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Scleroderma

New Zealand support group



Winter 2020

Greetings to you all.



Welcome to the Winter edition of our Scleroderma Newsletter. We hope everyone is well, and keeping warm on these cold winter days.

I would like to take this opportunity to thank Dianne Purdie for taking on another year as President of our organisation. I would like to acknowledge how hard Dianne works and thank her for all the support and dedication she gives to us and to our organisation.

I would also like to thank Gordon Purdie for also taking on another year as Treasurer for our organisation. Gordon's good knowledge of accounting is keeping our accounts in order.

I would like to congratulate our new Vice President Jenny Andrews and our new Secretary Jane Sainsbury. It is wonderful that they have taken on these two roles, to help.

We have information to share and news from our members in our Scleroderma Community.

We hear first from **Dianne Purdie** with the Presidents report. Dianne gives us good advice and keeps us up to date with what's going on around New Zealand.

Adrienne talks to us about Spin-SSLED, a very interesting read. It's amazing to have so many people and organisations there to help us all.

We learn how to manage our fatigue. This is something that will affect all of us so it is great to be able to know when you should be pacing yourself and not overdoing the good days, to then follow with a few of the bad.

We hear from Erena Bruce with her acrostic poem, something that is very relatable.

Jane Sainsbury shares her journey with us. A truly inspiration piece.

Also World Scleroderma Day and the International Art Exhibition 2020, Seminars, Upcoming Events and Members News.

Tina



Presidents Report:

June 2020



Presidents Annual Report 2020.

Greetings to all, and I hope you are all keeping well and warm and well done on all our efforts for COVID-19 a huge thanks to our families and friends for helping look after us.

We have one hundred and eighty-two members. We have had an increase of 21 new people join us in the last year.

A huge welcome to all our new members, it has been a pleasure getting to know you lovely people via email and some through our zoom meeting.

I would like to thank the committee for all their support over the past year, it has been much appreciated. I would like to thank Allan Edmondson for all his hard work and dedication as Vice President of Scleroderma New Zealand. Allan has travelled the country attending seminars and meetings and being a terrific patient advocate for people with PAH and Scleroderma. Allan is standing down as Vice President this year but we are grateful that Allan will be staying on the committee.

It is a sad farewell to Barbara and John Spavin and Kim Tocker, they are retiring from the committee after more than ten years of loyal service to Scleroderma New Zealand. I have appreciated them for their friendship, hard work, dedication, creativeness in many ways along with heart felt support. We all wish them well and we will look forward to catching up at meetings and correspondence. Barbara and John were our first newsletter Editors and John as our web Master for ten years.

Kim started the Christchurch support group a few years ago which is still running today with the much appreciated leadership of Carolyn Barkhausen.

I would also like to thank Nurse Maureen Anderson for her dedicated support and strong interest in Scleroderma. Maureen has done a lot for our organisation over the years and a lot of us have much appreciated her help. And a big thank you to Adrienne Burleigh for all her dedication and support to Scleroderma New Zealand on a number of levels, Adrienne has a wealth of knowledge and has helped a lot of our newly diagnosed members, Adrienne is very thoughtful and generous.

A big thank you to Cushla Marsters and Catherine Thompson for looking after the Scleroderma NZ Facebook page. Cushla has been on since the beginning of time and Catherine has joined forces this past year. It is a great friendly, helpful page and we get lots of interest. Thanks so much to you both.

It is not easy trying to think of something new each time, and they both do a terrific job. Thanks so much.

A huge thank you to Carolyn Barkhausen for all her great ideas, for also giving Scleroderma New Zealand a bright face with helping in the design of conference booklets, book marks and cards. Carolyn also donated these to Scleroderma NZ, for which we are very grateful and it has certainly given Scleroderma a bright lift.

I would like to thank Tina Mclean, from Wellington, and Jenny Andrews, from Winton, Southland, for taking on the task as newsletter editors. We can see that they have both done us proud this past year, they are making us shine out there on a global level carrying on the torch from Barbara and John. We have had lots of positive comments. So please keep supporting Jenny and Tina with your wonderful articles. Tina also helps out a lot with the newly diagnosed members which is much appreciated.

We have had some great activity throughout the country, we have meetings in South Auckland with Allan, Hamilton with Linda, Wellington, our group in Nelson with Beth, Christchurch with Carolyn and the ladies, and our very large group in Southland run by Jenny and Heather. It has been a great year for getting together.



Presidents Report:

June 2020.... continued

During the COVID-19 lockdown we were able to get together on Zoom, which proved to be appreciated by our members that could attend. Now we are back on deck to our face to face meetings, fingers crossed, as there were two new cases of covid today.

The seminar held in Christchurch last year was well received and run very well by Carolyn Barkhausen and Kim Tocker, they both put their heart and soul into a terrific day they had attendees from Invercargill, Hawkes Bay, Auckland, the West Coast, Christchurch and other great places around the country. It shows that these seminars are much needed and appreciated by our community.

This past year Scleroderma New Zealand has been made a partner with the Scleroderma Patient Intervention Network, SPIN, from Canada. It has been of great help to us, as an organisation. We have had Adrienne Burleigh and Maureen Anderson enlist for the leadership programme and a few of us joined the COVID-19 SPIN chat programme. It has certainly been a great experience and we have all gained a lot personally.

