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Scleroderma

New Zealand support group

Summer 2016

Welcome everyone to the last newsletter for the year. We had a great meet for our end of year meeting and had scleroderma people from Auckland, the Wairarapa, Kapiti Coast, the Palmy ladies, and a few from Wellington.

We had a great chat, a delicious afternoon tea, and many thanks to Adrienne, who made us all an edible reindeer.

In this newsletter we have a report from our President, Dianne. Also, we have an article from Pam who talks about living with Coeliac Disease. She also has a recipe and you can contact her if you have any more questions, or just want to chat about this disease. There is a piece on new research and clinical trials for scleroderma. Barbara has a piece on getting travel insurance, and there is an item on coping with the summer heat.

We hope you are coping well with the earthquakes. Pretty scary really. If it isn't earthquakes, then the rain.

We are having a seminar in Wellington next May and would like your input as to who you would like the guest speakers to be. Let us know what else you suffer from besides scleroderma and we can get someone to speak about that. For example if you have Sjogren's syndrome, psoriasis, digestive problems, etc. This will help us so we can help you.

Wishing you all a very happy Christmas, and look forward to catching up in the New Year.



President's Report November

Seasons greetings to you all, it isn't long now before we are all rushing around to get our last minute jobs done before we head off to get together with family and friends or just have a quiet one at home.



We have had a busy time here in Wellington with the printing of the booklets which have now been sent out to those of you who have requested them.

It has been a long process and one we couldn't have managed without help from our hard-working fund-raisers:

Linda Bell,

Allan and Sandy Edmondson and

Our Specialist Nurse Maureen Anderson and all of you out there that have sent in very generous donations for the printing of these booklets.

It is something that our families, medical teams and ourselves will benefit from.

We printed 1500 copies, which totalled \$3,969.80

The editing process was a team effort from Maureen, Gordon and myself and much was learnt particularly by me with the whole process.

All the rheumatology clinics will receive copies of the booklet with the opportunity to ask for more.

The hospital check lists are our next top priority, we hope to send them before the year ends.

I hope you all are looking after yourselves, and if you could, write to me with any thoughts in which Scleroderma

New Zealand could help you and others in our group please just send me an email at diannepurdie@xtra.co.nz.

Ideas could be in the area of support for you, whether you would like someone to contact you regularly or something that Scleroderma NZ Inc may be able to supply that could be of help.

If you have any concerns about your treatment plan please feel free to contact me also, I may be able to help you in some way.

One of our long-term goals of this society is to make sure there is equality, with monitoring and treatment plans throughout New Zealand. I will be working towards this from 2017, in conjunction with specialists.

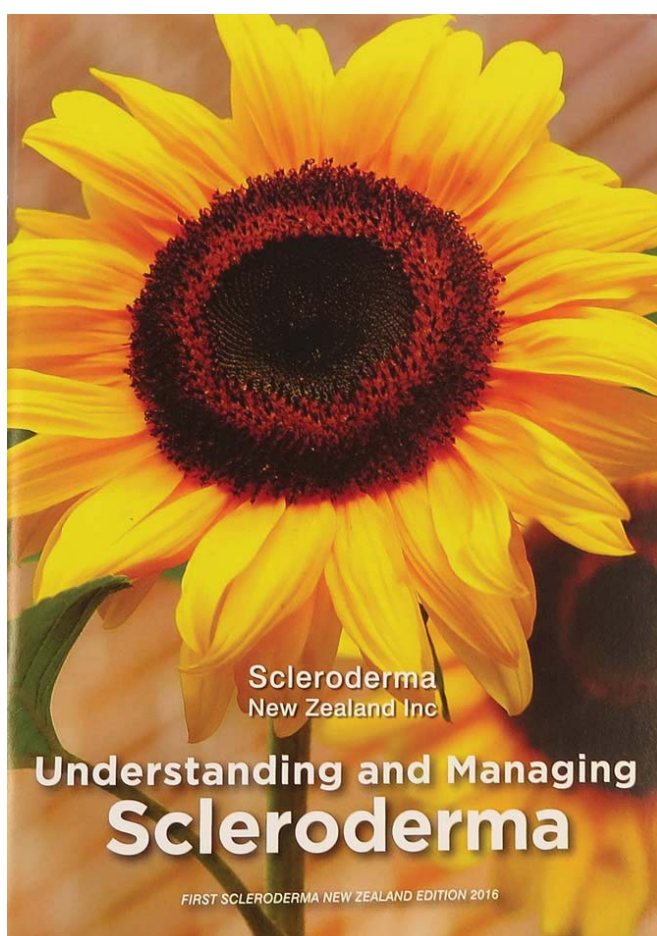
Further on in this newsletter, you will find out what is happening in Australia with the different types of scientific trials for systemic sclerosis.

