

- Welcome..... 1
- President's Report..... 2
- Lotions & Potions 3
- Tips For Summer 4
- Roundup 6
- Support Groups' Value..... 7
- Noticeboard 8

Scleroderma

New Zealand support group

Christmas issue

Greetings

Hi All and welcome to the last newsletter for the year. This year has just flown by, but we have had some very interesting talks at our meetings.

Our latest meeting was no exception because we had Maree Murphy talk to us about the good properties of herbs. You can read her story further down the newsletter.

It was also our Christmas-themed meeting and we had raffles, secret Santa gifts and a fabulous afternoon tea to share with each other.

A big welcome to Martine and Val, two new members from Palmerston North and Levin, it was lovely to see you.

Big thanks also go to Chris and Pam making it down from Palmy as well, with Martine too. It's a long way to come and we were happy to see you.

In the newsletter there is a report from the President Dianne Purdie.

The Mayo Clinic in the USA thinks support groups are just great and they describe the sorts of things that we have been experiencing as a group and give them all a big tick.

The days are noticeably warmer after a long winter and we have some tips that will help you cope with all that warm weather and sunshine.



President's Report - December

Seasons greetings to you all

We have some exciting news for December:

Kim Tocker, one of our members in Christchurch joined with Arthritis New Zealand to hold her second meeting in Christchurch.

Jan Ipenburg, a specialist Rheumatology Nurse from Christchurch Hospital, gave a talk about scleroderma, in general terms. She included a question and answer session.

Well done Kim. This is a big effort and I know that your work is very much appreciated by all who have attended.

Patients who belong to support groups and who take the time to attend support group meetings cope and feel better within themselves.

I have included some benefits of belonging to a support group later in the this newsletter. The advice comes from the Mayo Clinic.

Maureen Kirby our specialist nurse in Invercargill has been extremely busy and supportive of our cause.

Maureen produced calendars to help raise funds for Scleroderma, Arthritis New Zealand, Psoriasis New Zealand and Colitis New Zealand. This is a tremendous effort along with her busy full time position as specialist nurse and with a young family.

Maureen is very a dedicated nurse and is always there to help with any queries patients may have. Thank you so very Maureen for your exceptional commitment to scleroderma in New Zealand.

Scleroderma NZ Inc is developing well and I feel that we have achieved most of what we have set out to do this year.

We have the reprinting of the booklets on Understanding and

Managing Scleroderma under way, which is a little behind than expected but we are heading in the right direction.

That's pleasing and we'll all look forward to the New Zealand version in 2016.

New Zealand Post has donated a good number of prepaid envelopes.

This will help when we post our booklets to members and GPs who would like to receive printed copies of the booklet. That's a tremendous boost to our society.

Gordon and I had a meeting with Ken Scott, the representative for Acetelion.

Acetelion is the pharmaceutical company that manufactures the pharmaceuticals for **PAH**.

Acetelion has lost the contract with Pharmac for the drug Bosentan to a generic pharmaceutical company.

That means that Acetelion will not be able to help with funding to print the New Zealand edition of Managing and Understanding Scleroderma.

Ken has a wealth of knowledge of scleroderma and has offered us any new updates on patient information that comes his way, which is much appreciated.

I acknowledge all of the committee for a sterling effort in developing Scleroderma NZ Inc this year.

It's a remarkable effort from you all, knowing what you are all going through with this condition. And thank you to all of you for being members, you make Scleroderma NZ Inc.

Take care out there, have a very happy and healthy Christmas and New Year.

We look forward to lots of positive and helpful developments for you all in the coming year.

Dianne





Lotions and Potions - Naturally

Growing up on a traditional quarter-acre plot, eating home-grown vegetables and relishing weeding and gardening helped prepare Maree Murphy for her life as a herbalist.

Maree told the Wellington meeting that she began to take an interest in herbalism after her GP would tell her sometimes that he had no medicine to offer to counter a virus.

This was often the case as Maree brought up her 9 children, who all experienced the usual childhood ailments. Increasingly she wanted to discover more about natural remedies.

Maree has a BSc and is a former teacher so she has been thoroughly exposed to mainstream scientific theory. But herbs won out. Maree now runs a herbal medicine business, Heavenly Herbs, based in Lower Hutt.

Despite her studies into and belief in herbal remedies, she says she doesn't try to push patients away from researched medicines. But she says herbal products have few of the side effects that researched medicines have.