This year Scleroderma New Zealand is hosting an International World Art Exhibition for World Scleroderma Day in recognition of Paul Klee and his works. The exhibition runs from the 25th of June until the 9th of July, we have had a few entries so far with some brilliant works from Catherine Thompson, Erena Bruce and Carla Martin so far, we welcome more of you, I know you all have special talents out there. We have had a few people from overseas exhibiting too, well worth looking at the Facebook site.

We will look forward to seminars to be held in Hamilton and Invercargill later in the year, all going well with COVID. They have our support and I am sure they will be very well run. Linda Bell is a well seasoned seminar

organiser, Linda always puts on a great effort and her seminars are well represented. It will be Jenny and Heathers maiden seminar and I know it will be highly organised and thought out too. We are very much looking forward to attending. A big thank you in advance to all three of you, I know it will be difficult organising the seminar, if our situation changes here in NZ.

I would personally like to thank all of the members and their friends and family for their donations during the year and please continue helping us by donating to our National Appeal on the 29th of June, World Scleroderma Day. Some of the funds will go towards printing of our updated booklets on Understanding and Managing Scleroderma.

Last but not least I would like to thank Gordon, my husband, for his dedication to Scleroderma New Zealand, he works tirelessly for the organisation in many ways and has recently taken up the position as web master through John's much appreciated help. I wouldn't be able to do my job here as President if it wasn't for all Gordon's kindness and support.

We all work as volunteers and get rewarded by having the honour of being able to help others with Scleroderma and their families.

Take Care

Dianne Purdie



SPIN-SSLED...

Adrienne Burleigh talks to us about SPIN-SSLED

Have you ever heard of **SPIN-SSLED** ? Odd sounding name for an organisation? But when you can decipher it using the words represented by the initial letters it starts to make sense.

SPIN = Scleroderma Patient Intervention Network and
SSLED is Systemic Sclerosis Leader Education

SPIN describes their mission as:

SPIN's mission is to work with people with scleroderma to identify their needs and prioritize research in areas most important to them and to develop, test, and disseminate accessible patient programs that improve quality of life and empower people with scleroderma and their loved ones.



This organisation which is engaged in research as well as development and delivery of courses for those with systemic sclerosis, is based in Toronto, Canada and currently offers their excellent distance

delivery courses for no charge. Take a few minutes and Google them to see the extent of what they offer

Initially I met Dr Brett Thombs some years ago at a scleroderma patients' conference run by the Scleroderma Foundation of America. I was very interested in what they were doing but because I was unable to raise interest from our own medical profession was not able to proceed further at that time.

However, last year an invitation came from SPIN for a New Zealander to be a member of one of the groups trialling a new programme on establishing and maintaining support groups. Dianne put my name forward. It was an exciting opportunity when I was able to increase my own skills and learn many new ones as well as have the experience of learning using video conferencing. There were twelve of us involved in the course and we all got to know and appreciate the situations of the others. As an example, one of the course members had the task of keeping people who had systemic sclerosis and were scattered all over the wilds on Canada, in touch through a virtual support

group. A huge job, but this was the only way they could meet and talk with each other. Modern technology has made life easier for so many of us.

1st Being part of a group training to be support group leaders

2nd Joining in the discussions with others-in-training with qualified group leader/s on a monthly basis

As a result of this training I was asked to be a moderator for one of the new groups starting, with the focus on how SScl people were coping through the Covid19 crisis. It was fascinating to meet and share with course members and SPIN staff the worries and concerns that covid19 has brought, but also to expand my circle of friends across the world including two from New Zealand.

The highlights were.

- Making new friends from The Philippines through NZ to North America.
- Appreciating the levels of fear and worry Covid19 has imposed
- Looking for ways to ease that fear and worry
- Learning to laugh as part of the fear management process
- 12 x 90-minute sessions video course – this group was of 8 participants + me and a number of presenters

And now, via online meetings we are

- Keeping together
- Sharing our solutions of everyday living problems
- And continuing to laugh.



SPIN-SSLED...

Adrienne Burleigh talks to us about SPIN_SSLED...continued..

Keep a watch on the offered SPIN programmes for more people with Sscl to take part in this course and many other courses that are available – no fees, but a marvellous opportunity to link with others who are battling with this condition and share experiences and also give support. Perhaps the only possible drawback is the need to work within a timeframe that takes cognisance of the different time zones each course member lives in. One of the group leaders had to get up at some unearthly hour (6am) on Saturday morning to take part in the report back meetings and discussions with the rest of the leaders. I admire her very much for this, as I was muttering about being on line at 8am on Saturday mornings. Shame on me,

While many pictures were taken, they were all online ones and my level of technical expertise is not at the level required to access those pictures. But believe me, we all enjoyed it. Do plan to enrol for one of the courses and the experience it offers.

And, finally the following statement is taken from the SPIN website:

There is currently no cure for scleroderma. Thus, maintaining and improving the quality of life of people living with the disease is an important health care priority. Many people with scleroderma face challenges in daily life due to their illness, including pain, fatigue, limitations in hand function, and emotional distress. However, there are currently no evidence-based programs available to help people with scleroderma cope with these challenges.

To address this gap, SPIN was founded by McGill University researcher Dr. Brett Thombs as a partnership of researchers, scleroderma clinicians, patient organizations, and patients, who work together to develop and test online programs to help people cope with important problems related to scleroderma. SPIN was launched in 2011 with seed funding from the Scleroderma Society of Ontario and Scleroderma Canada. Since then, SPIN has benefitted from the funding of many different organizations,

including Sclérodermie Québec, the Scleroderma Society of Nova Scotia, the Scleroderma Association of BC, Scleroderma Manitoba, the Scleroderma Association of Saskatchewan, the World Scleroderma Foundation, Association des Sclérodermiques de France, McGill University, the Jewish General Hospital Foundation, the Arthritis Society, the Canadian Institutes of Health Research (CIHR), and the Canadian Initiative for Outcomes in Rheumatology Care (CIORA).