By the time you read this newsletter Linda Bell will have had her seminar in Hamilton. Linda has worked hard at getting this together, and I am sure you would all have enjoyed and benefited from the seminar. A big thank you to Linda for all her effort.

It takes many hours to produce each one of these newsletters, so a big thank you to John and Barbara for donating so much of their time and effort to reach out to you all out there, we all appreciate and benefit from the contact.

Take Care to you all, and thank you all once again for all your support in getting the booklets out there for good use.

Dianne



Coeliac Disease - finding support

Scleroderma NZ member, Pam Dempsey, has coeliacs. here's how she copes.

I was diagnosed with coeliac disease nearly 20 years ago and a few years later with scleroderma and then later became dairy intolerant.



Way back then it was difficult to be on a gluten-free diet as there was very little help available and the Internet was not an option for help.

These days it is so much easier as Coeliac NZ (Auckland) is an amazing

organisation that provides an excellent service to those with coeliac.

There is a wonderful website providing coeliacs with so much information in every way. There is plenty of information these days on the Internet.

There are also support groups throughout New Zealand who have local co-ordinators (I am the Manawatu co-ordinator).

Our role is to contact with newly diagnosed coeliacs and give them the support and help they require. We have frequent support-group meeting, a great way to chat, learn and share, especially with the newly diagnosed. If you are looking for some support or help, see website www.coeliac.co.nz or email admin@coeliac.co.nz and we'll help! Coeliac NZ publish a very good magazine with recipes, hints and new foods.

The range of gluten free food in supermarkets / organic stores these days is amazing. And when shopping the labelling / codes are clear and easy to understand if the product is gluten free. Reading labels is essential.

If you are not sure of the gluten content of any food, use the general rule 'if in doubt, leave it out'!!! It's so much easier than years ago. It can be challenging at times if you're invited to a friend's home for a meal or eating out. However, you usually find that cafés and restaurants offering gluten-free food are safe places to eat at with no cross-contamination.

There are lots of eating places now and your local area coordinator can help you find your local ones.



Coeliac disease is a permanent intestinal intolerance to dietary gluten.

In Coeliac disease the lining cells of the small bowel (intestine) are damaged and inflamed. This causes a flattening of the tiny, finger-like projections, called villi, which line the inside of the bowel. The function of the normal villi is to break down and absorb nutrients in food. When these villi become flat in coeliac disease, the surface area of the bowel is greatly decreased which interferes with the absorption of nutrients and minerals from food. This may lead to deficiencies in vitamins, iron, folic acid and calcium. Sugars (such as lactose), proteins and fats are sometimes poorly absorbed as well. Around 1 in every 100 people in NZ has coeliac disease.

Coeliacs are sensitive to gluten, the protein portion of wheat, rye, barley and oats. This reacts with the small bowel lining damaging it and causing loss of the effective absorption surface area of the villi. Coeliac disease is treated by a life-long gluten-free diet. Coeliacs will remain healthy so long as they adhere to a gluten free diet.