"I never say, 'don't take drugs', all I say is do investigate." She says she's seen a lot of conditions improve in people who use natural medicines.

As for the side effects, on her website, Maree gives the example of diuretics. Orthodox drugs require patients also to take a potassium supplement as their bodies lose it during treatment. But Dandelion leaves, a herbal alternative and effective diuretic, also contain potassium so there's no need for supplements.

Maree works with patients not just on their symptoms but looks at their lifestyle, diet and nutrition. She calls it part of helping them take responsibility for their own health. She concentrates on changing their nutrition, changing their



lifestyle and prescribing herbs. Maree says nutrition is very important.

"But if somebody's just going to eat chocolate and drink beer ... probably no amount of herbs is going to have any effect." Good eating, Maree says, is a diet rich in green vegetables and salads and wholemeal breads and grains.

At her clinic in Lower Hutt she has many clients with Raynaud's. She has found a mixture of genko and rosemary beneficial for them.

She's studied herbs and their effects and undertook study as she realised that some are very strong and can be dangerous in untrained hands. Maree advises anyone wanting to experiment with herbs to seek advice before diving in and risking eating something toxic.

In Maree's experience, the length of treatment required before a course of herbs takes effect is that for every year you've had a problem, allow a month on herbs.

Learn more about herbal medicine and Maree at:

www.heavenlyherbs.co.nz

Here comes the sun



After a long winter, summer is finally here. As we spend more time outdoors, it is important to protect against the strong summer rays.

Sunlight contains harmful ultraviolet rays that increase the risk of skin cancer, accelerate aging of the skin, and flare connective tissue disease.

Sunlight that reaches the Earth's surface contains two types of ultraviolet (UV) light, both A and B.

- UVB light is more damaging, causing sunburn and alters DNA in the body's cells.
- Sunlight contains about 10-20 times more UVA light, which penetrates the skin more deeply.

Both forms of UV radiation cause skin cancer and premature aging of the skin. Tanning beds also produce UVA and UVB radiation, often at much higher levels than the sun.

Sun protection is very important for people with connective tissue disease. Even for individuals with darker skin tones, sunlight can trigger disease.

- Lupus Erythematosus: Sunlight, both UVA and UVB, leads to a variety of symptoms ranging from skin rashes to internal organ damage, even weeks to months after exposure to the sun. UV light can trigger the butterfly rash of lupus and cause scarring in chronic lupus lesions of the skin.
- Dermatomyositis: Rashes in dermatomyositis arise in sun-exposed areas, such as the scalp, face, V-neck chest, and shoulders. These rashes can burn, sting, or itch.
- Scleroderma: Although certain types of UV light are used as a treatment to lessen skin thickening, some scleroderma patients are photosensitive and develop

rashes or sunburns quickly. UV light can also worsen the hyperpigmentation (darkening) of scleroderma skin.

Many medications make skin more sensitive to light, also known as photosensitizing. It shows up as sunburn or rashes after brief exposure to UVA radiation.

Common photosensitizing drugs include:

- Antibiotics (eg. Bactrim, Cipro, Levaquin, Doxycycline and other tetracyclines)
- Antimalarials (eg. Plaquenil)
- Blood Pressure Medications (eg. Diltiazem/Nifedipine, Hydrochlorothiazine)
- Immunosuppressant drugs (eg. Imuran, Methotrexate)

Some immunosuppressant medications like azathioprine and cyclosporine, used to treat connective tissue disease, may also increase the risk of skin cancer. These medications impair the immune system's ability to repair or destroy UV-damaged cells, allowing mutated DNA to develop into skin cancer.

Source: Isabela Wieczorek, MD , Horatio F. Wildman, MD
Department of Dermatology, Weill Cornell Medical College

[See full article.](#)



Martine, Linda and Chris prepared for the secret Santa at the November meeting. They made wheat bags for themselves and as gifts.

What is it about members from Palmerston North?



First, they drive two-and-a-half hours each way to attend the meetings in Lower Hutt. Then they win the raffle! Two of them!
Well done Martine and Chris.

Calendars fund-raiser

Maureen Kirby has been working very hard at fund raising for four conditions including scleroderma, with her great calendars.

These calendars are \$12.50 each.

You can order some by emailing Maureen Kirby at Maureen.Kirby@southerndhb.govt.nz.

Once you have deposited the money into this account

060501 001644 900

Maureen will post the calendars out to you.