About the SPIN-SSLED Program

- 13 weekly sessions of 60-90 minutes led by a trained instructor
- Each week tackles one aspect of leading a support group, including *structuring a group meeting, recruiting new members, fostering a positive group culture, supporting yourself as a leader*, and many other topics
- Participants can attend the online videoconference sessions from the comfort of their own homes
- Supplementary resources include:
 1. A workbook that summarizes all modules.
 2. An online forum where participants can discuss what they've learned with other participants.
 3. An online Resource Centre with educational videos and support group activity ideas.
- At the end of 13 weeks, participants receive a certificate attesting that they have successfully completed the program



Understanding and Managing Fatigue

With Catherine McCoy, an Occupational Therapy (OT) Advanced Practitioner working within the Rheumatology Service at Salford Royal NHS Foundation Trust. Due to the specialist services provided for scleroderma at Salford Royal, she has developed considerable expertise in supporting patients in managing the symptoms of scleroderma and works closely with the multidisciplinary team, helping people to manage their symptoms in order to enable them to maintain active and enjoyable lifestyles.

We talk to Catherine about understanding and managing one of the most frustrating side-effects of living with a chronic condition...fatigue.

Fatigue is a common issue for people living with chronic conditions. A study supported by the Scleroderma Research Foundation found that over 75% of people with scleroderma experienced fatigue, and for 61% of these, it was reported to be one of the most distressing symptoms of the condition.

What is fatigue?

Some people may describe it as 'feeling tired.' It is in fact much more than that. Everybody gets tired from time to time; for most people this is usually after a late night or being particularly busy or active.

People living with conditions such as scleroderma, rheumatoid arthritis, fibromyalgia or lupus, can experience fatigue day after day, no matter what they have been doing or how much sleep they get.

They can also feel overwhelming physical and/or mental exhaustion just from doing simple everyday tasks. The effects of fatigue can significantly impact on your experience of pain and impair quality of life.

What causes fatigue?

The reason that fatigue is so commonly experienced is likely to be due to a number of factors, including:

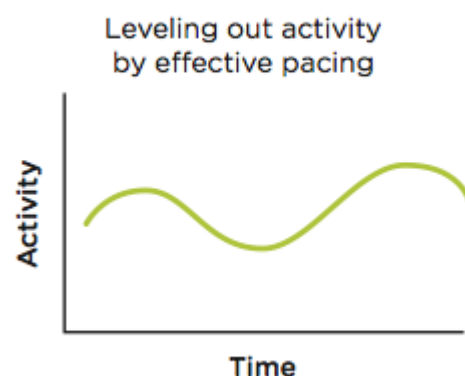
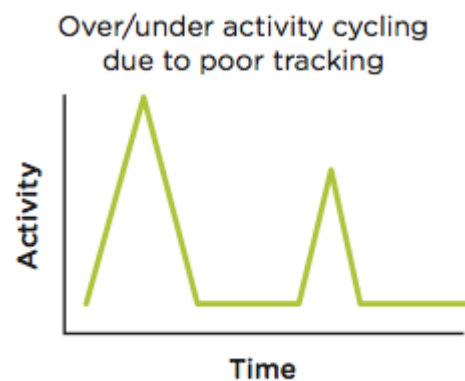
- The physical and emotional effects of living with your condition
- The side effects of medication

- Weakness of muscles, meaning that you use more energy to do everyday tasks that would usually be easy
- Sleep disturbance
- Pain

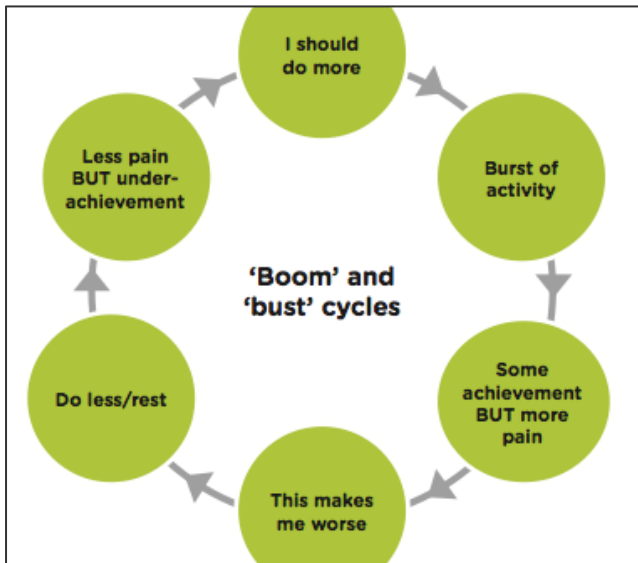
'Boom' and 'bust' cycles

Symptoms of fatigue can vary over the course of days and weeks. Frustrations relating to the impact of scleroderma on your lifestyle can mean that on a 'good' day, you may take the opportunity to do lots of tasks that you have been wanting or needing to do.

Unfortunately, the impact of this is often "doing too much," which can result in 'good' days being followed by 'bad' days. You may experience more pain and fatigue as a result of this burst of activity, and consequently be able to do less and need to rest more.



Understanding and Managing Fatigue continued



How can you better manage fatigue and activity levels?