Scleroderma Research Clinical Trials

Recently I had an enquiry asking for information on clinical trials in New Zealand and Australia. Gordon sent me to a clinical trial registry called the Australian New Zealand Registry (ANZCTR) on line: www.anzctr.org.au/BasicSearch.aspx

There are no trials in New Zealand on this register but there are a number in Australia, some of which they are currently recruiting for.

There are drug trials to test the efficiency and safety of Ambrisentan for pulmonary arterial hypertension (PAH). The trial will also evaluate the effects of Ambrisentan on other clinical measures of PAH, long-term treatment success, and survival.

They are trialling another PAH drug: apixaban, an anticoagulant, hoping that it will lessen the possibility of clot clots in the lungs. The 3-year study will be double-blind, placebo-controlled. It includes quality-of-life measures and health resource use.

Another one for PAH is nuclear perfusion tomography for the Assessment of the Pulmonary Circulation.

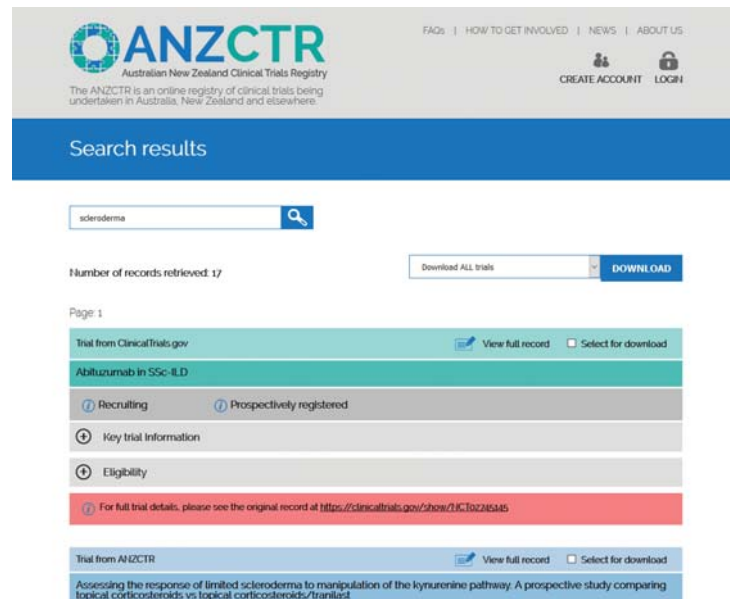
There are currently no widely available imaging assessments for blood flow to capillaries in the lung, which is decreased in PAH. Single photon emission computed tomography (SPECT) uses nuclear medicine to assess flow three-dimensionally. They wish to evaluate SPECT's usefulness to assess and detect PAH. Recruiting hasn't started.

There is also a study to investigate the effect of bosentan on pulmonary artery remodelling in PAH. It will investigate whether bosentan (Tracleer®) affects the wall thickness of the pulmonary arteries in patients with PAH of unknown cause and PAH related to systemic sclerosis. Recruitment has not started.

For patients with limited scleroderma there's a study to find responses to genetic disorders. It compares the effects of steroids that the body produces with introduced steroids and tranilast, an anti allergic drug, which inhibits collagen synthesis.

The trial compares the safety and efficacy of tranilast in localised scleroderma. The drug has a good safety record and has been available in Japan and Korea for 20-30 years. It has approval for the management of skin scarring in those countries.

The trial involves testing a corticosteroid cream on one affected part of the body and a second cream containing both corticosteroid and the trial agent on another for 3 months.



I found details of a study into the effect of gloves in combination with traditional Thai massage, heat, and stretching to improve hand mobility in scleroderma patients. Recruiting is complete on this study.

For Raynaud's there is Oral N-acetylcysteine in the Treatment of Raynaud's Phenomenon Secondary to Systemic Sclerosis: a randomised, double-blind, placebo-controlled clinical trial,

For severe cases of systemic sclerosis there is a study of the safety and efficacy of stem cell transplantation (HSCT) for severe auto-immune diseases. Many of auto-immune diseases, including scleroderma, resist available therapies. The study will try to find whether HSCT may work for them. Patients assessed for suitability undergo procedures that include chemo and immuno-suppressive therapy, followed by stem cell re-infusion.

