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# Scleroderma

## New Zealand support group

## Summer 2017

Greetings to you all.

In this month's edition we have a good line up of news. We start with the President's report. Dianne keeps us up to date with what's happening around the country.

We also have the sad tale of Callan and his struggle with Scleroderma. You can read this report his struggle and the support offered by Ann and Michelle in Auckland.

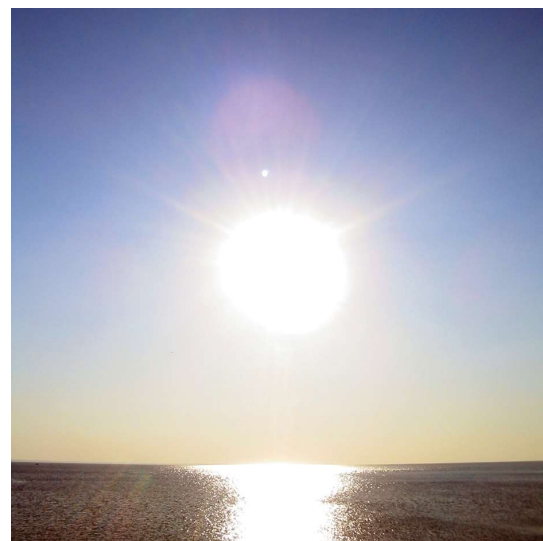
A good article offers help to cope with fatigue. Something we all must be aware of during this busy time of Christmas.

Rob, sent in a story about an interactive website he uses, where people with scleroderma can exchange ideas and get help with symptoms that bother them a lot. He has some good examples of this and a website we should all look at. It is good talking to someone who suffers the same things you do.

Chris sent her very delicious recipe for ginger crunch. I know it is delicious because I have tried it! A great thing to do when we have a bit of down time over the Christmas break. It will be on my holiday list.

Lots of good pics coming in from our groups around the country celebrating Christmas and birthdays. Happy birthday Chris. Please send us your pics from your Christmas activities or holiday fun to include in next year's newsletter.

Wishing you all a very happy Christmas. Have a safe and peaceful yuletide season and see you all again in the New Year.



# President's Report

November 2017

This year has gone by very fast. The weather has been quite difficult to contend with so I hope that you all have managed to cope well and look after yourselves, and now for our fabulous summer.

Our membership is growing, and we hope to be able to help as many people as possible with support. We just need to hear from you if you need some assistance in any way.

Our regional groups are coming along well, from Invercargill to Auckland and in between. Our members are supporting each other in these groups on various levels, catering for their groups needs.

Gordon and I are still chipping away at getting improved health care for all of our Scleroderma community here in New Zealand.

Renal Crisis cards are being considered by the rheumatologists presently, and also a possible GP management health-care plan along with a New Zealand hospital check-list. These are currently being considered and checked by Dr Grainger.

We have World Scleroderma Awareness Month coming up next June 2018, so we are thinking of how we can raise more awareness for the New Zealand Scleroderma community.

On a closing note, many thanks to all the Scleroderma NZ regional groups, you are all doing a fantastic job caring for each other, it makes a huge difference in each and every one of us.

We have made some fantastic long-lasting friends, and also once again a huge thank you to our Media team, Barbara and John Spavin for the web site and newsletters and Cushla Marsters for the Scleroderma NZ Facebook page and to the rest of the committee for all their input



this year, all much appreciated.

I hope you all have a Very Merry Christmas and a Happy Healthy New Year and for those of you going through some very tough times at the moment, I wish you the very best and I hope you are getting the best in health care and please don't hesitate to contact us for support if you would like it.

Kind Wishes

**Dianne and Gordon**

04 479 5548





# The sad case of Callan Fabian

## Auckland support group member, Callan, succumbs to scleroderma

The dramatic extremes of scleroderma were brought to the public stage when newspapers covered Callan's plight.

Diagnosed 10 years ago, Callan's scleroderma worsened over the past 3 years. He died on 16 November.