So how can you break into this cycle to better manage your activities and activity levels? Planning, prioritising and pacing activities can help you to take back control of your energy levels.

This allows you to:

- Balance the day's activities to divide time into periods of rest and activity – not doing too much or too little. Aim to maintain an even level of activity over the day and through the course of the week
- Take regular breaks, change activities regularly and switch between light and heavier tasks where possible. Is there an easier way of doing something? Can you sit rather than stand, push rather than lift etc?
- Decide what is important to you and what you are happy to ask for help with/leave for somebody else to do
- On a good day stick to your plan to avoid overdoing things – don't wait for pain/fatigue before you stop
- On a bad day try to break up the activities more and take regular short breaks when needed

Unfortunately, all of this is much easier said than done! To be able to incorporate this into your lifestyle takes practice

and effort. When you first begin to address this, using an activity chart can help you to plan your week and also to evaluate your activity and fatigue levels. Over time, you will find that this becomes more of a habit and it will take less conscious effort to plan your weeks and activities.

"I find the idea of colour-coding activities really useful. On some days I say to my husband 'I've had too much of a red day...I need some green time' and he knows exactly what I mean."

Managing stress and using relaxation strategies

Fatigue levels in people with scleroderma are believed to be higher when experiencing poor quality sleep, significant pain and low mood. Managing stress and learning how to relax can help to reduce the impact of these factors. Emotional stress causes blood vessels to narrow, which can worsen the symptoms and effects of Raynaud's. By identifying and managing the causes of stress you may be able to reduce the frequency and severity of Raynaud's attacks.

Like activity planning, relaxation strategies take time and practice to master. There are lots of different relaxation techniques and you often need to try a few before you find one that works well for you. While some people like to use relaxation to help them to get to sleep at night, it is also a good habit to build relaxation time into your day in order to help manage fatigue.

Exercise can also help people with fatigue; if fitness is improved you generally feel fitter, with an increase in wellbeing, strength and energy. Starting off slowly perhaps with 5-10 minutes a day, gradually increasing the amount of exercise or physical activity is the best way to start. Speak to your OT or physiotherapist for guidance and advice.

Source:



<https://www.sruk.co.uk/scleroderma/scleroderma-and-your-body/understanding-and-managing-fatigue/?fbclid=IwAR3utBbb2YX3z8oa4TNANsIBTbp6gynyHcvfS9-JYsanhetOmOr4h0IKB4>



Members Stories:

Scleroderma...

by Erena Bruce..

I write with the thought of 3 years having confirmation of Scleroderma following Raynaud's blood work. With great foresight my GP just knew something else was going on and continued testing coming up with a diagnosis within a couple of weeks!

Within a year endoscopic procedures were a monthly process after diagnosis of watermelon stomach confirming blood loss and being bed ridden through lack of energy. Battling a skin infection cellulitis didn't help, however after 6 months, I could sense small changes. I could manage self-care, eat a little, attempt chores around home, walk to the letter box even.

It was a slow recovery. On reflection my biggest memory was just wanting to sleep.

Today I am grateful, for simple pleasures that bring joy to the day, the warmth of the sun, reading books, the giggles of my two children, the love from my husband, family and the ability to be cognitively aware of everyday situations.

I have enclosed this acrostic as a way of telling a little bit of my short journey with Scleroderma.

By Erena Bruce
Cambridge



Systemic Sclerosis my introduction to my autoimmune condition, blood work confirms positive antinuclear antibody (ANA) test, I get to meet Anna Schollum (what a lovely empathetic, person), Doctor Kamal Solanki (ever so polite and so so knowledgeable)

Clothing a priority mainly for warmth, Smartwool socks, Ugg boots, merino under clothes, layers upon layers, not forgetting if you look after your feet your feet will look after you...worth spending on Skechers just magic for me

Life time of physiotherapy to aid the keep moving, keep active reality...we do not use it we lose it theory! To be honest one does not need Scleroderma to live by this mantra!

Everyday inflammation means adjusting to different ways of completing taskschallenging but always thinking outside the box, keeps the grey cells working

Raynaud's phenomenon, purple cold fingers that turn snow white and feel numb, why did the temperature change so suddenly? A good reason to have another hot cup of soup!

Omeprazole the pills that manage heartburn another symptom to manage, grateful spicy foods are not a big favourite of mine

Diffuse Scleroderma knowledge that internal organs in time will be affected, perhaps a little certainty of what the future holds, we all die of something...right!

Energy levels vary being grateful for simple pleasures and envious of those that have explosive endurance, now my distant memory..... but something to aim for even to achieve those small milestones, a marathon starts with the first step I am reminded

Rheumatoid arthritis curling fingers that remain curled without that daily forcing of uncurling, exercise using prayer position, fist pose, thumb taps, 24/7 work outs, essential to keep in touch with hand Occupational Therapist, any feedback gratefully received

Methotrexate and folic acid to manage skin changes....lumpy bulges, I know vitamin E is great for skin elasticity but my excess everyday build up is ridiculous, then there's the dry skin, at least the itchiness has stopped...yipee

A time every day to breathe, laugh, cry and surround yourself with positive knowledge to reflect upon the thought that everyone is managing something, sometime....somewhere..... take care



Members Stories:

My Journey...

by Jane Sainsbury..