Maureen has 125 more calendars to sell to reach her target so please help if you can. You will be helping with some very good causes. The calendars will make very good Christmas gifts.



Support groups: Make connections, get help

If you're facing a major illness or stressful life change, you don't have to go it alone. A support group can help. Find out how to choose the right one.



By Mayo Clinic Staff

Support groups bring together people facing similar issues, whether that's illness, relationship problems or major life changes. Members of support groups often share experiences and advice. It can be helpful just getting to talk with other people who are in the same situation.

While not everyone wants or needs support beyond that offered by family and friends, you may find it helpful to turn to others outside your immediate circle. A support group can help you cope better and feel less isolated as you make connections with others facing similar challenges. A support group shouldn't replace your standard medical care, but it can be a valuable resource to help you cope.

Understanding support groups

A support group is a gathering of people who share a common health concern or interest. It usually focuses on a specific situation or condition, such as breast cancer, diabetes, heart disease, addiction or long-term caregiving, for example.

Support groups are not the same as group therapy sessions. Group therapy is a formal type of mental health treatment that brings together several people with similar conditions under the guidance of a trained mental health provider.

Support groups may be formed by a lay person with the condition or by someone interested in it, such as a family member. In some cases, support groups may be formed by organisations like nonprofit, advocacy, mental health clinics or others.

Support groups also come in a variety of formats, including in person, on the Internet or by telephone. They may be led by professional facilitators — such as a nurse, social worker or psychologist — or by group members.

Some groups are educational and structured. For example, the group leader may invite a doctor, psychologist, nurse or social worker to talk about a topic related to the group's needs. Other support groups emphasize emotional support and shared experiences.

Benefits of support groups

Regardless of format, in a support group, you'll find people with problems similar to yours. Members of a support group usually share their personal experiences and offer one another

emotional comfort and moral support. They may also offer practical advice and tips to help you cope with your situation.

Benefits of participating in support groups may include:

- Feeling less lonely, isolated or judged
- Gaining a sense of empowerment and control
- Improving your coping skills and sense of adjustment
- Talking openly and honestly about your feelings
- Reducing distress, depression, anxiety or fatigue
- Developing a clearer understanding of what to expect with your situation
- Getting practical advice or information about treatment options
- Comparing notes about resources, such as doctors and alternative options

How to find a Scleroderma support group near You

Auckland: Allan Edmondson Email-
allanedmondson@xtra.co.nz

Hamilton: Linda Bell Email:-
linda.bell@hotmail.co.nz

Palmerston North: Chris Carlyon-
ningandalley@clear.net.nz

Invercargill: Maureen Kirby-
Maureen.Kirby@southernhb.govt.nz

Christchurch: Kim Tocker-
akaroakim@gmail.com

Wellington: Dianne Purdie-
diannepurdie@xtra.co.nz

New Support Groups

If you would like a support group in your area please contact Dianne Purdie 04 479 5548 or email diannepurdie@xtra.co.nz and I will be happy to help you set one up.

Spiced Christmas Cookies

A Christmas recipe

Ingredients

125g butter, softened
1/4 tsp vanilla essence
1 tsp ground cinnamon
1/2 tsp each: ground nutmeg, allspice
1/2 cup Chelsea Caster Sugar
1 egg, lightly beaten
2 cups flour
Decorate with Chelsea icing sugar, silver balls, glacé cherries etc.

Method

Preheat the oven to 180°C.
In a food processor, mix the butter, vanilla, spices and sugar, until light and fluffy. Add the egg and beat again. Add the flour to make a firm dough. Chill for 15 minutes in the fridge.

Roll out to about 5mm thickness and cut in shapes with Christmas biscuit cutters.

With a thick skewer, make a hole in the top of each biscuit large enough for a ribbon to be threaded.

Place on an oven tray and bake for 10-15 minutes, until lightly browned.

Decorate biscuits appropriately with coloured icing and silver balls - See more at: www.chelsea.co.nz



Noticeboard



Next Meeting:
February 7
see you there

Season's
greeting to all
members and
families

Contacts

Scleroderma New Zealand Inc.

President: Dianne Purdie
diannepurdie@xtra.co.nz

Newsletter: Barbara Spavin
barbara@netco.co.nz

Invercargill: Jenny Andrews
Ph 03 236 0068

Health contacts:
Southland Rheumatology Nurse:
Maureen Kirby
maureen.kirby@southerndhb.govt.nz

