

- Welcome..... 1
- World Scleroderma Day 2
- The Palmy Bunch..... 3
- Raynaud's 4
- US Research Money Found... 5
- What Is Sjögren's..... 6
- Noticeboard 7

Scleroderma

New Zealand support group

Winter 2014

5th Birthday Celebrations for Scleroderma NZ

It was our 5th Birthday on 2 August - how time has flown. A very good number of us braved the winter weather with Adrienne and Jan coming all the way from the Kapiti Coast. Kokila came all the way from Auckland. We all enjoyed Tina and Alistair's young lad Ian, who is a very happy three year old and we are all keen to be his auntsies.

We all had a very nice time where we told our story's about our journey with Scleroderma.

We all had a different stories to share, but it was very clear that we are part of a very strong sister and brotherhood, willing to fight the fight with the support of our families, friends and one another.

At the end Dianne suggested it would be good if all the Scleroderma patients in New Zealand were managed by a national vigilant monitoring protocol, something we can work towards in the near future.

Seminar 2nd of May 2015

Dianne has made enquires for a venue for a Scleroderma seminar on the 2nd of May 2015, to be held at the Hutt Hospital. Confirmation of this seminar and a list of speakers will in the November newsletter. This idea was met with great enthusiasm. Dianne would like to hear your ideas for the speakers. Email Dianne at diannepurdie@xtra.co.nz or phone 04 479-5548

Scleroderma NZ becoming an Incorporated Society

The idea of Scleroderma NZ becoming an incorporated society was raised. Members present thought that it would be worth pursuing. This will make fund raising easier and protect our members.

Dianne has sent out a draft of rules for all members to consider.

Happy Birthday

It's 5 years since a group with a common interest not to take scleroderma lying down met and decided a support group was the way to go. Here's to the next 5, and the next...



World Scleroderma Day Celebrated

It may seem a long time ago but it was only in June that World Scleroderma Day was celebrated. We had an enthusiastic gathering in Lower Hutt to celebrate the day with a photograph contest.



The photos that members shared showed that scleroderma hasn't completely taken over their lives. They showed some of us had been clambering around gardens and up banks in search of a perfect plant or bird picture, tramping or sitting quietly reading a book.



Smiles for the camera at our photograph fest to mark World Scleroderma Day

Palmerston North members put their fingers on the problem for World Scleroderma Day

"Us Palmy girls celebrated with a pamper day today - calling it 'Our World Sclero day pamper' " as Chris explains.

We started with pies from the great pie shop down the road from Linda's place and from there a manicure, paraffin wax treatment and polish. I must say my fingers tingled and felt super afterwards, quite a treat on a cold day! I know Maree was thinking the same :)

Our "Sclero day pamper" was held at Linda's place, and Linda was our therapist - she has a paraffin wax bath and all the gear for manicure and polish.



Both Maree and I just sat back and enjoyed a hand massage and then the waxing and last - the polish.

We were spoilt!

Chris was to attend her parents' 60th wedding anniversary a couple of days later at a family gathering and celebration, so she says she felt really smart with her nails polished and

painted, as it is something she rarely does.

Maree was looking and feeling relaxed as she had been shopping at Kathmandu and the hand therapy was a total bonus after an exciting time of shopping.

"We kept lunch simple and each took a plate and our wonderful hostess Linda brought some pies from the local pie shop, which tasted lovely and fresh, such a treat." :)

"I certainly would do it again and in fact have asked Linda if she would do the same for my niece's wedding in 5 months time!," Chris says.

"Lucky me, Linda said yes " :)



Raynaud's and winter bite in unison

Diane has plumbed the depths of the Raynaud's and Scleroderma Foundations to find helpful tips to look after ourselves until winter departs.

A Raynaud's attack often follows exposure to the cold, slight temperature changes or touching cold objects. Emotions, such as anxiety, may also play a part as can smoking.

Plan ahead and follow a few simple rules: wear suitable clothing and carry heating aids and you will be better able to keep warm in fluctuating temperatures.

Exercise

Learn a few basic, achievable exercises. Gentle exercise, such as walking or moving your arms and legs, even when sitting, will help stimulate circulation. Should the cold cause you to lose feeling in your fingers and toes, reheat them slowly.

At Night

Take the bedtime chill off with a hot water bottle or electric blanket. Wear flannelette night clothes, night cap, bed socks, gloves etc. Duvets are light and warm but use extra blankets during a cold spell. Thermal under blankets add extra warmth.

Clothing

Vanity has no place in the winter wardrobe: wear several thin layers of clothing rather than one thick layer, as air trapped between the layers will help to insulate your body. Avoid tight clothing so as not to restrict your blood flow.