It was in Kansas City, October 1987 that I married John, a Kiwi from Hawkes Bay, New Zealand. It was just 2 years earlier he was on his OE and just happened to run into my brother through a mutual friend in Denver, Colorado. He was given my phone number and told to look me up. He tells me occasionally he almost didn't make that phone call! His plan was to come to Kansas City for 5 days visiting friends, but he actually ended up staying for 4 months. A long-distance romance too-ing and fro-ing for 2 years led to finally getting married and an agreement to live in the US for at least 10 years. We had our daughter Libby 5 years later. A not so normal birth which was preceded with preeclampsia, then an emergency Caesarean and 3 weeks later I hemorrhaged. It left me unable to have another biological child. We then adopted our son Alex from Russia 3 years later.



We moved to New Zealand 10 years later in 1997. Within a 5-year period I came down with glandular fever, was diagnosed with GERD, an IGA deficiency (which I've had all my life and never knew) and then the crashing blow of being told I have Coeliac's. Little did I know this was nothing compared to what was to come and that it would be the first of many autoimmune diseases I would collect. I spent my forties enjoying life sans gluten and was generally in very good health. I played tennis twice a week, walked Te Mata Peak once a week, was secretary on the Parents Association at my Daughters high school, had a part time job and hosted many dinner parties. I was moving and shaking.

At 50 years old my children were just about to head off to university and/or travelling overseas. We were almost empty nesters and I found myself a fulltime job with a property developer in the accounts department. 3 years into the job I started getting stiff joints in my hands. A year later my face and hands started swelling up, and my hair started falling out, at least one hundred strands a day (I counted!). I also started developing

metatarsalgia (loss of the fat pads on the bottom of your feet) making walking barefoot very painful. Everyone told me it's probably menopause symptoms. Soon after that I started dropping weight. I had psoriasis on my ears, eyelids, and knees. My voice became raspy. A yearly check up at the dentist confirmed I had Oral Lichen Planus - an inflammatory condition that affects the mucous membranes inside your mouth. A routine bone density test confirmed I had Osteoporosis.

In 2014 at age 53 we joined a group of friends to cycle the Otago Rail Trail and then in 2017 the Alps to Ocean. I was always at end of the pack. My immune system was a mess and I didn't realise it had gotten so bad. I came down with shingles and was left with post herpetic neuralgia in my left hand. My wakeup call came when I was walking the Cape Kidnappers Challenge as a team from work. On the most vertical hill EVER I was practically on my knees crawling and gasping for air. I truly thought I was going to have to be life flighted out that day. My GP then sent me to a respiratory doctor at the hospital who after many lung function tests and an x-ray confirmed I had bronchiectasis, a lung condition where there is permanent enlargement of parts of the airways of the lungs that was brought on by the many bouts of bronchitis and croup I had as a child. Well, that was it. I'd had enough pooppy news and broke down crying, asking why do I feel so awful?

In 2016 I was referred to an immunologist in Wellington who did every single blood test under the sun. My positive ANA and further blood tests indicated probable scleroderma/overlap. My skin had thickened on my right hand up to my wrist. I was noticing my hands were sensitive and dry and felt like I was losing the oil in them. My Rheumatologist said I had no obvious signs of inflammatory arthritis at present and no signs of progression of my connective tissue disorder. He said it may take a number of years before we are clear what my underlying condition. I was prescribed Hydroxychloroquine. I was 56 years old by then.

Meanwhile, I was not accepting the fact that I may have a rare autoimmune disease, but over the course of 2 years I started getting calcifications on my sit bone, my right elbow, left heel and on several tendons of my left hand. Sometimes I felt like I literally leaked collagen out of my calcinosis blisters on my hands and elbow. I had numerous telangiectasia on my face, neck and thighs.



Members Stories:

My Journey continued...

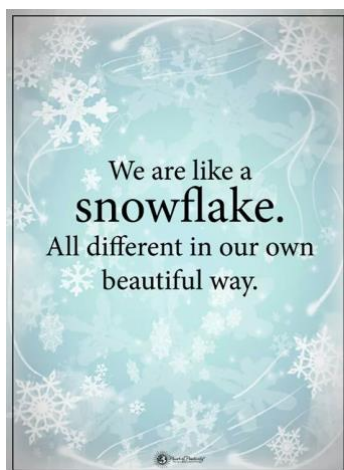
by Jane Sainsbury..

My Raynaud's seems to have ramped up and I have to cut my food to bits and drink lots of water so it doesn't get stuck in my throat.

My right little finger is contractured. The signs of this disease are much more evident. November 2018 I was finally diagnosed with limited cutaneous scleroderma (CREST). A year later I stopped the Hydroxychloroquine and started taking Methotrexate. That was 7 months ago. My lung function test is on par with the bronchiectasis diagnosis and the pulmonary test has come back ok as well. Since taking the Methotrexate I am very pleased I want to get out of bed in the mornings, and my joints aren't as sore. I also seem to have more energy, but as for the rest of the symptoms this disease is like a freight train doing more and more damage. If it wasn't for the support systems like Scleroderma NZ I would have found coping with this disease even more challenging. I am hoping to remain strong, positive (very hard at times) and pray for a cure. We truly are warriors.