There is also a review of past HSCT on patients with severe systemic sclerosis and rheumatoid arthritis. The trial aims to assess its safety and efficacy. HSCT is reserved for patients with severe disease who have failed multiple previous therapies.

Evidence suggests HSCT may help suppress the inflammatory conditions and perhaps re-educate the immune system, especially, the thymus. As well as assessing HSCT's success, the study will assess whether the thymus has a role to play in those who respond. They are currently recruiting.

All in all it is good to see that there are a few trials happening close to home and it will be interesting to see the outcome.

Dianne

Insuring yourself for travel - the hardest part is being believed

Barbara's battle with bureaucracy

I was excited about going away. With such a lot to do I thought I would get a start and apply for travel insurance.

Insurance is always hard when you have many health issues. We knew an insurance agent so rang her for advice. She put us in touch with an insurance company who dealt with travel insurance, as her's didn't. Ringing the 0800 number I had to answer 50 questions the operator had lined up for me. I also sent scans of two of the latest medical reports: one from my GP and the other from my specialist rheumatologist. All went well, and I answered the questions as best I could.

The next day, the woman I had talked to from the insurer rang back. She had been reading my doctor reports and lambasted me for not disclosing that I had been in hospital recently and or that I had autoimmune hepatitis. I tried to explain the reason I didn't disclose those things was because I had not been in hospital recently and I did not have autoimmune hepatitis. However, with her Gestapo training she knew best and wanted me to prove that these things were not true. I had to get more reports from the doctors concerned.

Knowing that if she couldn't read the reports already in front of her, she was not likely to be able to interpret the next lot either. I didn't know what to do so I contacted my two specialists and asked if they could write stating that what

Gestapo thought I was lying about was in fact incorrect. More phone calls from Gestapo lady at the insurance company: I was getting pretty stressed now and decided to take a step back from everything. I talked to others who had travelled and then I decided I'd seek another insurance company.

If you get 'red flagged' from one insurance company you have to declare that for any future insurance companies you deal with. I didn't want that, especially as it wasn't true, so I rang the travel agent I had used to buy the tickets, filled out a questionnaire on line, got a number, emailed the agent back with the number and WHAMO insurance covered!

A few weeks later I decided to write back to the original insurance company telling them why I decided not to go ahead with their insurance. The chap I spoke to listened to their internal recording of calls between Gestapo and me and agreed with me that 'things could have been much better'. I suggested Gestapo get more training on reading reports, sent him the copies of my letters from the specialists proving I was not lying and am happy I went elsewhere.

Now I am packed, insured and determined not to take crap from clipboard-wielding and poorly trained inquisitors again. I'll let you know how I get on when I get back.

Company not to go with: Allianz

Company to go with: FlightCentre



Understanding and Managing Scleroderma 5th Seminar

19th November. Booking essential

Venue	St Johns Methodist Church Hall cnr Grey Street and Wellington Street, Hamilton East.
Parking	At rear of building
Time	8.50 - 3. 30 pm. Registration \$ 10 - payable on the day
	Morning tea and time to chat with others on arrival.
9.30 am	Introduction Linda Bell Trevor Fredericks , Arthritis Educator Hamilton.
10.am	Registrar waikato Hospital
10.20	Anna Schollum Rheumatology Dept.
10. 45	Dr. Solanki Rheumatology Dept
11.45	Life Unlimited, plus display table.
LUNCH	

Helen Morton

Waikato Community Pharmacy Group

Raffles drawn - Afternoon tea

Sue Henderson

Waikato Community Dietitian

Please e mail Linda Bell linda.bell@hotmail.co.nz or Ph 07 8535434 for more details.