Callan, 44, was living in a Glen Eden retirement village. An RSA volunteer, Ray Farrell, visited him daily. He was personally paying for some of Callan's needs.

Auckland Scleroderma Support Group members, Anne Wills and Michelle Helleur, started a Give A Little page on 8 November for Callan, a member of the group. To say it took off is an understatement. The fund-raising was to provide for Callan's everyday living, including transport and visits to his specialist.

When the appeal closed on Callan's death, donors had pledged nearly \$24,000. The intention of the fund-raising was to care for Callan, with any excess being passed on to the Auckland group.

Ann and Michelle say local members were saddened by Callan's death. They'd expected he might last until Christmas but they'd given him an early Christmas present and donned Santa hats to celebrate it. She was saddened to see the only medications he was on were painkillers and sedatives.

Callan's ordeal made news here and abroad, unusual for this rare disease. The John Hopkins Scleroderma Centre's Facebook page also carried it.

Lessons from Callan's plight are that support groups can help people find specialised help. The shared experiences of group members, each dealing in their own way with the disease, can create shortcuts for the newly diagnosed. In Callan's case, scleroderma was too far advanced but each year more New Zealanders receive a diagnosis of scleroderma. Ann says it's a shame he didn't seek us out earlier, as we may have been able help him find appropriate medical care.

If publicity about Callan's sad demise lets them know that others who share their experience can offer support and companionship, then that will work to preserve memory of him.

Ann says many people have contacted her group because of the publicity. Most didn't know there were support groups.



Auckland Support Group member, Ann, at Callan's last Christmas celebration

"Callan would be proud of that as awareness is the one thing he really wanted to help with," she says.

Ray, his volunteer carer, wants to continue raising awareness on Callan's behalf and will become an honorary member of the Scleroderma Auckland Support Group.

# Fatigue and scleroderma

The Johns Hopkins Scleroderma Centre has published a series of guides on coping with scleroderma.

The following is an extract from the chapter on dealing with fatigue.

Fatigue often develops gradually in Scleroderma. You may not notice how tired you are until someone else points it out to you or you find you can't do many of your old activities.

## Don't blame yourself

It is wrong to think of fatigue as a personal weakness, a failing or a sign of laziness or a lack of motivation to get things done. Blaming yourself for fatigue just adds to the problem.

Fatigue is hard to treat. There aren't medications that will return your old energy. But there are some things you can stop doing that might be making your fatigue worse.

Before you had Scleroderma, running a home and a full-time job may not have been enough to make you tired. You may find now that balancing work and family leaves you exhausted. Even doing a couple of loads of laundry and making lunch can leave some patients very fatigued.

## Know your limits

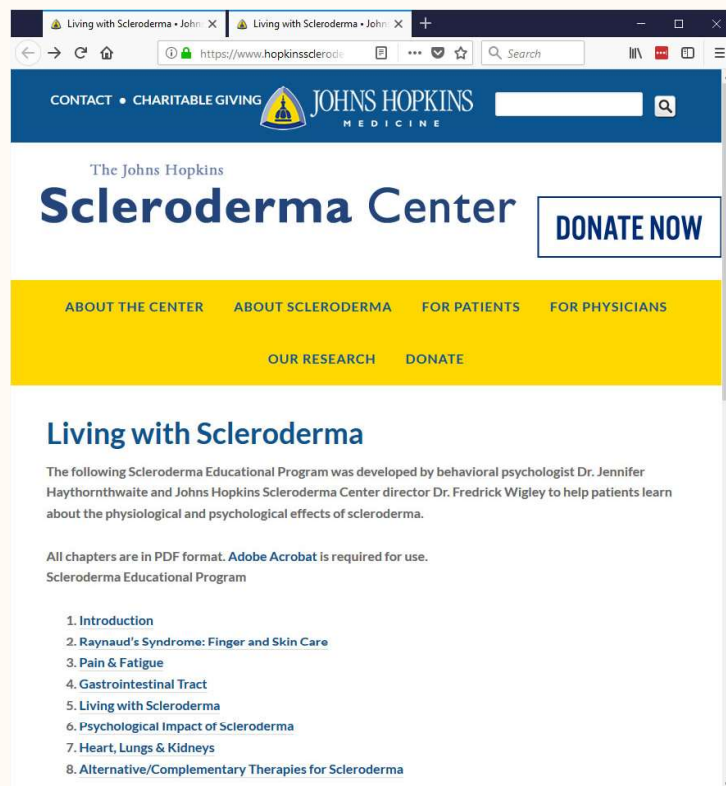
Know your limits and work within them so that you can gradually increase them. You must be careful not to overdo it when you are beginning to feel good again. This can cause fatigue or more pain.