Thought for the day:

***'A smile is happiness you'll find right
under your nose'
(Tom Wilson)***

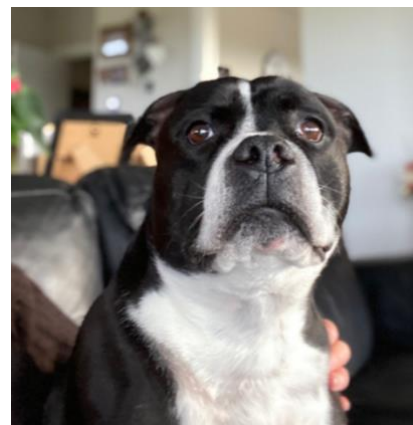
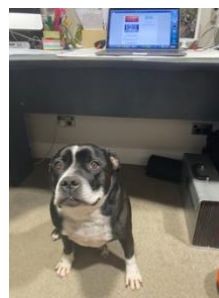


Pet Corner:

Readers you are welcome to submit a photo of your companion animal and write a little story about your pet and how your pet makes life a little more joyful for a scleroderma patient.

I was never a dog person but after years of harping from the kids and a lot of research as to which dog would suit our family best we decided on a Staffordshire Bull Terrier. It was met with much excitement adding to our family. We named him Taz. As it turned out he loves his Mum the most and became my dog. He is a real Mummy's Boy. You will always find him under my desk or outside my office door when I am working. Sitting at the edge of the paddock while I shift the stock and if anyone loses me on the property they just have to find Taz and that's where I am. He is such a big softie and when I need to have a wee sleep through the day Taz is right there with me. It is very comforting to have him with me constantly and he loves cuddles.

Jenny Andrews



World Scleroderma Day

Why 29 June - World Scleroderma Day?

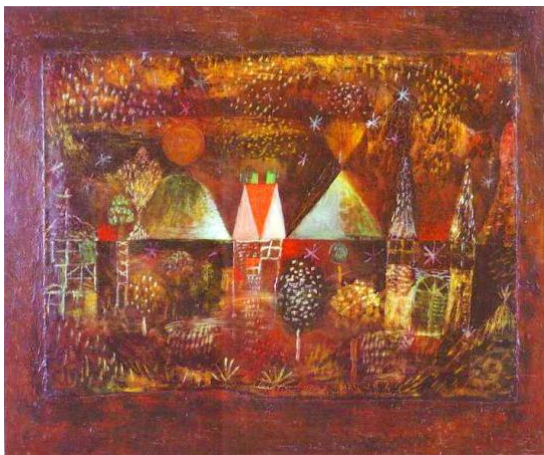


The Swiss artist Paul Klee was strongly affected by scleroderma, and he died on 29 June, 1940. At a meeting in 2008, FESCA agreed on this date and since 2010 after the very first Systemic Sclerosis World Congress in Florence it was agreed to have 29 June as World Scleroderma Day, a very special day in June being awareness month of scleroderma all over the world.

Source:



**Fesca - Federation of European
Scleroderma Associations**



What is World Scleroderma Day ?

The first European Scleroderma Day on the 29th June 2009 was celebrated in almost all of FESCA's member countries as it was decided by the FESCA at a meeting in 2008.

Having a disease that nobody has heard of is a lonely business. When even the doctors cannot recognize it, or tell you what is going to happen, it is lonelier still. So Scleroderma Awareness Day was created to tell people, including the medical community, what it means to have this disabling disease. June 29 is a day to recognize the bravery of those who live with scleroderma, and to demand equal treatment and equal care for people with scleroderma across Europe.

History of World Scleroderma Day

In February 2010 the 1ST **SYSTEMIC SCLEROSIS WORLD CONGRESS** was held in Florence, Italy, with participants from countries from all over the world. At the world congress it was agreed that June 29th would be celebrated all over the world. Scleroderma day grew from zero to world scleroderma day in 2 years, and is celebrated in countries in Europe, Australia, Canada, Brazil, India and many more countries.

Why 29 June ?

The gifted Swiss artist Paul Klee made painting his life's work, but it was strongly influenced by his illness, systemic scleroderma, as the painting chosen for Scleroderma Day demonstrates. He died June 29, 1940.

The Swiss Paul Klee Zentrum in Bern boasts the world's most important collection of paintings, watercolours and drawings as well as archives and biographical material from all the creative periods of Paul Klee's life which also can be visited through their website:

www.zpk.org

Source:

<http://worldsclerodermaday.org/what-is-world-scleroderma-day/>



World Scleroderma Day

International Art Exhibition 2020

Celebrating Paul Klee...

Hosted by Scleroderma New Zealand,

Date: 25 June at 1.00am – 9 July at 1.00am

Event: Online

Calling for all people with Scleroderma to exhibit in the first Annual World Scleroderma Day Art Exhibition.

The Art Exhibition is open to all people with Scleroderma from around the world. This exhibition is to honour the creative spirit that shines through during the difficult days of today and beyond to better days!!

Please post your photos of paintings, drawings, crafts, photos and other visual arts. We would love to read your poems and stories or see videos of your music and dance. Artists are encouraged to explain their work and we are open to all levels of creativity.

To enter the exhibition post your work on the World Scleroderma Day International Exhibition Facebook page at this link:

<https://www.facebook.com/events/682657225635808/>

This is an opportunity to connect us in a new way, to share and appreciate our talents and bring some joy and fun into our lives.

We dedicate this exhibition to the life and works of Paul Klee.

Artist Adrienne Burleigh



Artist
Erena
Bruce



Artist
Catherine
Thompson



Artist
Beverley Smit



Members News:

Scleroderma Waikato Group

We have a number of members and we have been meeting at Robert Harris Café, Chartwell, Hamilton once a month for the past 8 Years now...

My Coffee Group in Waikato are all good and looking forward to starting again in June.

In June we have a Luncheon to celebrate **World Scleroderma Day**. This year will be at **St Andrew's Golf Course** on **27th** at **11.30 am**. Will contact all later.

