston Flyer, and Te Anau in time for a quick walk by the lake before dark. Next morning our plans were again threatened: low cloud hiding mountains between Te Anau and our boat in Breaksea Fiord.

Our helicopter pilot reckoned he could make it. And for 50 minutes of rapture and occasional terror we wheeled and dived over incredible terrain till safely landing on a pontoon beside our boat. She was a joy. Only 22m long, with the entire top deck one compartment and 360deg. vision, the wheelhouse in the bow, then the cosy mess and tiny galley where Wendy the chef somehow created fantastic food, including the blue cod we caught. On deck were 3 "bathrooms," each smaller than the average house toilet, comprising shower, toilet and wash basin. Understanding the various levers and switches operating each was essential to avoid a sudden deluge while seated on the toilet! For one accustomed to a steep muddy

continues...

CONTACTS

Newsletter: Barbara Spavin barbara@netco.co.nz

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

Tackling the Bucket List *contd.*

scramble to the long-drop far from a bush hut or tent, and an aversion to hotels, these were another special part of our adventure.

Down a steep narrow staircase were 8 tiny double cabins; thanks to "sensible" people avoiding Fiordland in winter and thus only 4 passengers, Dianne and I had a cabin each. But we were far from lonely. Brian the skipper asked if we minded some of his family joining us; we were pleased, especially as all were sea-lubbers and his son a racing yachtsman. We did have reservations about the grandchildren, aged 6, 8, and 10, imagining noise and squabbles, but they were a delight. I overheard Grandma warn on our first night. "Now you know the rules: one foot wrong and you spend the whole time in your cabin." We all became great friends.

Words cannot describe the the haunting magic of Fiordland in winter, by far the best time to go. No other people, the forest all around as we sailed deep into each cove, the constant mist and above, towering snowy peaks. The utter silence and peace as Brian cut the engine, leaving us to drift, almost brushing the lush, ancient foliage, unchanged since Cook visited in 1769. The exquisite birdlife, dolphins and seals, especially the baby who greeted us warmly on one of our walks and tried desperately to board our dinghy as we left. The history – we trod on Observation Point where the explorers plotted the Transit of Mercury, saw the heroic, tragic efforts of Richard Henry to save the kakapo, and heard from Brian at night of incredible acts of bravery – and foolishness – over the centuries.

The 4-5 hours of open sea between Dusky and Doubtful were, as warned, very rough but exciting, and Gail our wonderful deckhand somehow kept upright while scurrying around with sickbags; we passengers were ordered to stay on our bunks. From glorious Dusky Sound, we later sadly, and in my case tearfully, bade farewell to dear little "Affinity," Brian our marvellous skipper and his wonderful family and crew, and that most magic, haunting place, Fiordland. Then unwelcome civilisation – bus trip over Wilmot Pass in swirling snow, the obligatory tour of the power station, exciting boat trip across Lake Manapouri, and Te Anau.

We had hoped to return to Picton via the same glorious Tekapo route next day, but snow had closed Lindis Pass and Milford, and opened ski fields. So, 14 more hours to Picton via Dunedin, Grumpy's Motel, another hour of joy

with the baby seals, and again among 60 passengers on the evening ferry that took 2 and a half hours to reach Wellington! Way to go, apart from missing the scenery, especially as ours was the first vehicle off and we were home in Belmont in 13 minutes. And in bed 5 minutes later.

This was a fantastic, happy week, well worth the initial travel dramas and health concerns. Most of us will be familiar with the latter. My GP washed his hands over my latest "crazy, unrealistic" dream to do this trip. Some friends and relatives agreed. But my children and their families, and those who really know me, were supportive. Dr Travers, respiratory specialist, was enthusiastic. "Do it," he urged. "Now!" Most of its success was due to my wonderful daughter Dianne, who took a week off work, drove 4 demanding winter days, and was repaid by a damaged Achilles tendon on that **stormy** sea segment. A bouquet too for skipper Brian, the boat owner, and his crew for accepting me on board. Ancient, partially sighted, with one near-useless hand, and a cocktail of medication for a cocktail of problems. What I had feared most, apart from falling overboard, was being made to feel a nuisance when groping, exhausted or fumbling. Or patronised. By well-meaning or irritable warnings: "Watch out for the step" or taking my arm when I could manage. I was treated like everybody else, all grateful for a helping hand when scrambling on rocky shores from the dinghy, and treated like everyone else: one of the family.

One item from the bucket, but guess what? Yes. Another has already refilled it.

Valerie W.Smith.



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