Too little activity can make fatigue worse. A nap can help fatigue but staying in bed all day may make it worse. A physical activity program may help you feel more energized.

## Sleep

Think about your sleep habits. If you often feel fatigued you may want to consider your sleep habits. Not getting enough sleep or having poor quality sleep can add to your fatigue.

Your diet and nutrition is important. We can feel fatigued if the fuel we take in isn't top quality or in the right amount. Being overweight can add to fatigue for some people. Extra weight causes you to use more energy to do your daily tasks.



The full series is available to download from the Johns Hopkins website.

They are linked from this page:

[www.hopkinsscleroderma.org/patients/living-scleroderma/](http://www.hopkinsscleroderma.org/patients/living-scleroderma/)

Note that they are all PDF files. The various documents cover:

1. Introduction
2. Raynaud's Syndrome: Finger and Skin Care
3. Pain & Fatigue
4. Gastrointestinal Tract
5. Living with Scleroderma
6. Psychological Impact of Scleroderma
7. Heart, Lungs & Kidneys
8. Alternative/Complementary Therapies for Scleroderma

# Inspire!

Rob Tomkies finds useful information on the web, sharing information and experiences with people who live with scleroderma

A member of the association suggested that I look at [www.inspire.com](http://www.inspire.com)

I duly viewed, subscribed with a discrete user name and selected the items of interest.

The site is a worldwide chat and communication forum. Most members seem to be based in the US but there is a good smattering from right across the globe. A lot of subscribers are wanting support or to confide with other sufferers of the same malady.

But interspersed with the comments offering support and prayers are some real gems of interest. There are a few really experienced people (Choclit and Crunkie), who have had Scl for many years, who offer great insights and help.

I have viewed daily for at least 2.5 years, spending maybe 5 to 10 minutes per day on the task. I have given some advice to some sufferers that has been appreciated. The one that sticks in my mind is the Celiac who knew all about gluten-intolerance but whose doctor suggested that she use bananas as her staple food.