And November we end the year with a Christmas Luncheon.

Scleroderma is like a Roller coaster up and down in health but since starting the coffee group and doing the seminars I have met wonderful, caring people, I love them all. So, blessed to have met them all.

It's that time of year again when you either need an Entertainment Book to save you some Money or your current book has expired. To get the latest Entertainment Book go to my Facebook page where you can get it online anywhere in NZ. Every purchase raises \$15 for **Scleroderma Waikato** to help with the cost of Seminars, so be sure to let your friends and family know. If it is your first time, I bet it won't be your last. It is only in Digital form this year but works extremely well and you can share with your partner husband or wife and will always have the book with you. Also another digital benefit is, there are always updates with new offers.

Thanks for Supporting Scleroderma Waikato
Regards,

LINDA BELL
SCLERODERMA WAIKATO

PH: 07 8535434
MOB: 027 548 1214

Nelson Scleroderma Group

Hello to our Scleroderma friends.

Lisa Furness and myself met up in Mapua for a catch up. We had a lovely lunch at Albertas by the Mapua wharf. It was a rainy cold day but we had a nice time.

Lisa is still biking and running and is feeling well. I'm still getting out on my mobility scooter most fine days. Sadly Rosemary couldn't meet up owing to a hospital appointment.

We hope to meet up again after the school holidays. It's so good to be able to share our journeys with each other. I learned a lot from Lisa's battle with Scleroderma and I'm sure she has learned a lot from my 20yr journey.

Hopefully Rosemary and Terry's wife Maggie can meet up again soon. I've attached a photo of us all from earlier in the year.

Cheers from us all from Nelson.

Beth Richards 🌻.



*Nelson Ladies
from earlier in
the year*

Southland Scleroderma Group

We had a very small personal zoom chat during lockdown as we had to postpone our May meeting. This is going ahead this weekend. Will be great to catch up with everyone.

Scleroderma NZ AGM

AGM was held on 17th June via email from: 8am-8pm

A huge thank you to those on the committee
Maureen Anderson, Linda Bell, Adrienne Burleigh,
Allan Edmondson, Jo Harris, Cushla Marsters,
Tina McLean, Heather Milligan, Julie Rolston, Catherine
Thompson and Judy Trewartha



Jokes of the day:



<http://TheFunnyPlace.net>



Upcoming Events:

Waikato

World Scleroderma Day:

Event: Celebrating World Scleroderma Day with Lunch
Date: On the 27th June Saturday
Time: 11.30 am
Place: St Andrews Golf Course

The Scleroderma Waikato members are celebrating **World Scleroderma Day** which is on 29th June.

I will be ringing as I need to know who is attending you may bring your partner-friend but let me know.
Have a great day.

Waikato Seminar:

This year will be another seminar for Hamilton which helps the newly diagnosed and family's to learn and understand and most of all to meet other people around the Waikato area.

More information about the seminar coming soon – keep an eye out for it in the next Newsletter.

If you would like to join in with the Waikato Group, please contact:

LINDA BELL
SCLERODERMA WAIKATO
PH: 07 8535434
MOB: 027 548 1214

Southland

Southland Seminar: Saturday 26th September 2020
Southland Hospital, Invercargill

More information about the seminar coming soon – keep an eye out for it in the next Newsletter.

If you would like to join in with the Southland Group, please contact either:

Heather: milliganseeds@xtra.co.nz
Jenny: jennyred@xtra.co.nz

For COVID-19 health advice and information, contact the Health line team (for free) on:

0800 358 5453

Remember to follow the advice of Government

- Cough or sneeze into a tissue, your elbow or clothing, not your hands.
- Wash your hands as often as you can, for 20 seconds with soap and water, and dry thoroughly. If you can't do that, use hand sanitiser.
- Don't touch your face.
- For official information go to www.covid19.govt.nz

A reminder that you all should have had your flu jab by now, if not please remember to get it soon with your GP.

Remember to keep your activity levels up, there are gentle exercises you can do in your own home. Even if it is walking around your garden a few times.





**Scleroderma
New Zealand Inc**

**You are Invited to the
*Scleroderma New Zealand
Southland Seminar***

26th September 2020

**Southland Hospital
Kew Road**

**Registrations to Jenny Andrews by the 14th of September
Email: jennyred@xtra.co.nz**

Any special dietary requirements please let Jenny know.

Cost \$25-00 for the Day.

Lunch, morning and afternoon teas included.

**Please pay directly into Scleroderma New Zealand's Bank Account
by the 14th of September 2020. Reference :- your name and seminar**

SCLERODERMA NEW ZEALAND INCORPORATED 38-9017-0107454-00

**If you have trouble with making a deposit please contact Jenny Andrews
jennyred@xtra.co.nz or Phone 027 3166124**

Programme

9:00am Registration

9:30am Welcome

9:35 am - 10:05am Speaker

10:10am - 10:30am Morning Tea

10:35am -11:05am Speaker

11:15am- 11:55:am Speaker

12:00 - 1:00 pm Lunch

1:10- 1:55pm Speaker

2.00- 2:30 pm Speaker

Afternoon Tea and chat- Finish around 3:30pm



Things to do in Southland:

A perfect time to take that wee break from your norm and come down South to see what we have to offer and join us at our first ever Seminar. Not only will we have fantastic speakers to keep you enthralled during the seminar but we offer a wide range of things to do and see while you are here within a couple of hours drive.