Wear headgear, as your head sheds a considerable amount of heat. Keep your trunk warm to protect the major organs of the body.

Thermal clothing is excellent, especially long-sleeved and long-legged underwear. Natural fibres such as wool, cotton or silk will keep you warmer than most synthetic ones. A pair of thin cotton or silk gloves under thicker mittens or gloves add warmth. Wear a scarf to keep your nose, mouth and cheeks warm. There are face masks to give full face, neck and ear protection in the cold. Polo necks will help too.

Air conditioning

Wear a headscarf when in air conditioned buildings and on aircraft when the cold air blows around your neck.

Eating for Warmth

Your body needs warming 'fuel' to fight the cold. Start the day with a bowl of hot porridge or cereal with warm milk. Try to eat lots of small meals to maintain your energy and heat levels and whenever possible have a hot meal at midday.

Plenty of hot drinks between meals and before retiring to bed are essential. Keep a good supply of food in the house and eat plenty of fresh fruit and vegetables.

Good sources of protein and energy are bread, milk, meat, fish, eggs, potatoes and baked beans. Keep a pair of oven gloves by the fridge.

Attacks can be brought on just by going into the freezer or picking up a cold object.

When going out, microwave a couple of jacket potatoes then wrap in tin foil and put in your pockets. They will warm your hands warm then you can eat them when they cool!

In your house.

- Breathe in through your nose and out through your mouth when outdoors - this stops cold air being sucked in through your mouth and sent straight to your lungs. The nose acts as a filter.
- Use shoulder bags for shopping where possible rather than ones with handles as these can cause restriction of blood to the fingers.
- Make a delicious warming drink with finely minced crystallised ginger. Just add lemon juice, ginger and a teaspoon of honey to boiling water. It is not only tasty but will also help to boost the circulation.

Plan ahead

Make sure you have hand warmers with you.

Carry a pair of gloves or mittens with you at all times – frozen food aisles in supermarkets can be extremely cold, especially when handling food packaging.



US Research Funds Earmarked for Scleroderma

The US Scleroderma Foundation has achieved what it called its number one goal in this legislative session - access to federal research funds.

The Foundation's lobbyists have been badgering the Senate to include scleroderma as an approved condition that can receive research funds through the Department of Defense Peer Review Medical Research Program (PRMRP).

The Foundation's success in gaining approval opens an additional \$US247.5 million in federal funding for which scleroderma researchers may apply.

Much American funding results from paid lobbyists bringing issues to the fore in the minds of Congress and Senate members. The Foundation has encouraged its members to meet their local representatives to press the case for recognition of the need for research into scleroderma. It has also gone to Washington to lobby senators directly, with apparent success.

The rub-off for those of us in New Zealand is that the research should result in better knowledge for treatment and drugs to counter scleroderma's effects.

"This just shows that our approach to advocacy works,"

Foundation CEO Robert Riggs says.

"Our primary objective in the Foundation's advocacy work is to ensure that scleroderma gets its fair share of research funds available through Federal entities such as the National Institutes of Health and, in this case, the Department of Defense."

The Foundation is also seeking support from legislators to sponsor an Act to amend the Public Service Health Act to "expand, intensify, and coordinate" activities relating to scleroderma, with particular emphasis on scleroderma's causes and treatment.

It would also research the links between scleroderma and secondary conditions, such as pulmonary hypertension, gastroparesis, Raynaud's phenomenon and Sjögren's Syndrome.



Fighting Raynaud's and winter - one hint at a time

- Avoid cold surfaces and objects such as milk bottles.
- Wear insulated gloves when using the fridge or freezer.
- Don't have ice cold drinks straight from the fridge.
- In a car, take a flask of hot water or soup with you.
- Get children to wear plastic gloves over their woollen ones in the snow to keep their hands dry and warm.
- Ironing will warm you up. Metallised ironing board covers reflect heat and help to keep you warm.
- Warm clothes and shoes with a hair dryer prior to dressing.
- A hot bath before bed warms you and aids sleep. Leave the water in while you dress - it will keep you warm.
- Stop smoking. Cigarettes reduce the body's temperature by one degree over a twenty minute period.
- Use warm-air hand dryers to warm your hands when out.
- Store clothes and shoes in the airing cupboard overnight.
- The colour red signifies warmth and can make you feel warmer - red, glowing fires make you feel warmer than a fan or convection heater. Try a bowl of red flowers, a red lamp shade or bulb to add a warm look to your home.
- When watching television cuddle a hot water bottle.
- Fill a box with polystyrene packaging balls, and place your hands in it. This is a good way of warming the hands.
- Keep doors closed - leaving a door open to talk to the milkman or neighbour causes cold drafts.