Coeliac Mini Christmas Cakes

Pam Dempsey's, Christmas recipe for those needing a gluten-free treat

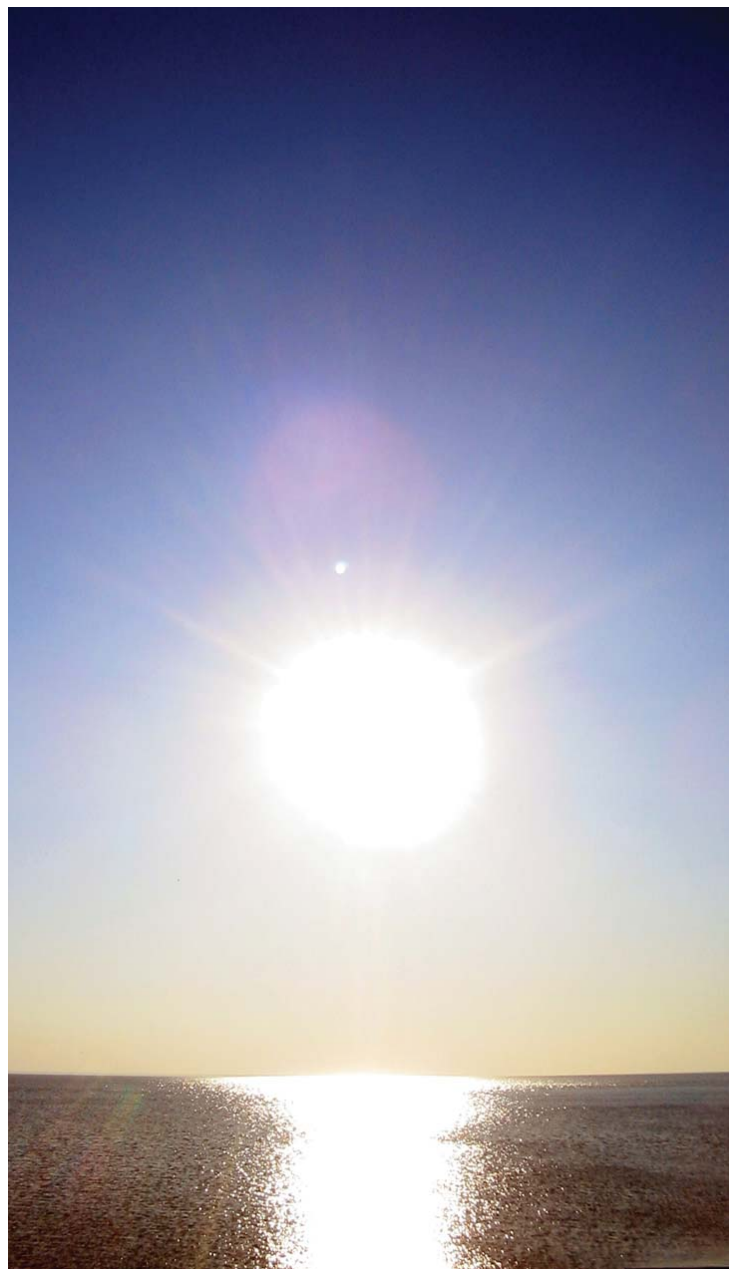
50g	butter softened (or if dairy intolerant use dairy free margarine)
1/4 cup	firmly packed dark cane sugar
1 egg	
1tsp	vanilla essence
1tbsp	rum essence
1/4 cup	Edmonds gluten free self raising flour
1tsp	mixed spice
1/2 cup	chopped dates
1/4 cup	currants
1/4 cup	raisins
1/2 cup	chopped mixed nuts (such as almonds, Brazil nuts, pecan nuts)

- Heat oven to 150 degrees
- Place butter and sugar in a bowl and beat until pale and creamy.
- Beat in egg, vanilla and rum
- Stir in sifted flour and spice, then stir in dried fruits and nuts.
- Spoon mixture into mini paper cases (Mrs Rogers)
- Put paper cases into mini baking muffin tray.
- Decorate as desired.
- Freeze well.

Coping with Summer Heat

Some tips for summer from the US Pulmonary Hypertension Association for keeping cool when all around you are feeling the heat.