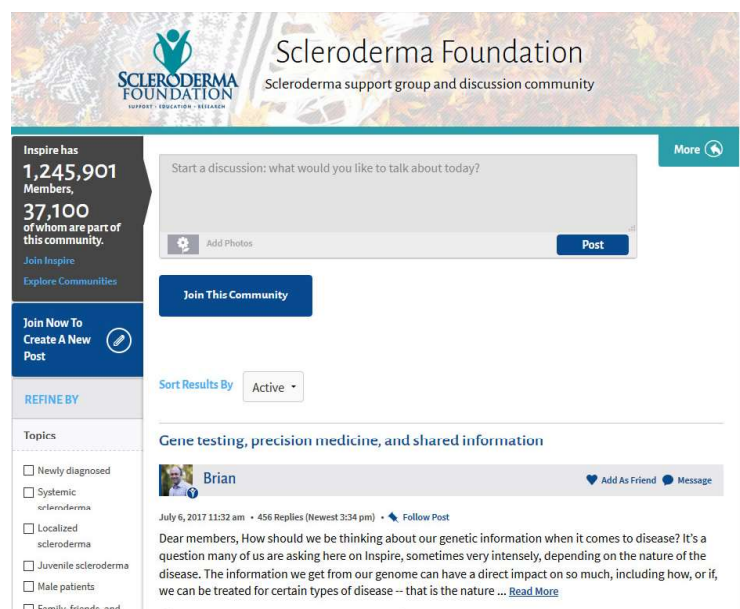
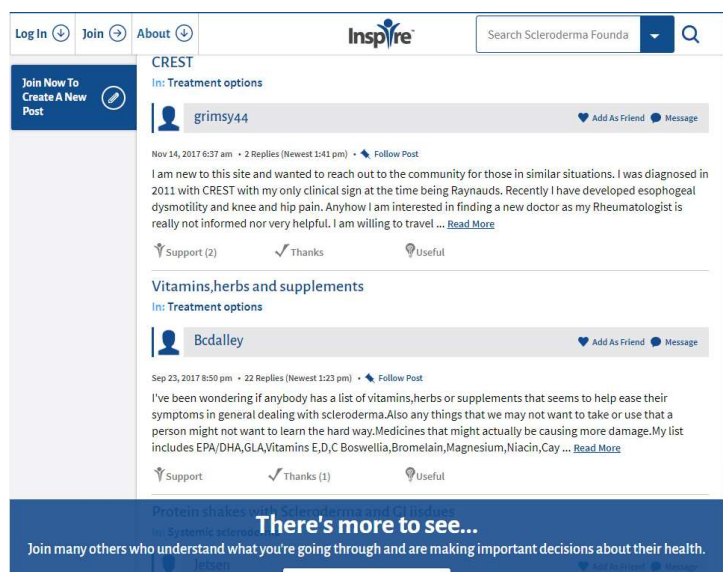
Her symptoms remained the same (constant diarrhoea etc.) until I told her that bananas have an enzyme that replicates gluten. She stopped eating bananas and the next day, for the first time in 10 years, felt sufficiently confident to visit her local supermarket.

An advantage that I have gained is reading and absorbing comments about anti-biotic protocol (A/P). A lot of informal comment and some very good advice and leads to official sites from experienced subscribers. That and some Googleing led me to conclude that there is merit in trying the A/P. I have taken 50 mg of minocycline per day for 6 months now and the improvement in my health has been dramatic.

I saved and printed the better contributions about A/P on Inspire to convince my doctor to get the drug funded and prescribed for me. I have good reason for great thanks to all the subscribers to [www.inspire.com](http://www.inspire.com)

I highly recommend that you have a look at [www.inspire.com](http://www.inspire.com)

Wishing you the best, **Rob**.





# Hamilton's Christmas Plans

Linda Bell reports from Hamilton

As it is the festive season I would like to wish everyone a Merry Christmas and Happy New Year.

We hope the warmer weather will make us feel better as it's been a long, wet winter, My Coffee Group and myself are going to Allan and Sandy's Xmas Break up on the 25th. It will be great meeting other auto immune members.

As for next year, yes there will be a seminar no details as yet but we will work on that next year.

Coffee Group will meet in February 2018.

Linda Bell Ph: 8535434



Hamilton coffee group on World Scleroderma Day.

## Southland Scleroderma get together.

We met up on Sunday the 12th November for lunch.

Thank you so much to Jenny Andrews for organising us and the venue in Winton. We welcomed Beverley, recently diagnosed, and her partner Gerard.

Jenny has listed those of us with Scleroderma and Beverly brings the number 25 in Southland who have contacted Jenny.

One member described how both her and her doctor were unable for many months to make an urgent specialist appointment at Southland Hospital, when she felt unwell. When she finally did see the rheumatology nurse, she was immediately put in hospital and diagnosed with PAH, not a good outcome. As we noted in the previous newsletter, here in

Southland we have 2 part-time rheumatologists, one works 2 days a month, the other 4 days, both travelling from other centres to see their patients. Not an ideal situation.

Jenny invited Rachel, the rheumatology nurse, who works 3 days a week, to be with us. Rachel introduced herself and listened to our concerns. She hopes to make a difference to our ability to be seen in an emergency at the hospital. She also made a commitment to work with the other professionals within the hospital to make sure we have heart/lung etc tests once a year.