Queens Park; in the heart of Invercargill is a wonderful place for a wander through and make time to have afternoon tea in the café.



Don't forget to visit Bluff, only a 20 minute drive away and get a photo with the sign. Then you can catch the ferry to Stewart Island for a night or two in pure tranquillity.



Half an hour's drive from Invercargill is our seaside town of Riverton. With cafes and yummy fish & chips, it's a must see.



Just two hours from Invers is Queenstown. Or you could even fly into Queenstown and rental car to Invercargill, in time for the seminar.

The Catlins are a fantastic scenic drive from Invercargill with the Nugget Point Lighthouse, Purakaunui Falls, Cathedral Caves and lots of other lovely sights and cafes along the way.



If you have a few more days up your sleeve you could go through to Te Anau for the night and a day trip from there to Milford Sound. Beautiful on a sunny day and even more so after the rain.



Come and experience our Southern Hospitality.



Welcome to Scleroderma New Zealand Inc.

To all our new members, who have recently joined us – Welcome....

Scleroderma New Zealand Inc. is for people with scleroderma and their families and friends. As there are not too many of us, we would like to be able to provide support, friendship, exchange of ideas & information.

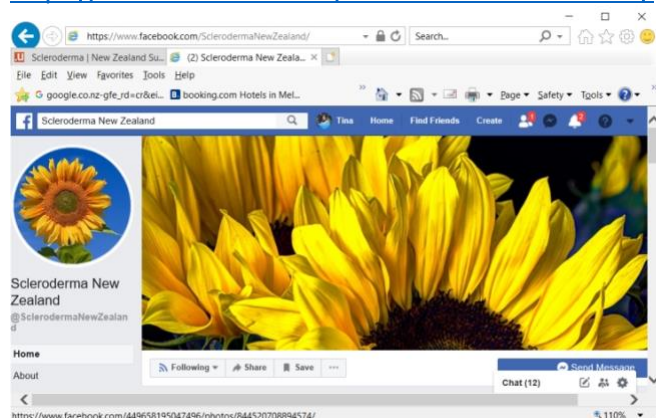
Our **Website** address Link is as shown below: -

<http://scleroderma.org.nz/>



Link to our **Scleroderma NZ Facebook** page and **Auckland Facebook** page as shown below: -

<https://www.facebook.com/SclerodermaNewZealand/>



<https://www.facebook.com/groups/sclero.ak/>



Virtual Support Group Meetings

Our First Zoom Virtual Meeting

As we meet as a community group..... some of us in public places, others in homes or meeting rooms, we need to take special care because most of us have a compromised immune system and have underlying complications with our lungs and other organs.

Scleroderma NZ had to cancel previous physical group meetings due to Covid 19 but fingers crossed we can get back to meeting in person.

There are a few meetings happening in the coming weeks. Always remember though that if the country is taken over by Covid in the future that the Zoom Meetings are a fantastic way of supporting each other.

Below is a screen shot taken during the first Zoom meeting. It was fantastic to see everyone on there.



<http://scleroderma.org.nz/>



Noticeboard:

Wellington support group meets:

Saturday 15th Aug 2020 1.30pm to 4.00pm
Saturday 14th Nov 2020 1.30pm to 4.00pm

Venue:

Hardwick Smith Lounge, Belmont Domain, Lower Hutt

Christchurch support group meets:

Saturday 25th July 2020 2:00pm to 4:00pm
Saturday 26th Sept 2020 2:00pm to 4:00pm
Saturday 28th Nov 2020 2:00pm to 4:00pm

Venue:

McDonalds Merivale, 217 Papanui Road, Merivale, Christchurch in the free community room, as long as you buy a coffee at the Mc cafe.

Auckland Respiratory support group meets:

Venue:

327a Whangarata Road, Taukau Auckland 2694

Southland support group meets:

Sunday 28th June 2020 **Buster Crabb** Invercargill
Sunday 16th Aug 2020 Winton
Sunday 8th Nov 2020 **Thomas Green** Gore

Hamilton support group meets:

Group meets once a month at Robert Harris Café, Chartwell, Hamilton

If you would like to join in with the Hamilton Group, please contact Linda Bell.

Email: Linda.bell@hotmail.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 she will be happy to help you set one up.

Contacts:

Find a Scleroderma Support Group near You

Auckland Respiratory: Allan Edmondson, Email: alsand327a@gmail.com

Waikato: Linda Bell, Email: linda.bell@hotmail.co.nz

Hawkes Bay: Jane Sainsbury, Email: jsainsbury@xtra.co.nz

Palmerston North: Adrienne Burleigh, Email: Adrienne.burleigh@xtra.co.nz

Wellington: Dianne Purdie, Email: diannepurdie@xtra.co.nz

Nelson: Beth Richards, Email: ronbethrichards3@gmail.com

Christchurch: Carolyn Barkhausen , Email: barkman@xnet.co.nz

Southland: Heather Milligan, Email: milliganseeds@xtra.co.nz

Scleroderma New Zealand Inc.

President: Dianne Purdie
diannepurdie@xtra.co.nz

Vice President: Jenny Andrews
jennyred@xtra.co.nz

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jsainsbury@xtra.co.nz

Treasurer: Gordon Purdie
gordon.purdie@xtra.co.nz

Newsletter: Tina McLean
altinamclean@xtra.co.nz

Jenny Andrews
jennyred@xtra.co.nz

Does your area plan a meeting? For times, venue and directions to all meetings that we know about: www.scleroderma.org.nz/calendar/