1. Remember that chronic illness interferes with your ability to tolerate heat. The body cools down by increasing heart rate, breathing rate and sweating. Medications can alter the body's response to heat and ability to cool down.
2. Talk to your doctor before summer to make sure your health condition is at its best. Monitor your symptoms and call your doctor if you have weight loss or increased light-headedness, headaches or nausea. Water pills and fluid intake may need to be adjusted if you are in the heat and producing more sweat.
3. Pay attention to weather reports. Plan outside activities around the forecasted temperatures and heat index.
4. Move your outdoor exercise activities inside to a location with air conditioning. Run errands early in the day or late in the afternoon. Be sure to avoid peak temperatures. Never sit or rest in a parked car or enclosure where temperatures can soar.
5. Take a cool bath or shower. Lounge in a pool. Dip your feet in a tub of cool water.
6. Carry an umbrella or floppy hat for instant shade.
7. Wear cotton, loose-fitting clothing. Wear lightweight socks and shoes or switch to sandals.
8. Cool off with a fan — even outdoors.
9. Place ice on your wrist at the pulse site or a damp washcloth on your forehead or neck. Cool your skin with a mister or damp washcloth.
10. Use air conditioning and keep your blinds closed during the day. Even at higher temperatures, air conditioning takes the humidity out of the air, making it easier to breathe. If you don't have air conditioning, go to a mall or library or friend's home.



By Traci Stewart, RN, MSN

University of Iowa Hospital
and Clinics

Final Meeting For the Year



Final Meeting For the Year



We had a good discussion about living with scleroderma at the meeting. Here are some of the thoughts:

Doctor are human too. They put their trousers on one leg at a time - just like you.

Keep a diary. Give it to the doctor. "Here's what's been troubling me."

Does your partner over-compensate for your illness? Tell them if they fuss too much. They probably don't even know that they're doing it.

You can take a support person with you when you go to see a specialist. That will help you remember what the specialist tells you about your illness.

You can change a doctor who you feel is not taking you seriously or treating you as you'd like.

Be positive. You are a person first. You happen to have scleroderma but you shouldn't let that define who you are.

How about saving your medical details, medications and other documentation on a USB stick and carry it around your neck on a chord when you're out. It's a cheap Medic Alert and will inform doctors.

Be positive. It's easy to say but don't look too far into the future to worry about the unknown. If you worry a lot about something years away, remember a bus may hit you tomorrow.

Buddy up. Don't suffer alone. And you become your buddy's support.

Christmas Recipe

Cranberry Christmas truffles

- 1/2 cup dried milk powder
 - 4 tbsp brown sugar
 - 2 tbsp cocoa
 - 1 cup sultanas
 - 1/2 cup sweetened dried cranberries
 - 4 tbsp milk
 - 2 tbsp butter
- cocoa and icing sugar,
to coat truffles

Tips

Make the same truffle and roll in coconut for a taste sensation that's just as good!



Steps

1. Place the first 5 ingredients in a large bowl.
2. Heat the milk and butter together very gently until the butter melts. Do not boil.
3. Pour this over the cocoa mixture. Mix well together.
If the mixture is too weak, add a little more milk powder.
4. Roll into small balls, about walnut size – these truffles are rich. Roll them in the additional cocoa or icing sugar and then gently cover.
5. Store in the fridge in an airtight container to be eaten when desired.

See more recipes at: www.foodtolove.co.nz

Bloke walks into a bar with a newt on his shoulder.

The barmaid looks at the creature and asks the man what he calls it.

"Tiny" answers the bloke.

"Why's that?" The barmaid asks.

"Because he's my newt" replied the bloke.



Noticeboard



Next Wgtn
Meeting:
Saturday, 11
February

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: Heather Milligan
03 248 5147

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.

Contacts

Scleroderma New Zealand Inc.

President: Dianne Purdie

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Newsletter: Barbara Spavin

barbara@netco.co.nz

Invercargill; Jenny Andrews

Ph 03 236 0068