What Is Sjögren's Syndrome?

Sjögren's (SHOW-grens) syndrome is an autoimmune disease in which the immune system turns against the body's own cells. Disease-fighting cells attack various organs, most notably the glands that produce tears and saliva (the lacrimal and salivary glands).

Damage to these glands causes a reduction in both the quantity and quality of their secretions, resulting dry eyes and dry mouth.

Technically, eye dryness associated with Sjögren's syndrome is called keratoconjunctivitis sicca, or KCS, and the symptoms of dry mouth are called xerostomia.

Your doctor may use these terms when talking to you about Sjögren's syndrome.

General Tips for Eye Care

Don't use artificial tears that irritate your eyes. If one brand or prescription bothers you, try another. Preservative-free eye drops are usually essential for long-term use.

- Practice blinking: You tend to blink less when reading or using the computer. Remember to blink 5 to 6 times a minute.
- Protect your eyes from drafts, breezes, and wind.
- Put humidifiers in the rooms you frequent, including the bedroom, or install a humidifier in your heating and air conditioning unit.
- Don't smoke, and stay out of smoky rooms.
- Apply mascara only to the tips of your lashes so it doesn't get in your eyes. Restrict eyeliner or eye shadow to the skin above your lashes, not on the sensitive skin under your them. Avoid facial creams on the lower lid skin at bedtime if you are waking with eye irritation.
- Ask your doctor whether any medications that you are taking contribute to dryness and how to overcome that.

The Importance of Oral Hygiene

Natural saliva rids the mouth of the bacteria that cause dental decay and mouth infections. Good oral hygiene is extremely important when you have dry mouth. Here's what you can do to prevent cavities and infections:

- Visit a dentist regularly, at least twice a year.

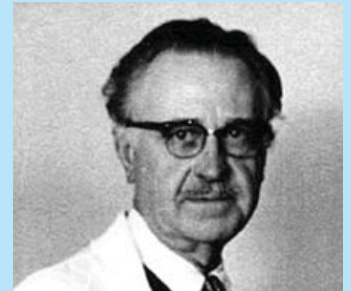
About that name

Henrik Samuel Conrad Sjögren was a Swedish ophthalmologist.

Sjögren received his medical degree in Stockholm 1927 and in 1933 published a doctoral thesis at Karolinska Institutet titled "On knowledge of keratoconjunctivitis" that eventually served as the basis of Sjögren's syndrome.

The syndrome had first been described in 1892 by Johann von Mikulicz-Radecki when he examined a 42-year old man.

Ninety per cent of cases reported affect women,



Henrik Samuel Conrad Sjögren

with most contracting it between the ages of forty and sixty.

In New Zealand there is a Sjögren's Syndrome support group.

See them at

sjogrensnewzealand.co.nz

- Rinse your mouth with water several times a day. Don't use mouthwash that contains alcohol, because alcohol is drying.
- Use fluoride toothpaste to gently brush your teeth, gums, and tongue after each meal and before bedtime. Nonfoaming toothpaste is less drying.
- Floss your teeth every day.
- Avoid sugar between meals. Choose sugar-free gum, sweets, and fizzy drinks. If you do consume sugary foods, brush your teeth immediately afterward.
- See a dentist right away if you notice anything unusual or have continuous burning or other oral symptoms.
- Ask your dentist whether you need to take fluoride

Another day on the web...

Username

Password

Remember Me

Please enter your new password:

cabbage

Sorry, the password must be more than 8 characters.

boiled cabbage

Sorry, the password must contain 1 numerical character.

1 boiled cabbage

Sorry, the password cannot have spaces.

50bloodyboiledcabbages

Sorry, the password must contain at least one capital.

50BLOODYboiledcabbages

Sorry, the password cannot use more than one upper case character consecutively.

*50BloodyBoiledCabbagesShovedUpYourNose,
IfYouDon'tGiveMeAccessnow*

Sorry, the password cannot contain punctuation.

ReallyAngry50BloodyBoiledCabbages-

ShovedUpYourNoseIfYouDontGiveMeAccessnow

Sorry, that password is already in use.

Noticeboard



Next Meeting
Sat. 8th
November

Proposal
Seminar 2nd of May
2015
Your ideas for the speakers please.

Sept. 20th
Don't forget to
vote!

Wanted!

Your news item about your experiences
and achievements living with scleroderma