As I have said before, everyone knows everyone in Southland. Rachel's husband's godmother is Joan who is a member of our group!

Thank you again Jenny.



A long lunch at a long table and it didn't take us long at all to start talking.



Rachel and Jenny

# Palmerston North



Chris, Catherine and Elaine.



Chris' birthday was an excuse for an expedition to the Esplanade Café

## Sing Your Lungs Out

A singing group for patients with chronic lung disease.

A community-based choir that started in Wellington has spread to Palmerston North

Sing Your Lungs Out caters for people with COPD (Chronic obstructive pulmonary disease) and other chronic lung diseases.

SYLO began in Wellington in 2014 and patients were enrolled as graduates of the Wellington Hospital Pulmonary Rehabilitation programme.

If you live in or near Palmerston North and are interested, call Sarah Dixon 06 355 4949.



Wellington group's Facebook page: [www.facebook.com/Sing-Your-Lungs-Out-279477085595109/](https://www.facebook.com/Sing-Your-Lungs-Out-279477085595109/)

# Ginger and oat crunch.

For those of you who were not lucky enough to be at the Wellington quarterly meeting this month - here is the ginger and oat crunch recipe from Chris Tomkies. It's delicious and gluten-free too.

125g butter

15g honey

30g GF cornflakes

85g coconut

95g GF rolled oats

85g butter

110g golden syrup

250g icing sugar

10g ground ginger



## 180° C

Heat the oven to 180C and grease and line a sponge roll tin.

1. Melt first portion of butter and honey, then stir in the brown sugar, cornflakes, coconut and rolled oats. Press into the prepared tin and bake until golden- about 20 minutes.
2. When the base has cooled to room temperature, make the icing by melting the second portion of butter and golden syrup together. Stir in icing sugar and ground ginger and beat until smooth. Add more icing sugar if needed. Pour over cooled base and allow to set before cutting.
3. Cut and store in fridge, keep layers separate with greaseproof paper. Can be stored in deep freeze and is delicious frozen on a hot day.





Merry Christmas to all  
members and supporters!

## Find a Scleroderma support group near You

**Auckland:** Allan Edmondson Email:-  
[allanedmondson@xtra.co.nz](mailto:allanedmondson@xtra.co.nz)

**Hamilton:** Linda Bell Email:-  
[linda.bell@hotmail.co.nz](mailto:linda.bell@hotmail.co.nz)

**Palmerston North:** Chris Carlyon  
[ningandalley@clear.net.nz](mailto:ningandalley@clear.net.nz)

**Invercargill:** Heather Milligan  
03 248 5147

**Wellington / Christchurch:** Dianne Purdie-  
[diannepurdie@xtra.co.nz](mailto: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](mailto:diannepurdie@xtra.co.nz) and I will be happy to help you set one up.

# Noticeboard



## Next Wellington Meeting:

10 February

For times, venue and directions to all meetings:

[www.scleroderma.org.nz/calendar/](http://www.scleroderma.org.nz/calendar/)



Scleroderma New Zealand Inc.



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### Respiratory Support Group September Meeting

Please mark up your calendars so we can get together. Your life's experiences could be a major help.

[Read More](#)

Upcoming Events  
Respiratory Support Group  
September Meeting  
Saturday, September 30 @ 11:00  
am - 2:00 pm

Auckland Scleroderma Group  
meeting  
Sunday, October 29 @ 1:00 pm -  
4:30 pm

Respiratory Support Group  
November Meeting  
Saturday, November 25 @ 11:00  
am - 2:00 pm

### Auckland Scleroderma Group meeting

Pop along for a relaxed afternoon with others who know just you feel! We plan on having a meeting in ...

[Read More](#)

### Respiratory Support Group November Meeting

Please mark up your calendars for our final meeting of the year. Your life's experiences could be a ...

[Read More](#)

## Contacts

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